

FAMILY AND COMMUNITY INTERVENTIONS FOR CHILDREN AFFECTED BY AIDS

LINDA RICHTER, JULIE MANEGOLD
& RIASHNEE PATHER

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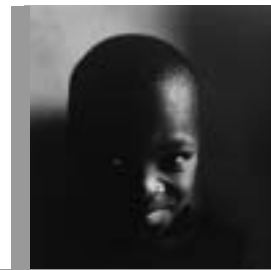


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PREFACE

In the operational framework to implement the strategy for the care of orphans and vulnerable children (OVC) in Botswana, South Africa and Zimbabwe funded by the WK Kellogg Foundation (WKKF), the goals of the project are to:

- Improve the social conditions, health, development and quality of life of vulnerable children and orphans;
- Support families and households coping with an increased burden of care for affected and vulnerable children;
- Strengthen community-based support systems as an indirect means to assist vulnerable children; and
- Build capacity in community-based systems for sustaining care and support to vulnerable children and households over the long term.

The key deliverables of the project are to monitor and evaluate the impact of the following programmes:

- Home-based child-centred health, development, education and support programmes;
- Family and household support programmes;
- Strengthening community-support systems; and
- Programmes to build HIV/AIDS awareness, advocacy and policy to benefit orphans and vulnerable children.

Steps in the process to achieve the deliverables include reviews of the available scientific, programmatic and network information on the three key levels of the interventions – children, families and households and communities. Three reviews were articulated as follows:

- Evidence-based interventions for home-based child-centred development programmes focusing on health and nutrition, psychosocial care, management of inherited assets, among others;
- Evidence-based interventions directed at supporting families and households to cope with the HIV/AIDS problem (an increased burden of care for affected and vulnerable children);
- Evidence-based interventions directed at building capacities of communities to provide long-term care and support for children and households.

The review of home-based child-centred development programmes was conducted independently by a third party and has been reported separately.¹ That document contains descriptions of the Community-based Options for Protection and Empowerment Programs (COPE) programme in Malawi, the Strengthening Community Project for the Empowerment of Orphans and Vulnerable Children (SCOPE) programme in Zambia, Thandanani Association and the Children in Distress Network (CINDI) in South Africa, and the Family AIDS Caring Trust (FACT), the Farm Orphan Support Trust (FOST) and the Families, Orphans and Children Under Stress (FOCUS) programme in Zimbabwe, all of which have been subjected to some form of evaluation. As information about these programmes is widely available, they are not covered in further detail in this report. There are several compendiums of programme examples in Africa and other parts of the world, listed in the attached Annotated Bibliography, and further details about these programmes are also not included in this review (see, for example, the Alliance 2003

¹ See A Strelbel A (2004) *The development, implementation and evaluation of interventions for the care of orphans and vulnerable children in Botswana, South Africa and Zimbabwe: A literature review of evidence-based interventions for home-based child-centred development*. Cape Town: HSRC Publishers

series; Cook 2002; the Displaced Children and Orphans Fund (DCOF) 2001; Family AIDS Caring Trust (FACT) 2002; Lorey & Sussman 2001; WHO/UNICEF 1994; UNICEF 1999; USAID 2001; USAID-PVO Steering Committee on Multisectoral Approaches to HIV/AIDS 2003).

This report focuses on interventions directed at supporting families and households, and on building the capacities of communities. In the main, the emphasis is on *intervention principles* rather than on actual programme implementation details, because it is widely agreed that interventions need to be tailored for each particular situation. As Williamson says, 'Interventions to mitigate the impacts of HIV/AIDS must be tailored to the particular economic, social, cultural, and environmental contexts of the countries and communities concerned. There is no one-size-fits-all approach' (2000a:20). These intervention principles, although not subjected to rigorous outcome evaluation, are derived from reflection on practice and experience coming out of various forms of process evaluation.

Interventions to support children, families and communities run into each other with inevitable overlaps. Where this occurs, the review ranges across children, families and communities without artificial demarcation.

Method

As part of its work in the field of interventions for vulnerable children, the Child, Youth and Family Development (CYFD) research programme maintains comprehensive bibliographic databases and conducts ongoing document surveillance on topics related to vulnerable children and policy and programmatic interventions.

Using these resources, documents for this review were sourced through electronic journal systems, web-based searches, networks with bulletin boards, reports of meetings, exchanges of documents between colleagues, and so on.² It should be noted that the already very large literature in the field of orphans and vulnerable children is overwhelmingly informal and exists largely in the so-called 'grey literature'.

The documents reviewed have the following characteristics:

- They exist in full in electronic or print form;
- They deal specifically with orphans and children made vulnerable by the HIV/AIDS epidemic;
- They deal in the main with southern Africa, except where the programme information from another region is clearly applicable to southern Africa.

There are a large number of government policy documents from several countries in the region that were excluded because they are specific to the country concerned.

There is also a very substantial literature on interventions at the level of the child, family and community that are both directly and indirectly applicable to children affected by AIDS. These include children living in poverty; children exposed to violence; street children; children declared to be in need of care; and children in a variety of what UNICEF term '*extremely difficult circumstances*'. It is a notable limitation of the HIV/AIDS

² The assistance of Jule Manegold in undertaking this review is gratefully acknowledged.

PREFACE

field that many problems with respect to children are being approached *de novo* when, in fact, valuable information exists which is generalisable to children made vulnerable by the HIV/AIDS epidemic. This is especially true of interventions to support orphans and vulnerable children but is also true, for example, of efforts to improve livelihood activities in impoverished communities. However, in terms of the brief, this literature is excluded from the report.

Given these broad parameters, the report is based on more than 400 documents. A reference list is appended to the report and an annotated bibliography of the source documents is included. Given the proliferation of material in this field, and the fact that new documents appear on a daily basis, it is likely, although regrettable, that some important materials have been omitted. For example, four major new reports on issues related to programmes for orphans and vulnerable children appeared in late July and early August 2003.

In order to render the most valuable pieces in some of the selected documents, large sections of reports, especially tables and lists, have been extracted and are included here. Every effort has been made to duly acknowledge the source.

Material cited in the review, which is not included in the bibliography, is listed in the references.

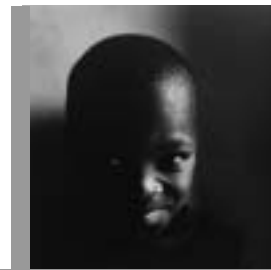
Linda Richter



SECTION ONE

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I. INTRODUCTION

1.1 Definitions of orphans and vulnerable children

Children are affected in different ways by the HIV/AIDS epidemic. Many children are infected with HIV, and all children in regions with high HIV prevalence are likely to be affected by the ensuing deterioration of services, the weakening of social institutions and high levels of stress. A third category of children affected by HIV/AIDS are children who lose a parent or parent-substitute; children who live in a household in which one or more people are ill, dying or deceased; children who live in households which receive orphans; children whose caregivers are too ill to continue to look after them; children living with very old and frail caregivers; children older than 15 years of age (World Vision 2002).³ An orphan is defined by UNAIDS as a child under 15 years of age who has lost their mother (maternal orphan) or both parents (double orphan) to AIDS. Orphans and the third category of children, described above, are commonly referred to as orphans and vulnerable children (OVC) and/or as children affected by AIDS (CABA). There has recently been a debate in programme circles about the use of the terms OVC and CABA as abbreviations that are sometimes used in ways that objectify or dehumanise children. For this reason, the abbreviations CABA and OVC are generally avoided in this report.

Community definitions of vulnerability are very likely to differ from those of external agencies. For this reason, a fundamental task in dealing with the crisis is to define who are vulnerable children (Baingana in Levine 2001). Smart (2003) illustrates this in the table that follows, showing how children are defined as vulnerable in different African countries.

Table 1: Children defined as vulnerable

Country	Definitions
Botswana (policy definition)	<ul style="list-style-type: none"> • Street children • Child labourers • Children who are sexually exploited • Children who are neglected • Children with handicaps • Children from indigenous minorities in remote areas
Rwanda (policy definition)	<p>Children under 18 years exposed to conditions that do not permit fulfilment of fundamental rights for their harmonious development, including:</p> <ul style="list-style-type: none"> • Children living in households headed by children • Children in foster care • Street children • Children living in centres • Children in conflict with the law • Children with disabilities • Children affected by armed conflict • Children who are sexually exploited and/or abused



³ These have been referred to, respectively, as 'afflicted' and 'affected' households (Barnett & Blaikie 1992).

	<ul style="list-style-type: none"> • Working children • Children affected /infected by HIV/AIDS • Infants with mothers in prison • Children in very poor households • Refugee and displaced children • Children of single mothers • Children who are married before the age of majority
South Africa (local/community definition)	<p>Child who:</p> <ul style="list-style-type: none"> • Is orphaned, neglected, destitute or abandoned • Has a terminally ill parent or guardian • Is born of a teenage or single mother • Is living with a parent or adult who lacks income-generating opportunities • Is abused or ill-treated by a step-parent or relatives • Is disabled
South Africa (working definition for rapid appraisal)	<ul style="list-style-type: none"> • A child who is orphaned, abandoned or displaced • A child under the age of 15 who has lost his/her mother (or primary caregiver) or who will lose his/her mother within a relatively short period
Zambia (definition for accessing support)	<ul style="list-style-type: none"> • Community Committees identify orphans and vulnerable children who qualify for the Public Welfare Assistance Scheme in terms of the following criteria: <ul style="list-style-type: none"> • Double/single orphans • Does not go to school • From female-/aged-/disabled-headed households • Parent/s are sick • Family has insufficient food • Housing below average standard

Source: Smart 2003

1.2 Rights and development as the bases for interventions

The constitutional and conventional rights of children affected by AIDS, their rights to a home, care, health and education, are challenged by the impact of the HIV/AIDS epidemic. As a result of this, the future potential of many children is being compromised. In addition, it has been argued that, particularly where children are concerned, HIV/AIDS needs to be treated as a broad developmental concern rather than as a narrow health or even public health issue. Most children affected by HIV/AIDS are affected also by conditions of poverty and exclusion. As a result of their marginalised conditions, they lack access to health, education and welfare services, and they lack legal protection of their rights.

Targeting so called 'AIDS orphans' with relief and services may discriminate against other vulnerable children; it may lead to the stigmatisation of orphans; it may encourage the labelling and even rejection of children, and it may result, perversely, in children being called orphans to access services. Orphan targeting may also misdirect valuable resources

because not all orphans are vulnerable (Subbarao & Coury 2003). Within the framework of the United Nations Convention on the Rights of the Child, the recommended approach is the inclusion of orphans in broader programmes that address the needs of all vulnerable children in a community (Grainger, Webb & Elliott 2001). The guiding principles of the Convention are: non-discrimination; best interests of the child; survival and development; and participation. The need is to target assistance to the most needy children in a non-stigmatising fashion. A generic definition of the most needy children is *children facing worse odds and outcomes than the 'average' child in their society* (Heitzmann et al. 2001). In some countries, too much effort is being devoted to counting orphans, and too little effort to identifying risks and compound risks to children's health and development (Subbarao & Coury 2003).

Similarly, a common developmental approach in programmes is the mobilisation and support of households and communities to cope with the impact of HIV/AIDS. '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 means that, over time, mitigating the impacts of AIDS will become a developmental response, fully integrated into the wider processes of social and community development' (Grainger, Webb & Elliott 2001:113).

1.3 The long-term nature and size of the problem

The HIV/AIDS epidemic in southern Africa is not expected to peak until 2010–2020, after which it is anticipated that incidence and prevalence will begin to decline. Because orphaning follows deaths by 8–10 years, orphaning is likely to remain high until 2030 (Gregson et al. 1994; UNAIDS, UNICEF, USAID 2002). The HIV/AIDS epidemic affects all children by changing the nature of the society in which we all live. The quality and availability of health, welfare and education systems are deteriorating because of demands caused by HIV/AIDS for resources and services, because of loss of staff to AIDS-related illness and death, and because of a reduced tax base. Similarly, there are knock-on human and economic effects leading to reduced productivity and growth (Lorey & Sussman 2001).

Whilst conceding the human dimension of the problem, such as the distress of orphaned children, Williamson (2000a) has emphasised that the magnitude and scale of the epidemic demands a strategic approach that matches the impacts of the epidemic. The aim, he says, is not to save a few orphans in those rare communities in which external agencies are focused, but to strengthen the capacities of families and communities to cope:

Developing programs that significantly improve the lives of individual children and families affected by HIV/AIDS is relatively easy with enough resources, organizational capacity, and compassion. Vulnerable individuals and households can be identified, health services can be provided, school expenses of orphans can be paid, food can be distributed, and supportive counselling can be provided. Such interventions meet real needs, but the overwhelming majority of agencies and donors that have responded so far have paid too little attention to the massive scale of the problems that continue to increase with no end in sight. As programs to date

have reached only a small fraction of the most vulnerable children in the countries hardest hit by AIDS, the fundamental challenge is to develop interventions that make a difference over the long haul in the lives of the children and families affected by HIV/AIDS at a scale that approaches the magnitude of their needs. (Williamson 2000a:3)

Williamson argues that:

The way a problem is understood has a major influence on what is done about it. The starting point for effective responses to the impacts of the pandemic on children is recognising that families and communities are the first line of response to HIV/AIDS. Whether outside bodies intervene or not, families and communities are going to be dealing with the impacts of HIV/AIDS, often with great difficulty. Consequently, interventions by governments, international organizations, NGOs, religious bodies, and others will have significant, sustainable impacts on children's vulnerability and well-being to the extent that they strengthen the ongoing capacities of affected families and communities to protect and care for vulnerable children. Building family and community capacities is not enough, but it must be the foundation for addressing the impacts of HIV/AIDS on children. (2000a:6)

The long-term nature of the problem, the prolonged duration over which assistance for children and families is required, makes reliance on donor funds for specific projects a tenuous affair. Uganda, for example, has a widespread network of national and international agencies devoted to orphan welfare, yet these agencies are currently addressing only 5–10 per cent of the estimated number of affected children (Subbarao & Coury 2003). This makes it imperative to encourage and sustain indigenous, local, community-based approaches to support vulnerable children. In addition, the broad conclusion of a variety of evaluations indicates that community-driven interventions at the household level appear to be the most cost-effective (Desmond & Gow 2002; Subbarao & Coury 2003). What is urgently required is rigorous assessment of programme approaches that can be scaled up to match the extent of the problem. Finding ways to channel government and non-government funds, whether from external or internal sources, to households and communities is one of the major challenges in this effort.

The main criticism of current programming efforts are that, in general, they are 'all over the place', they have no consistency of approach or target group, and they are tiny in proportion to the urgent need to scale up (Hunter 2000). Scaling up requires a national response, such as free education, that benefits a very large number of vulnerable children simultaneously without bureaucratic strain and cost. It also requires that the range of services offered be enlarged and that programmes are expanded geographically. Hunter (2000), among others, provides a detailed framework for both mainstreaming and scaling up.

1.4 The status of evidence about family and community interventions for orphans and vulnerable children

Programmes to assist children, families and communities have proliferated throughout the region as governments, foreign donors, local non-governmental organisations (NGOs) and community-based groups have responded to the plight of affected children. Very few of

these programmes have been systematically monitored and evaluated, and none that we could identify has been subject to rigorous experimental test. '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 responses should be in any given context' (Grainger, Webb & Elliott 2001:112). Several very good integrations of the available knowledge are available, for example, the recent template assembled by Subbarao and Coury 'to collate and organize the available bits and pieces of information from diverse sources on the profiles of risks faced by OVC, costs and pros and cons of interventions ... to offer guidance on what kind of intervention or approach might work under a given country context or situation' (2003:iv). (See Appendix.)

Attempts have been made here to identify and document good practice with respect to programme approach and principles, and the criteria for good practice have been used in selecting topics for the review. The largest body of information on programme and practice guidelines can be distilled from the planning and evaluation reports of the major international agencies working in the field of children affected by AIDS – UNAIDS, UNICEF, Save the Children, USAID, Family Health International, the World Bank, the Synergy Project, and the Displaced Children and Orphans Fund (DCOF) are examples. However, throughout the literature, there is a strong call for research, monitoring and evaluation of innovative ideas and practices, both to test their effectiveness and explore their possible unintended adverse impacts on children's welfare and programme sustainability.



2. THE IMPACT OF HIV/AIDS ON CHILDREN, FAMILIES AND COMMUNITIES

The impacts of HIV/AIDS on children, families and communities is influenced in the main by the legal and policy environment, access to basic services, socio-economic status, the social and cultural environment, and the extent of knowledge about and acceptance of HIV/AIDS as a problem that affects everyone.

It is widely agreed that the problems of HIV-affected children, families and communities overlap considerably with the problems associated with poverty. However, HIV/AIDS exacerbates these problems, partly because of stigmatisation and partly because multiple stressful events are repeated in affected families and communities. Hunter and Williamson (2000, 2002) have outlined the impacts on children, families and communities as follows:

Table 2: The potential impact of AIDS on children, families and communities

Potential impact on children	Potential impact on families and households	Potential impact on communities
<ul style="list-style-type: none"> • Loss of family and identity • Depression • Reduced well-being • Increased malnutrition, starvation • Failure to immunize or provide health care • Loss of health status • Increased demand in labour • Loss of educational opportunities • Loss of inheritance • Forced migration • Homelessness, vagrancy, crime • Increased street living • Exposure to HIV infection 	<ul style="list-style-type: none"> • Loss of members, grief • Impoverishment • Changes in family composition, and family and child roles • Forced migration • Dissolution • Stress • Inability to provide parental care for children • Lack of income for health care and education • Demoralisation • Long-term pathologies • Decrease in middle generation in households, leaving the old and young 	<ul style="list-style-type: none"> • Reduced labour • Increased poverty • Inability to maintain infrastructure • Loss of skilled labour, including health workers and teachers • Reduced access to health care • Elevated mortality and morbidity • Psychological stress and breakdown • Inability to marshal resources for community-wide initiatives

Source: Hunter & Williamson (2000, 2002)

2.1 Impacts on children

A large number of papers document the impact of HIV/AIDS on children (for example, Desmond & Gow 2002). There is also a substantial literature on the impact of poverty and war on children, both of which have impacts on children very similar to those caused by the HIV/AIDS epidemic (see, for example, Save the Children 1996; UNICEF 2000; Volpi 2002).

Indirect impacts on children include changes in the population structure, household support and livelihood activities, poverty and insecurity, quality and availability of health and education services, and in the morale of the communities in which they live. As Desmond and Gow put it, every child in South Africa will feel the impact of HIV/AIDS, whether first-hand or in the changed nature of the society in which they grow to maturity.

Direct impacts of HIV/AIDS on children occur in the domains of material problems affecting poverty, food security, education and health, as well as non-material problems related to welfare, protection and emotional health, as indicated below:

Material problems

Livelihood

Increased poverty
Loss of property and inheritance
Loss of food security, especially in rural areas
Loss of shelter

Health

Lower nutritional status
Less attention when sick
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

Education

Withdrawal from school to care for others & to save costs
Increased skipping of school
Lower educational performance
Premature termination of education
Fewer vocational opportunities
Traditional knowledge not passed on

Non-material problems⁴

Protection, welfare, emotional health

Decreased adult supervision
Decreased affection, encouragement
Increased labour demands
Harsh treatment
Stigma and social isolation
Forced early marriage
Sexual abuse and exploitation
Abandonment
Institutionalisation
Grief and depression
Antisocial and difficult behaviour

⁴ Adapted from Grainger, Webb & Elliott (2001).

Lorey & Sussman (2001:6) have depicted the impact of HIV/AIDS at the level of individual children in the following way:

Decreased access to and quality of food and nutrition because of:

- Less labour in the household for agricultural and income-generating tasks;
- Difficulty affording and accessing inputs for agricultural and income-generating tasks;
- Declining incomes leads to buying less food and less nutritious food;
- Higher quality, labour intensive crops are replaced with crops that require less labour but offer fewer nutrients;
- Land cultivated by a household may be taken by relatives, creditors, or other parties after the death of a parent;
- Limited food availability in households fostering large numbers of children.

Decreased access to and quality of education because:

- Insufficient funds for fees, books, uniforms, supplies and so on;
- Need for child's labour at home for household tasks, caring for ill adults or siblings, agricultural or income-generating responsibilities, and other tasks;
- Perception of school or travel to school as too risky;
- Perception of education available as poor or irrelevant and therefore unworthy of investment of child's time;
- Diminishing capacity of child to concentrate and interact;
- Illness and death of teachers, principals, administrators, and others responsible for the provision of education – weakening the entire system.

Decreased access to and quality of healthcare because of:

- Less income to pay for medical expenses (medicine, food for patient and caregiver etc.) or for transport to medical facility;
- Less likely to be immunised – unable to cover transport costs; caregiver/parent may not have time, energy or knowledge needed;
- Illness and death of healthcare providers and weakening of entire healthcare systems.

Decreased access to and quality of shelter because of:

- Reduced ability to maintain/repair house;
- Less income to pay for housing rent or upkeep;
- Loss of job can lead to loss of housing;
- Overcrowding when vulnerable children are absorbed into the home.

Increased psychosocial distress caused by:

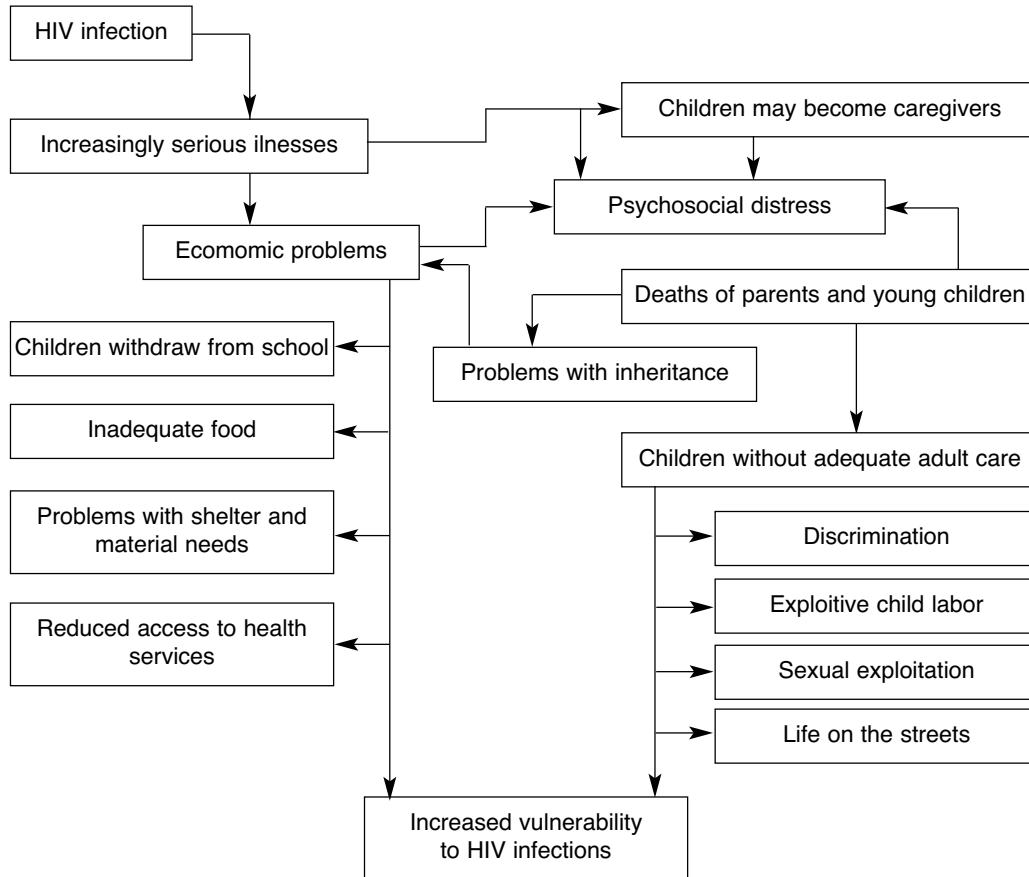
- Grieving for illness and death of parent;
- Worsening economic circumstances;
- Anxiety about the future;
- Separation from siblings;
- Being removed from school and required (by caregivers or circumstances) to work, leading to deprivation of healthy social interaction;
- Stigma, and resulting isolation and discrimination – within community, at school, and sometimes within household;
- Diminishing love, attention and affection.

Higher risk of:

- Abuse (physical and sexual);
- Labour exploitation;
- Early and/or frequent sex due to loss of income, loss of parental care and attention, and interrupted socialisation processes;
- Early (sometimes forced) marriage for girls;
- Exposure to HIV infection, tuberculosis, pneumonia and other diseases.

Foster and Williamson (2000) have represented the inter-related nature of the problems that affect children in the following way, following a time-line for children whose parents become ill with HIV/AIDS:

Figure 1: Problems among children and families affected by HIV/AIDS



Source: Williamson 2000

Orphans and foster children may be additionally disadvantaged by their pre-existing low socio-economic status at the time of their parents' deaths as well as by their biological distance from breadwinners and decision makers in households in which they are placed. Case et al. (2002) found, for example, from data drawn from ten African countries, that orphans tend to live in poorer households than non-orphans. They also found that orphans were less likely to attend school than non-orphans, though this finding was explained largely by the distance of the biological relationship between orphans and the fostering family. However, data on this topic is inconsistent. Ainsworth and Filmer (2002), for example, found that any differences between orphans and non-orphans are dwarfed by the gap between children from poorer and richer households.

2.2 Impacts on families and households

Donahue (1998) and others (Donohue & Williamson 1996) have described a fairly predictable series of stages that households go through as they try to cope with disaster and loss, including those associated with HIV/AIDS. These loss management strategies are described as follows:

Stage 1: Reversible	Seek wage labour Temporary migration to find work Switch to low maintenance subsistence crops Liquidate savings Sell items of property Exchange labour for food Seek help from extended family and community Borrow from formal and informal sources Reduce consumption Decrease spending on education, health etc.
Stage 2: Undermines ability to recover	Sell land, equipment, tools Borrow at debilitating rates Further reduce consumption and expenditure Reduce land farmed and crops produced
Stage 3: Destitution	Dependent on charity Break-up of household Distress migration

Within this process of progressive loss and adaptation to loss, specific impacts on children, families and communities can be discerned. The loss of economic coping capacity causes both stresses in household members as well as loss of social support from others as well as towards each other. Under these circumstances, children and other dependent members become vulnerable to harsh treatment.

Direct impacts of HIV/AIDS on families and households are discernible as families attempt to adjust to the stresses of economic decline and demoralisation. These include:

- The emergence of child- or adolescent-headed households;
- An increase in elderly caregivers, and children caring for old people;
- Increases in household dependency ratios;
- Separation of siblings;
- Family breakdown;
- Child abandonment;
- Remarriage.

Apart from economic issues, such as the livelihood activities of household members, a number of key demographic dimensions mediate the impact of HIV/AIDS on children, families and communities. These include gender, ages of affected children, and the location of the household.

Gender

In some southern African countries, the education of girls is considered to be less important than that of boys, and girls are more likely to be withdrawn from school to perform household work and care for sick family members. On the other hand, in some contexts boys are regarded as more likely to contribute to production and so are more likely to be fostered under conditions of emergency (Caldwell 1997).

The gender of the head of the household is also an important factor. In general, women and young girls take on the burden of caring for sick members and for children, and female-headed households tend to be poorer than households headed by men. On the other hand, female household heads allocate more resources to children and to food, healthcare and education than male heads (Donahue 1998; Donahue & Williamson 2000). So, while female-headed households might be poorer than male-headed households, children's needs are more likely to be addressed in female-headed households.

It is of concern that women are additionally burdened by the reliance on home-based care in many parts of the region.

Ages of affected children

Children will be affected in different ways depending on their age. Infants and toddlers are especially vulnerable to health risks and to the negative effects of group care. Preschool children are especially vulnerable to nutritional deficiencies, abuse and neglect and to loss of stimulation and opportunities for schooling. Children in their pre-teen and teen years are vulnerable to dropping out of school, to overwork and to sexual exploitation. Children of all ages are vulnerable to the emotional stresses of losing caregivers, and of being dislocated from home and community. A recent Guideline for Early Childhood Development has attempted to address the issues of young orphans under five years of age,⁵ but less attention has been given to the needs of children in middle childhood and early adolescence.

Location of the household

Households in rural and urban areas face different challenges. Rural households tend to be poorer, with fewer working-age adults as compared to urban households. Children in rural areas carry a substantial burden of subsistence activities. In informal urban areas, social networks are less developed and less supportive, caregivers are frequently absent as a result of livelihood activities, and this leaves children less protected.

2.3 Impacts on communities

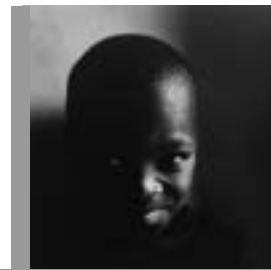
Communities are affected by the decline in skilled and professional services as the HIV/AIDS epidemic progresses, as well as by the strain on service delivery, particularly in health and education. Stresses increase as familiar people become ill and die, and morale declines. Kin and neighbours take on the support of affected families, thus stretching the resources of everyone. In small communities, a pall hangs over normally happy occasions such as weddings.

5 Young (2002). <http://www.worldbank.org/children/ECDGuidelines.html>

According to the Jaipur Paradigm developed by Barnett, Whiteside and Decosas (2000), the speed and extent with which the epidemic affects communities depends on the overall wealth of the community and the degree of social cohesion that pertains in the society. By social cohesion is meant the strength of community groups such as parent-teacher associations, faith-based groups, and others who are in a position to act in a united way to mitigate the effects of the epidemic on the community.

There are no short cuts or quick solutions. A sustained commitment to protecting and improving the lives of these children needs to link local actions with those at the national and global level, so that new interventions can achieve the widest possible impact. (Levine 2001)

3. COMMUNITY-BASED APPROACHES TO CARING FOR CHILDREN AFFECTED BY HIV/AIDS



There is general agreement in the literature reviewed that there are five key strategies necessary to assist vulnerable children. These five strategies, which were endorsed by the UNAIDS Committee of Co-sponsoring Organizations in November 2001, are:

1. Strengthen and support the capacity of families to protect and care for their children;
2. Mobilise and strengthen community-based responses;
3. Strengthen the capacity of children and young people to meet their own needs;
4. Ensure that governments develop appropriate policies, including legal and programmatic frameworks, as well as essential services for the most vulnerable children;
5. Raise awareness within societies to create an environment that enables support for children affected by HIV/AIDS.

At the same time, the Committee of Co-sponsoring Organizations endorsed 12 principles to guide organisations helping children affected by HIV/AIDS. These principles are:

1. Strengthen the protection and care of orphans and other vulnerable children within their extended families and communities;
2. Strengthen the economic coping capacities of families and communities;
3. Enhance the capacity of families and communities to respond to the psychosocial needs of orphans, vulnerable children and their caregivers;
4. Link HIV/AIDS prevention activities, care and support for people living with HIV/AIDS, and efforts to support orphans and other vulnerable children;
5. Focus on the most vulnerable children and communities, not only those orphaned by AIDS;
6. Give particular attention to the role of boys and girls, and men and women, and address gender discrimination;
7. Ensure the full involvement of young people as part of the solution;
8. Strengthen schools and ensure access to education;
9. Reduce stigma and discrimination;
10. Accelerate learning and information exchange;
11. Strengthen partners and partnerships at all levels and build coalitions among key stakeholders;
12. Ensure that external support strengthens and does not undermine community initiatives and motivation.

Additional programming principles, added by Family Health International (2001) and other organisations, include:

- Work to prevent HIV infection among children and adolescents made vulnerable by AIDS, and among adults, to prevent further orphaning;
- Continue to advocate for care and support of orphans and other vulnerable children within the family and community contexts;
- Contribute to the development of and remain abreast of current national strategy and, where possible, undertake innovative activities to inform the further development of that strategy;
- Link care programmes with other HIV/AIDS programmes to provide a holistic and comprehensive system of support to families and communities;
- Link with other partners to co-ordinate programme efforts and provide services.

Extended families, kin and communities remain the principal supports for children affected by HIV/AIDS in sub-Saharan Africa. In rural Tanzania, for example, 95 per cent

of orphans are taken care of by relatives (Urassa et al. 1997). Studies in many countries in Africa and elsewhere find that families and communities will absorb orphaned and affected children as long as their resources are sufficient (Family Health International 2001).

In the main, surviving mothers and related women are the mainstay of support for affected children. While surviving fathers are less likely to care for children than surviving mothers, this tendency seems to be changing (Case et al. 2002). In most settings, grandparents are the most common caregivers. Community-based approaches focus on supporting adults in households and communities in an effort to benefit affected children on the assumption that children are dependent on adults. However, more family or informal fosterage is occurring as a result of necessity and children are pushed into households, rather than being pulled, and this makes them very vulnerable (Subbarao & Coury 2003). In addition, older caregivers may have difficulties responding to the economic, health and psychological needs of children and households in which very old caregivers have responsibility for children may suffer severe resource constraints. In addition, grandparents themselves may die, leaving children who have experienced multiple losses. Although child-headed households are reported to be increasing, there are problems with available data (Desmond, Richter, Makiwane & Amoateng 2003).

Spontaneous community-based initiatives, devised by local communities to help vulnerable children and families, include:

- Communal land and crop production;
- Orphan registration and home visiting programmes to provide relief food, clothing, school fees;
- Home-based care for ill people and their families;
- Labour sharing to relieve carers and to enable children to attend school;
- Communal labour to repair houses and schools;
- Organised individual or group income-generating activities (IGA), often involving small trade selling home-made food or vegetables.

These activities may be driven by local groups such as faith-based organisations (Family AIDS Caring Trust 2002), but frequently also by the charismatic leadership of one or more concerned individuals. The activities are not sustainable in the long term without additional assistance. While people volunteer their time, they frequently do not have the resources to continue to provide material support to affected children and families.

Subbarao and Coury (2003) have summarised approaches to community-based interventions developed to date (see Appendix 2, Tables 9, 10 and 11). In summarising this material they note that there are a number of problems with community-based programmes. To date, most programme initiatives have been sporadic and piecemeal, rather than well-funded national programmes; there are few success stories to inform the sustainability of programmes; most programmes are run by volunteers without the expertise to evaluate their efforts or to conceive their activities on a larger scale; and there have been few developmental interventions (for example, that focus on IGAs) in comparison to the large number of programmes which attempt to provide direct assistance to orphans. The key challenges of spontaneous community-based initiatives are for government to stimulate community awareness and response and to achieve sustainability through stable government and donor support.

Care and support for vulnerable children has tended to focus on meeting material needs. A secondary focus is sometimes to address the education of children and skills transfer. Very few programmes adequately address the medical, social, welfare and psychological needs of children affected by AIDS. In addition, attention has to be given to socio-economic support, human rights and legal assistance in a mutually reinforcing way. Only a handbook of programmes are comprehensive and all programmes have difficulties in reaching anything like the required number of needy children (Family Health International 2001). For this reason, replication, scaling up and sustainability are key issues for all programmes (Family AIDS Caring Trust 2002).

Comprehensive care and support programmes should include:

- *Policies and laws* to ensure the care and protection of vulnerable children, including clauses to prohibit discrimination in access to medical services, education, employment, housing; laws to prevent abuse and neglect; and to protect inheritance rights of women and children. Policies should also prevent inappropriate institutionalisation of children and ensure better alternative forms of care for children without adequate family care such as foster care, adoption and small group homes that are integrated into the community. The application and implementation of existing laws and policies must be strengthened.
- *Medical care* that includes access to preventive and clinical health services, nutritional support, palliative care and home-based care.
- *Socio-economic support*, 'When families and children are forced to focus on daily needs to decrease their suffering, attention is diverted from factors that contribute to long-term health and well-being' (Family Health International 2001:4). This contributes to secondary socio-economic effects on health and development. Micro-finance programmes, especially in the form of village banking, managed with expertise, need to be targeted to overlap geographically with programmes for orphans and vulnerable children rather than specifically targeting AIDS-affected households or children.
- *Psychosocial support* continues to be one of the most neglected areas of support for vulnerable children. 'The HIV epidemic has increased the urgency to address psychological problems of children in equal proportion to other interventions' (Family Health International 2001:5). The long-term consequences for children who experience profound loss, grief, hopelessness, fear and anxiety, without assistance, can include psychosomatic disorders, chronic depression, low self-esteem, low levels of life skills, learning disabilities, and disturbed social behaviour. In addition to other mechanisms, teachers should be trained to recognise and respond supportively to withdrawn or disruptive behaviour, or a drop in academic performance or school attendance. Structured community activities that include recreation, religious, cultural and sports activities provide opportunities for the integration of isolated orphans and other vulnerable children.
- *Education* needs to be maintained, both at the level of the individual child, as well as at the systemic level where the quality of education is affected by teacher shortages related to illness, family care responsibilities, and funeral duties. Education needs to be linked to other interventions such as nutrition and psychosocial support so that programmes act holistically to maintain children's school attendance and maximise the benefits of education.
- *Human rights*-based approaches are essential as a framework for programmes to support vulnerable children.

'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). International experience suggests that every effort has to be made to preserve and strengthen the traditional safety net of family, kin and community (Subbarao & Coury 2003). Very little programme information is available on community-based approaches and it is difficult to discern principles of good practice in this area (Grainger et al. 2001). However, one of the means for doing this is through livelihood support and income-generating activities .

3.1 Needs of adult caregivers

Family structure and function is changing as a result of the HIV/AIDS epidemic. Emerging family forms include: elderly household heads with young children; large families with unrelated (fostered or adopted) children; child-headed households; single-parent households; formal or informal cluster foster care; and itinerant or homeless families (Hunter 2000). All these family forms need to be supported because they provide care for children and other dependent members.

Because families are absorbing the care of affected children, this does not mean that they are doing so without difficulty. 'In private', observes Hunter, 'some guardians express dismay at having to restart families late in their lives, both in terms of their loss of personal freedom and in their anxiety about meeting the needs of small children financially, physically, and emotionally. They are also frustrated by the behaviour problems of children and young people who have been traumatised by the sequence of events surrounding their parents' deaths. The adults may be traumatised themselves by repeated deaths within their families' (2000:15).

An operations research study in Uganda which looked at how to achieve maximise programme benefits for vulnerable children, drew attention to the fact that adult caregivers, parents and guardians, have needs of their own that must be addressed to support and prolong their capacity to care for children affected by HIV/AIDS (Gilborn et al. 2001). This study recommended the following broad principles to include in caregiver support programmes:

- *Reach children affected by AIDS before they become orphans* and enable people living with AIDS to address their concerns about the future welfare of their children;
- *Increase community awareness and accountability about the property rights of women and children.* This is especially important because most surviving caregivers are women, and a substantial proportion is young. Efforts to promote the writing of wills must be accompanied by commitments by relatives and community leaders to uphold property rights. Community groups and local leaders (government, traditional and spiritual) must be mobilised to help enforce property rights;
- *Address the critical health needs of adult caregivers, including guardians.* Care and support services need to be provided to caregivers to maintain their health and prolong their capacity to care for children. This will minimise the toll of illness and death on children, improve their access to school, and delay their primary, secondary or tertiary orphaning.
- *Improve adult-to-child communication and provide counselling on difficult issues, including parental illness, parental death, and sex education.* Many parents and guardians express a need for support and advice on discussing difficult issues with

children. It is important to respond to this need to avoid children's psychosocial needs from being overlooked.

- *Address the material needs of AIDS-affected households, including those headed by HIV-positive parents and guardians.* This can be done through IGAs, vocational training, food, clothing, home repairs, or school fees.
- *Improve the morale of children affected by AIDS by keeping children in school and offering sports and recreation facilities.* School and other activities maintain the psychological well-being of children and reduce the burden of childcare on stressed caregivers.
- *Address stigmatisation of and discrimination against AIDS-affected adults and children.* Fear of disclosure limits parents' ability to appoint guardians and to take other steps to secure the future of their children. Strategies include communal monitoring to reduce mistreatment of children and AIDS-affected households, including teasing, gossip, neglect and abuse.
- *Involve future guardians in intervention efforts,* including income-generation projects.

3.2 Role of external agencies

In this respect, concern has been growing around the role of external donors and external organisations, and the need to find ways to ensure that external forces support, rather than undermine, the emergence and sustainability of community-based activities. This problem is not unique to HIV/AIDS, but the scale and urgency of the problem of the HIV/AIDS epidemic can lead to ill-planned actions by external agencies with insufficient consultation. External agencies may divert the agenda of community actions; inappropriate targeting may leave vulnerable groups unsupported and cause resentment; material support from the outside may have the effect of disrupting community actions or relieving communities of a sense of responsibility; and communities may be left worse off when the programme is terminated because spontaneous initiatives did not develop or were suspended (Grainger et al. 2001).

There is also concern that an emphasis on community-based initiatives should not reduce the role of government in creating an enabling environment for community initiatives, including financial and infrastructural support.

There is consensus that it is inappropriate for external agencies to plan to provide material and financial support directly to affected households and children except in emergencies. It is too expensive to maintain over the long term and such relief is able to assist only a small proportion of children at risk (Williamson 1995).

The key roles of international organisations in supporting community-based activities include:

- Raising awareness about the impacts of HIV/AIDS, particularly on children;
- Training and capacity development;
- Strengthening institutions and developing systems;
- Supporting the collection and analysis of information about and for affected communities;
- Disseminating examples of good practice;
- Linking communities with appropriate sources of support;

- Monitoring and evaluation;
- Advocacy on behalf of affected groups. (Donahue 1999; Grainger et al. 2001)

Lorey and Sussman (2001) also suggest that external agencies can provide several kinds of aid, including the provision of incentives and other forms of compensation for community volunteers; provision of material assistance and other emergency relief commodities for vulnerable community members; and provision of funding for community projects through small grant schemes. Providing incentives for volunteers is a debatable point, as it is frequently considered unsustainable. It is also difficult to expand or scale-up volunteer programmes if incentives are included. The argument that payment distorts an individual's sense of responsibility is not an acceptable reason for not paying community workers, particularly given that the NGO staff managing the project are paid. It is also clear that when people are living on and below the breadline, it is difficult to give up the one resource they have, which is time. It is remarkable that voluntarism is as prevalent as it is in very poor communities, and it demonstrates the maintenance of a high level of common humanity.

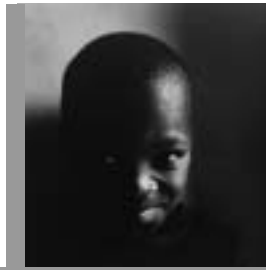
In their desire to support community initiatives, external organizations must be careful to avoid undermining community coping. There is a proverb from the Congo that goes 'When you call for rain, remember to protect the banana trees.' In other words, the provision of external resources can, if we are not careful, actually make matters worse by flattening local responses. External agencies would do well to remember that community initiatives are the frontline response to orphans and vulnerable children and plan their responses accordingly. (Foster 2001)

One of the major challenges facing efforts by international and local governments, donors and philanthropic organisations to assist vulnerable children is the development of mechanisms for channelling resources to grassroots organisations. Large-scale international assistance often has had disappointing results and, 'increasingly, donors are recognising that the most sustainable and cost-effective efforts to protect, support and assist orphans and other children made vulnerable by AIDS are those that are carried out by grassroots community groups' (Williamson, Lorey & Foster 2001). Grassroots organisations can be overwhelmed when they receive too much funding too quickly without parallel increases in management capacity. On the other hand, donors have no mechanisms for channelling small amounts of money in keeping with the needs and capacity of community-based organisations (CBOs) and informal community initiatives. Based on a meeting held in 2001, the following mechanisms for channelling resources were suggested (Williamson, Lorey & Foster 2001:5):⁶

- Creation of a network of groups working for children, such as the Children in Need Network (CHIN) in Zambia;
- A multi-layer committee structure such as the Orphans and Vulnerable Children Committees (OVCCs) in Zambia;
- Capacity-building NGOs, such as the Family AIDS Caring Trust in Zimbabwe;
- A Request for Applications (RFA) process, such as that used by USAID;
- A national or area fund, such as the Nelson Mandela Children's Fund in South Africa
- International funding structures, such as the Firelight Foundation.

⁶ It should be borne in mind that each mechanism has potential advantages and disadvantages, and the combination of approaches most effective for a particular situation has to be assessed.

4. ORPHAN REGISTRATION PROGRAMMES



Both the rights-based approach recommended for interventions for vulnerable children, and efforts to avoid stigmatisation of affected children, advocate that the targeting of orphans, particularly AIDS orphans, should be avoided. Definitions of vulnerability and criteria for targeting should be developed with and agreed by the community.

Orphan registration programmes aim to increase the accuracy of estimates of the numbers of orphans and to identify children and households for relief programming and monitoring. However, it is argued that the accuracy of national orphan numbers is only partially relevant to the issue of determining and responding to vulnerable children.

To date, orphan registration programmes in the region have been largely unsuccessful because they are costly and difficult to maintain, they tend to be unreliable and they raise expectations for assistance which is not always forthcoming or consistent. The national orphan registration programme in Malawi, for example, is considered to have failed although the evaluation team recommended registration in small areas as preparation for the introduction of programmes. Localised orphan registration and visiting programmes have overcome the problems associated with national efforts, and are considered a good entry point into communities, and for creating awareness of the impact of HIV/AIDS on children (Grainger et al. 2001).

Some concerns, however, have been expressed about the value of even localised orphan registration programmes on the basis that:

- Material assistance in the forms of food and clothing is not sustainable given the level and scale of the epidemic;
- Programmes tend to focus on the material needs of orphans because they are easier to address than psychosocial needs;
- Programmes seldom respond to sensitive issues, such as the sexual abuse or labour exploitation of children.

One recommendation to counter these concerns is to include affected children in programme activities (Mc Kerrow 1997).

At the local level, registers of vulnerable children are helpful for record keeping and monitoring, and usually include basic information on names, location, ages, health status, and needs of vulnerable children, some assessment of the main causes of children's vulnerability, age and health status of caregivers, records of visits and assistance given, and so on (Lorey & Sussman 2001).

Community-based programmes to support vulnerable children through orphan identification

Despite some negative views regarding their role and impact, faith-based organisations (FBOs) offer some of the most viable programmes to address the impact of HIV/AIDS on children and families. In a recent study which sought to measure the impact of care projects run by FBOs, Foster (2003) reported that FBO-run initiatives are more numerous, and are reaching more orphans and vulnerable children, than previously thought. According to his estimates more than 140 000 children in six southern African countries are being given spiritual, material, education and psychosocial support by over 7 800 volunteers. Although most of these projects are small in scale, their cumulative impact exceeds that of NGOs.

The success and effectiveness of numerous faith-based projects operating in Africa is attributed to the fact that care and compassion for the vulnerable is intrinsic to religious doctrines. Religious bodies are an integral part of community infrastructure, and provide a coherent social network within which projects can be initiated and sustained. There is also a rationale, beyond lack of resources, for volunteer work. FBOs generally receive little or no external financial support and technical expertise, and are willing to commit their own time, skills and resources to ensure the well-being of vulnerable children.

Mudekunye (2002), points out that FBOs have a number of inherent qualities that make them particularly effective conduits for community based care interventions. For example, FBOs are able to:

- Identify vulnerable and needy children. The presence of members of FBOs throughout communities who make it their business and religious duty to care for vulnerable people, are able to identify these children within the community;
- Refer children on to other services, and can assist in the distribution of emergency relief to children;
- Play a significant role in reducing stigma and discrimination through a spirit of acceptance of those who are infected and affected by HIV/AIDS and other disease;
- Offer support to caregivers (who are generally female, elderly or very young, poor, and/or ill);
- Also to be actively involved in offering guidance and advice on succession planning, and will-preparation;
- Facilitate communities to respect the rights of children to an inheritance, and to discourage property grabbing;
- Also to offer support in the form of counselling, for children with ill parents, and for children whose caregivers have died;
- FBO members can visit children and families, and actively discourage abuse from caregivers and neighbours. They can also act as significant adults in children's lives.

FOCUS: An example of a faith based organisation

An example of such a FBO is the FOCUS (Families, Orphans and Children under Stress) programme, a Christian-based AIDS service organisation, initiated in 1987 by FACT (Family AIDS Caring Trust), Zimbabwe's oldest and longest running AIDS service organisation. FACT has built a large church- and community- based response to HIV/AIDS in rural Mutare in the Eastern Highlands of Zimbabwe. In the late 1980s, paediatrician (and founder Director of FACT), Geoff Foster, noticed that many children who attended the Mutare Provincial hospital clinic had terminally ill parents, or were accompanied to the clinic by relatives because their parents were dead or too ill to bring the child to the health services. In addition, FACT home-based care workers were noticing that children were being left orphaned and uncared for. This resulted in an orphan identification effort, which was linked to an existing maternal and child health survey in Manicaland. One in every 15 children was found to be orphaned, and that many of these children were being cared for by their extended family. This led to the establishment of FOCUS, which aimed to work with communities to assist in caring for orphans, by building on existing community visiting practices.



FOCUS's main aim is to assist communities to care for orphans, and they do this by:

- Identifying orphaned children (accurate identification is crucial for the successful operation of FOCUS);
- Assessing and prioritising those in greatest need (children living without adult supervision, withdrawn children, children being cared for by a terminally ill caregiver, children in rags, children in homes where there is clearly no food, or no sign of food preparation, etc.);
- Visiting the most needy at least twice a month;
- Establishing partnership and co-operation with other community groups, leaders and organisations;
- Maximising community response, involvement and ownership of the project, thereby reducing dependence on FACT;
- Increasing sustainability by limiting provision of material support, and encouraging maximising community resources where possible. This also minimises counter-productive dependency and avoids undermining effective community coping mechanisms.

In 1993 a Pentecostal congregation piloted the new FOCUS programme, recruiting 25 women from 18 villages in an area with a population of 10 611 living in 2 089 households. Further requests by traditional leaders of other communities for inclusion in the programme resulted in the recruitment of more volunteers. The case load was approximately ten households per volunteer.

The programme emphasises monitoring of and caring for orphans through visitation. Volunteers, of which there are now over 140, identify and count all orphans in their communal area, and these are recorded in a register. The poorest of the poor orphans and households are recorded in a Priority Register, and these households are visited regularly by the volunteers.

To ensure transparency and fairness in the selection of priority households, a committee of community leaders reviews the selections of the volunteers. Respected and credible people of good standing were nominated by the community and church leaders to be volunteers. Most volunteers were widows or women already caring for orphans and vulnerable children. Volunteers were originally trained by FACT staff, and ongoing training, supervision, and monitoring were provided by the programme co-ordinator on a monthly basis during meetings in the community. Mafuka (2002) points out that this involvement of community members in selecting the orphans for assistance enhances the degree of confidence and faith that community members place in the programme. Volunteers are given the responsibility of caring for the identified households within a 2km radius of their own homes, and of visiting them regularly. Whilst the main role of volunteers is to support and advise caregivers, sometimes the volunteer needs to work directly with the child especially if no caregiver is present. During visits, volunteers can undertake any of a range of tasks including support in the form of counselling and encouraging children to cope, as well as practical assistance and home management help such as cleaning the house, fetching water, and teaching mending skills. Sometimes children need medical care, and volunteers take them to a clinic. In other cases, volunteers may bathe the younger children and sing and pray with them. Extremely needy households



are provided with essential material support such as maize seed in summer, and clothes and blankets in winter. School levies are also paid. Income-generating activities included gardening, poultry and goat-keeping, sewing, crocheting, knitting, and mushroom growing.

Volunteers were trained by FACT staff, and were given ongoing training, supervision and monitoring at monthly meetings. A record-keeping system ensures that track is kept of all homes visited and activities carried out. These records are used for research purposes, for funding, and for evaluations. However, the records are also used to reassure volunteers that their work is meaningful. The altruistic commitment of volunteers (who receive no salary for their work), and the community ownership of the project, are seen to be the main reasons for the sustainability of FOCUS's activities. Volunteers receive only small incentives such as bus-fare to supervision meetings, a T-shirt, skirt and training shoes once a year, as well as a Christmas bonus of US\$10. Volunteers who care for orphans in their own homes are given a subsidy of about US\$11 per annum.

The first evaluation was of the pilot project in 1995. FOCUS was found to be a low-cost project with high levels of community ownership, requiring a minimum of external support, effective in reaching the poorest of orphan households, and replicable. An evaluation and best practice analysis was conducted in 1999 and 2000.

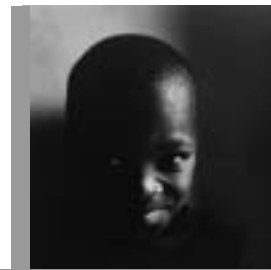
In 1999, seven FOCUS sites reported having made 93 000 visits to 2 170 households with a population of about 6 500 orphans and vulnerable children; 992 children were able to attend primary school because their school levies of between \$2 and \$4 were being paid. Additional impact indicators showed that, in nine FOCUS sites:

- 2 764 households were on priority registers;
- Between 1996 and 1999 households visited increased from 798 to 2 170;
- Between 1996 and 1999 volunteers increased from 81 to 142;
- Total programme costs per annum = US\$20 000 to US\$30 000;
- Annual cost per family = US\$10;
- Of 178 volunteers, 97 per cent were female. Of the few males involved in the programme, almost all were pastors paid monthly allowances by FACT.

FOCUS was replicated in 1995 by the Marange Methodist Church, and the programme now operates without FACT support. This project has enrolled 98 volunteers who provide care and support for about 1 500 needy children. Two more replications followed, the fourth replication involving 35 volunteers who support 320 orphans.

Foster, G. (2003). Study of the responses by faith-based organizations to orphans and vulnerable children: Preliminary summary report. World Conference of Religions for Peace/UNICEF.

5. FACILITATING ACCESS TO ADEQUATE NUTRITION AND HEALTHCARE



5.1 Nutritional assistance for preschool children

Preschool children are particularly vulnerable to the effects of undernutrition, which stunts growth, reduces children's resistance to disease and slows their cognitive development. Nutritional assistance, in the form of community-based feeding programmes, needs to be given to children at risk of becoming malnourished. Donors are frequently willing to support feeding programmes, but this renders such programmes susceptible to termination when donor agendas change.

Some experience suggests that feeding needs to be targeted directly to vulnerable children, to avoid the problem of food intended for children being consumed by adults or families taking in children in order to obtain nutritional assistance (World Bank 1997). In contrast, it is argued that all children in communities affected by HIV/AIDS are more equitably served by a broad-based feeding programme, which is often easier to manage than targeted programmes.

Early Child Care and Education (ECCE) centres, schools and community centres can be used to provide assistance to affected communities, including feeding, and school-feeding programmes can ensure that children have at least one meal a day.

Nutritional assistance – Africa KidSAFE

Zambia has been hard hit by the HIV/AIDS epidemic. Figures estimate that approximately a fifth of the population is infected. The high adult mortality has meant that the country is also faced with a severe orphans crisis. About 1.2 million children (constituting 27 per cent of all children under the age of 15 years of age) have been orphaned. Many of these children have also lost their homes and are forced to live on the streets. By 2002 it was estimated that there were 75 000 street children in Lusaka alone, a number that was expected to grow with the worsening HIV/AIDS situation.

Project Concern International (PCI) had been operating HIV/AIDS programmes in Zambia since 1996. PCI is an international non-profit health and humanitarian organisation, which was established in California in 1961. The primary goal of the organisation is to foster community mobilisation and partnerships in their projects and the inclusion of volunteers and local organisations is highly encouraged. In 2000 the organisation decided that a strategy to deal with the increasing numbers of street children needed to be put into place. In that year PCI formed a partnership with Fountain of Hope (FOH). FOH was established in 1996 by a few people in their 20s. Many of the staff are volunteers who receive no salaries for their services. They go into communities trying to identify street children and get them placed in their programmes. They are in regular contact with over 1 500 children on a daily basis. In terms of their programmes, they ensure that over 400 children get to school every day and that others get to their skills training programmes. They are also responsible for shelter and food for 600–700 children every day.

In 2000 PCI and FOH established KidSAFE, SAFE being an acronym for Shelter, Advocacy, Food and Education. The objectives of this programme were to assess



existing community resources that could be used to deal with the orphans crisis and to identify sustainable solutions. KidSAFE supports partner groups in five Zambian cities with the largest numbers of street children.

PCI and FOH have instituted food programmes with partner organisations. One such project is a pig- and chicken-raising initiative which serves both as a source of income and food. Many partners also have feeding schemes set up on their premises. An accomplishment of the programme is that within 6 months of it being established, about 2 000 children were being provided with food, schooling and access to health facilities. At their centres, the Africa KidSAFE partners have feeding programmes for the children, medical staff (or referral relationships with outside medical facilities), trained counsellors, and regularly scheduled recreational activities for the children.

The Africa KidSAFE initiative is based on the idea that in order for communities to respond effectively to the overwhelming orphans and street children crisis, the capacity of local community-based groups to design and implement programs must be strengthened. The existence of local organisations capable of conducting meaningful assessments of community needs, designing effective and sustainable programs, raising funds to finance their operations, and appropriately evaluating the impact of the programmes and the potential for successful scale-up, will greatly increase the country's ability to address the needs of the street children. Accordingly, Project Concern's role in the Africa KidSAFE network is to build the capacity of the local partners so that they can help more children more effectively. Through training workshops, technical assistance, assistance with proposal design and preparation, and guidance on monitoring and evaluating performance, Project Concern is helping the partners become strong, effective and stable institutions that can form a safety net for Zambian children.

Lemba, M. (2001). Evaluation Report Zam 2001/ 009: Rapid assessment of street children in Lusaka. UNICEF Database PCI (2002). Annual Report: Healthy families for generations to come. California: Project Concern International Synergy Project (2001) USAID project profiles: Children affected by HIV/AIDS. Washington DC: USAID

5.2 Assuring access to healthcare for affected children

Children require preventive health services such as immunisations and growth monitoring, as well as access to treatment for the variety of ailments, injuries and infections to which children living in marginal conditions are liable. Apart from poverty, children affected by HIV/AIDS are sometimes victims of stigmatisation that may prevent their access to health services

In HIV/AIDS-affected communities, access to health services may be limited and the health service itself may be incapacitated by the epidemic. In severely affected communities, external agencies may have to bolster the capacity of the health system.

Home-based care services and outreach clubs, as well as ECCE centres and schools, provide opportunities to monitor children's health and to identify children for referral to the health service. Assistance with transport may have to be provided by external

agencies. It has also been recommended that the capacity of traditional healers to support affected children should be strengthened.

For older children and adolescents, 'youth-friendly' services are important to deal with sexual abuse, sexual exploitation, to provide information and protection to deal with threats of HIV infection, as well as to offer treatment for sexually transmitted infections.



6. FACILITATING ACCESS TO EDUCATION

Apart from the rights, social development and individual adjustment arguments for ensuring continued access to education for vulnerable children, education is a basic HIV/AIDS prevention tool. There is a well-established correlation between educational attainment and safer sex behaviour, which can translate into lower rates of new infection. In addition, schools are an important point for providing information about HIV (Ainsworth in Rosen 2002).

As noted by a number of people, the education needs of children and adolescents vary enormously depending on a child's age, whether they are in school or not, whether they have lost one or both parents, whether they have economic and care responsibilities, and whether they are HIV positive (McDermott in Rosen 2002).

Children affected by HIV/AIDS drop out of school for a variety of reasons. '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 also do not attend school because elderly caregivers are not convinced of its relevance and they prefer to keep the child at home to assist with household work. For this reason, a variety of approaches have been tried to give assistance to families and communities to keep children in school.

Some programmes focus narrowly on the provision of formal education. In seeking appropriate interventions for particular communities and households, education broadly needs to include formal schooling, revision of the curriculum in formal education, informal education, vocational training, apprenticeships, and the transfer of traditional knowledge and skill by community and kin.

Five primary obstacles to schooling have been identified: prohibitive informal and formal costs of primary education and the corresponding increases in poverty with the epidemic; increasing reliance of households on children for domestic responsibilities; stigmatisation of children from AIDS-affected households; decreasing quality of education, which is devaluing school for parents and children alike; and a growing fear that the school setting increases the vulnerability of children, especially girls. Sexual harassment and the abuse of female students by teachers is a long-standing problem.

Hepburn (in Rosen 2002) lists four categories of initiatives to increase primary education for orphans and vulnerable children in AIDS-affected areas:

- Subsidising school-related costs;
- Restructuring educational delivery, for example, through communal schooling;
- Increasing access indirectly, through microfinance or advocacy;
- Improving educational quality through curriculum revision or by providing psychosocial support and other services in schools.

Hepburn's review also covers lesson learned in educational programming. One of the most important of these is to serve all vulnerable children in affected areas. 'Although orphans deserve special consideration, orphans-only schools or programs are programmatically inappropriate because they isolate orphans and increase stigmatisation' (in Rosen 2002:9).

6.1 Direct assistance

School fee waivers, school vouchers, and payment for uniforms, books and fees are a common element of community-based support programmes for children affected by HIV/AIDS. Although it is often necessary to provide emergency relief, there is concern that the scale of the epidemic makes direct assistance difficult to maintain in the long-term. It also necessitates targeting of children, and sometimes inappropriately, only of so-called 'AIDS orphans' at the expense of other vulnerable children. It is feared that this kind of targeting will encourage destitute families to offer children up as orphans in order to secure assistance.

6.2 Provision of early childhood care and education (ECCE)

In many parts of the region, ECCE networks extend into remote communities. ECCE facilities can provide safe care for affected children while caregivers are busy at home or at work, nutrition, shelter, access to healthcare and much needed stimulation and support for young children. The expansion and improvement of ECCE is a national-level intervention with the potential to benefit a very large number of vulnerable children.

6.3 Community-based schools and schooling for working children

Some communities have set up alternative schools with volunteer teachers to enable affected children to remain in education. Community schools are cheaper than government schools, but need extensive volunteer input and donations for facilities and teaching materials (Nampanya-Serpell 1998). In the long term, community schools are unlikely to be sustainable.

Informal education has been provided to working children and street children to become numerate and literate and to get some vocational training. In South America, many such programmes provide education alongside income-earning activities, such as waste collection for recycling, and this concept has been incorporated into some programmes in Africa (Williamson 1995).

Interactive Radio Instruction Programme for Out-of-School children, Zambia

This programme was implemented as a response to the dramatically declining number of children enrolled in school in Zambia. The AIDS epidemic has played a significant role in this crisis. Parental deaths and the high rates of mortality amongst teachers has impacted negatively on the education system and the orphan crisis (approximately 700 000 in the country) has presented an almost insurmountable predicament. The large number of school-age children out of school has also been attributed to the inability to pay school fees, teenage pregnancy, shortage of facilities and the long distances to some schools.

The Interactive Radio Instruction Programme for Out-of-School Children (IRI) is a joint effort between communities, churches, non-governmental organisations, and community-based organisations, the Ministry of Education, and the Peace Corps. The programme was funded by USAID for the period 2000–2003. The chief implementing body is the Education Development Centre, which trains the producers of the radio



broadcasts. The Centre also trains the instructors who in turn train the tutors who facilitate the community-based programmes. Each participant body fulfils certain roles. The programmes are developed and aired by the Education Broadcast System, which is part of the Ministry of Education. The Department of Education provides training for tutors who are based at the various learning centres. Churches, community-based organisations and non-governmental organisations provide venues for the learning centres, some of the tutors and radio equipment. These groups are also responsible for recruiting children for the programmes.

Children between the ages of 8 and 10 years age are placed in groups that meet at designated IRI venues. A mentor facilitates each group. This tutor is provided with a guide to the lessons that are being broadcast and is able to assist the children with the lesson.

The mentors are individuals who have completed Grade 9 or Grade 12 and are subsequently trained by the Educational Broadcasting Services. The programme has some degree of sustainability in that these mentors are compelled to coach another community member during the lessons to be an assistant mentor. This assistant mentor is also required to conduct the IRI lesson in the event that the mentor is unavailable. The mentors are assisted financially and in kind (with food and other material goods) by communities via community IRI committees, which administer the programme at the community level.

The IRI programmes follow the same syllabus as normal schools though each grade takes six months to complete, half the time for an ordinary school. The Education Broadcast Service broadcasts 30-minute programmes everyday. The programmes, in addition to broadcasting the normal syllabus, also include inserts on practical issues, such as nutrition and health. The lessons are structured so as to avoid many of the disturbances that children in classrooms face. Furthermore IRI pupils are required to come to class half an hour early in order to go over the lessons of the previous day and leave half an hour after the session to complete all the lessons.

The pilot stage of the programme was evaluated in 2002 and was deemed to be successful. At the time of the baseline evaluation in 2000 there were 22 centres in the country, mainly in and around Lusaka. By 2002 there were 1 153 centres across Zambia. The number of pupils registered for the programme increased from 841 to 7 782 during the same period. The evaluation also found that the programme was doing much in the way of improving access to educational services and facilities for girls.

The programme has nonetheless also faced difficulties. Some of these include a sometimes-inefficient link between the producers and broadcasters of the programmes. The community stations that are distant from the city most frequently experience difficulties with the delivery of tapes. Further problems arise when the mentor is unavailable since so much is dependent on the presence of the mentor. Other problems include problematic equipment and too many pupils in a class for the tutor to cope with.



Despite these problems the IRI programme has also achieved much. Evaluations showed that each centre had an average of 60 enrolled students without about 78% of them returning for subsequent lessons. The government has recognised this system as a viable means of targeting half of all school-age children not in school. Staff are upwardly mobile and 14 mentors went on to become scriptwriters.

Herbert, P.A. et al. (2002). Review and analysis of Zambia's education sector, Final Report. Washington DC: LT Associates Inc.

Synergy Project. (2001) USAID Projects Profiles. Children affected by HIV/AIDS. Produced by The Synergy Project for the US Agency for International Development. Washington DC

Wakumelo-Nkolola, M.M. (2003) Interactive Radio Instruction Programme in Zambia. Presentation at the Forum on ICTS and Gender. 20–23 August 2003, Kuala Lumpur, Malaysia.

6.4 Assisting schools to provide psychosocial support for affected children

Care programmes can negotiate with schools to be flexible around schedules to accommodate the work and care burden of vulnerable children. Programmes can also work with schools to make curricula more directly relevant to children's lives by including life skills, business and household management training, agricultural training and care for children and ill adults.

Teachers need to be trained to address the psychological problems of children that lead to poor performance and children dropping out of school. Training curricula include helping teachers face their own fears about HIV/AIDS (Baggaley et al. 1999), helping them to recognise distress, depression and abuse, assisting teachers to counter the stigmatisation of children, and providing teachers with techniques to support children

6.5 Government intervention to support the education of affected children

In response to the impact of HIV/AIDS on children's education and its threat to social development, Malawi and Uganda introduced free primary education with the assistance of donor funds. According to government policy, children may not be denied entrance to school for any reason. In order for this policy to be effective, government has to ensure that schools do not levy their own fees and thus prevent access by children affected by HIV/AIDS. Sufficient preparation has to be made before free schooling is made available. Uganda, for example, experienced great difficulties with the steep rise in pupils and the quality of education declined as a result. Continual monitoring of children's attendance, performance, and physical and mental health is required to maximise the benefits of free schooling initiatives.

Government also needs to address the impact of the HIV/AIDS epidemic on teacher mortality and morbidity, and its impact on the education system as a whole in order to maintain the availability and quality of education.



7. ADDRESSING CHILDREN'S EMOTIONAL NEEDS

7.1 The provision of psychosocial support for children and families

Although many organisations are aware that children are affected emotionally by the losses associated with HIV/AIDS in their homes and communities, there is generally less attention given in programmes to children's psychosocial as compared to their material needs (Subbarao & Coury 2003). In many contexts in southern Africa, children's emotional needs are not responded to in ways which help children to cope. For example, children are seldom told about their parent's death in an effort to protect the child. Creating awareness of children's needs and engendering support for children is an important component of psychosocial interventions for children. The Regional Psychosocial Support Initiative (REPPSI) for children affected by HIV/AIDS is one attempt to redress the imbalance.

Families also need support, not only to deal with the stress of poverty and loss, but also to cope with additional children and the possibility of children in affected households developing behaviour problems as a result of stresses and losses. Assistance for children and families can be targeted to particular children or households identified to be exhibiting emotional problems, or offered on a wide scale in affected communities. Broadly-targeted programmes are normally based on group work which helps people build relationships and trust. Groups are also helpful for the discussion of 'unacceptable' feelings and behaviour, such as anger, revenge and conflict. These feelings can be given expression in drama, pictures, storytelling, films, poetry, and the like. Group work is also an important component of building community cohesion. Broadly-targeted programmes aim to increase the capacity of the whole community to cope.

Good practice model: Masiye Camp, Zimbabwe

This programme opened in 1998 and is supported by the Salvation Army. Children from HIV/AIDS-affected families attend the camp, which focuses on development, experiential learning and life skills. The camps aim to build confidence in children, strengthen relationships between them, and build links within the communities involved.

Programmes should not defer the inclusion of psychosocial support to families and children until trained specialists and therapists are available. Such specialists are often inappropriate to supporting families and communities to cope, and several approaches have been developed to train sensitive lay counsellors to give assistance to affected children and their families (Hundeide 1991; Richman 1996). Adults who regularly come into contact with children – guardians, teachers, health workers, faith-based groups and youth volunteers – can be trained to identify children's emotional needs and to give children support. Amongst others, children's sadness, apathy, fearfulness, aggression, poor concentration and social isolation, are easily recognisable, but adults and young people need training and support to respond to these manifestations of children's distress.

Communicating with children and gaining their trust is an important source of support for children, and counselling assistance of this kind can be provided by trained non-professionals as well as by youth volunteers (Richter 2002). Play and learning are

important compensatory experiences for children and can assist children to recover from trauma and distress. Children also need to be given opportunities to express fears about their parent's illness or impending death, and about their future and security.

Psychosocial support – Masiye Camp, Zimbabwe

The Salvation Army developed the Masiye Camp Initiative in 1994 with the aim of addressing the lack of psychosocial support in programmes that were working with orphans and vulnerable children. In the course of their work, Jabulani Siwela and Stefan Germann of the Salvation Army Tshelanyemba Hospital in Zimbabwe, observed that many programmes in the country were providing material support but were not focusing at all on psychosocial support. This was of particular concern since many of the children in these programmes displayed mental and emotional problems such as depression and low self-esteem. Coupled with these disturbances was a serious lack of practical life skills.

Masiye began as a Zimbabwe-based project though it was envisaged that its principles could be extended to other locations in Africa. It is based in Matopo, which is approximately 65km southwest of Bulawayo. The Salvation Army Zimbabwe and UNICEF were the initial partners in the project. Since 1998 funding has come from Swiss Solidarity and The Salvation Army Switzerland. In 2002 Swiss Solidarity donated CHF49 600.00 to the programme.

The primary objectives of Masiye Camp were to put in place support interventions for children affected by HIV/AIDS that are both cost-effective and high-impact. These interventions would have to be environmentally and culturally sensitive and geared towards assisting vulnerable children in dealing with their situation as well as providing assistance to other children in their communities. Support at the community level also became a significant goal.

Masiye Camp was implemented through life skills camps where emphasis was placed on experiential learning. The first camp was held in May 1998. An integral component of the programme was the training of staff and volunteers, including in counselling and leadership. More than 60 youth were trained in 1998, with the next step being the recruitment of youth volunteers into Masiye. By year end 2002, Masiye had trained 4 200 AIDS affected children in 10-day camps. Evaluations showed that the camps had contributed significantly to strengthening the children's ability to cope. Another positive outcome of the intervention is that the youth who worked with the orphans were more likely to change their own behaviour with regards to AIDS prevention.

Programmes were structured in a manner that ensured that youth who had passed through the intense psychosocial support training courses were then able to attend future camps as assistant group leader. This contributes to the sustainability of the intervention. These youth were also drawn into the Kids Clubs, which were established in 2001. These clubs served as points of follow up and support for children who had passed through the training camps.



In 1999 Masiye Camp introduced training workshops for staff from other bodies that were working with orphans and vulnerable children. Discussions and exchanges with other organisations led to Masiye being featured in the United Nations Best Practices Guide on psychosocial support for children affected by AIDS in Tanzania and Zimbabwe in 2001. August 2001 also witnessed the Masiye Camp hosting the First Regional Think Tank on Psychosocial Support for Children affected by HIV/AIDS. In 2002 Masiye combined with UNICEF to produce a training video.

Facilities at Masiye

- Holiday camps for children;
- Budget conference and workshop facilities;
- Facilities for holiday makers to experience a traditional rural setting – this is a means of obtaining additional income;
- Practical vocational training for orphans.

Programmes at Masiye

- *OVC Camps* – This is the primary activity of the Masiye Project. There are two sets of camps – the first provides life skills training to 6- to 11-year-old children and 12- to 16-year old children, while the second provides youth parenting camps which are primarily for children who are heading households. There is a permanently employed co-ordinator who, via an organisational network, identifies potential camp attendees as well as following up on those who have already attended. A very positive outcome of this approach is the increasing number of youth who are attending the camps, as well as their motivation to become counsellors and leaders themselves.
- *The Strive Project* – For this project Masiye partnered with Hope for a Child in Christ (HOCIC), an organisation encompassing over 20 faith-based bodies in Bulawayo. The benefits of this partnership include HOCIC's proximity to people on the ground and a large group of volunteers. In turn, Masiye aimed to improve the logistic and skills capabilities of HOCIC. HOCIC has obtained from Masiye two permanent staff and 56 trained facilitators. The Strive Project has definite objectives, which include interventions to provide various means of support to approximately 8 000 children affected by AIDS by May 2004 in eight locations supported by HOCIC; to increase safety nets for these children and to strengthen HOCIC's capabilities in their area of operation. Strive's activities range from training teachers and child care workers in counselling to setting up an emergency fund to cover affected children's physical and practical needs. Strive has also established five offices for the administration and running of the project. It is envisaged that HOCIC will take over these offices in the future when they institute programmes of their own.
- *Youth Drop In Centre* – This project is funded by HopeHIV and provides assistance and counselling for AIDS-affected youth in and around Bulawayo. Services provided at the centre include counselling, information provision, talks, recreational activities and business and entrepreneurship advice. There is a broad range of activities as well ranging from beauty pageants to drama clubs.
- *Mobile Law Clinic* – This project was initiated to deal with the difficulties orphans and vulnerable children were facing when trying to access certain legal and medical services. The mobile clinic aims to improve this access by outreach to children. A referral network has been established that will connect the child to the



particular service that he or she needs. Thus this project has at its core the aim of improving the system of service delivery rather than trying to establish new services. On a more practical level the vehicle carrying the unit is a colourfully painted one that is attractive to children. The staff of this unit includes a puppetry team that conveys the message via puppet shows.

- *Regional Scaling Out Project* – This project is a cross-national one aiming to strengthen the capacity of organisations working with children affected by AIDS in eight countries in the SADC region by 2006. The plan is to identify potential partners in each country and create a system of information exchange and programme replication. Masiye intends to work with the most promising organisations that need support by fostering visits to other programmes; workshops; evaluations and participation in the Masiye Camps.

The Masiye Project has highlighted the need for psychosocial support mechanisms to be included in all programmes and services being provided for children affected by HIV/AIDS. Masiye has demonstrated that these interventions can be low-cost and high impact.

(2002). *Masiye Camp – Psychosocial support for children affected by AIDS*, Bulletin des Netzwerks Medicus Mundi Seweiz. No. 87 – www.medicusmundi.ch/bulletin/bulletin8718.htm
 Germann, S., Madorin, K., and Ncube, N. (2002). Psychosocial support for children affected by AIDS. *Online paper Official website of the Masiye Camp. www.masiye.com. Accessed 5 January 2003*
 The Salvation Army, *Mission and Development. www.heilsarmee.ch. Accessed 5 January 2003*

7.2 Planning for the future and remembering the past

All children need stability and security. For this reason, ill parents are encouraged to plan for their children's future (Kamya 1997). Several issues need to be considered for discussion with children and adolescents, including:

- Disclosure of HIV status to children. Being open with children about parental and child HIV status may help children to cope better with the situation. There is also some indication that children who are informed about their parent's status are more willing to take on household chores and responsibilities (Grainger et al. 2001);
- Provision of substitute care whether this be in the household or family or beyond. Research indicates that siblings who stay together are better adjusted than those who are separated (Nampanya-Serpell 1998);
- The compilation of memory books or boxes with family history and memorabilia has been shown to assist children to maintain continuity and a sense of identity;
- Ensuring legal protection of assets and inheritance due and intended for the child.

Parents and guardian need support and assistance to accomplish disclosure, provision of substitute care and legal protection. External agencies can train local non-professional workers to take on this role, and mediated discussions with extended family and neighbours can help to ensure that the wishes of affected parents and children are implemented.

Memory boxes: The Sinomlando Project, Pietermaritzburg

Memory boxes are designed to help the millions of families affected by HIV/AIDS in Africa to cope with disease, death and grief, and to plan the children's future. After parents and adult relatives die, many orphans go and live with foster parents, in institutions or on their own. Cut off from family, children's memories – their personal history – fade quickly. Orphans risk growing up without a clear sense of identity and roots, without the traditions and beliefs of their heritage.

Memory books or boxes help children build an identity and strengthen emotional capacity, to understand the past and be less afraid of the future. As the family collects photos and souvenirs, draw a family tree and writes about their life, they grow closer. The process opens a window for parents to disclose their HIV positive status and to talk frankly about the child's future. Memory books became popular in the early 1990s among a group of HIV positive African parents living in Britain. Together with the children's organisation, Barnardo's, they developed a framework to write down their family history, so children could keep their memories alive. Ugandan NGOs took the idea further. The text was translated into Luganda and Kiswahili in 1996 and adapted to African needs in 1999.

Created in 2000, the Memory Box Programme is an initiative of the Sinomlando Project, an outreach programme of the School of Theology, University of Natal, Pietermaritzburg. In 2001 the Sinomlando Project and Sinosizo Home-based Care, a community organisation that provides AIDS patients and their children with vital support, jointly launched a pilot study to evaluate the effects of a memory project among 20 Zulu-speaking families in the Durban area. The original mission of Sinosizo was to take care of AIDS patients but its service providers soon became aware of the equally pressing need to take care of AIDS orphans. From this experimental setting in Durban came a new model of intervention called 'memory boxes', which took inspiration from a similar project created in 1997 in Uganda by NACWOLA, an association of women living with HIV/AIDS.

Since 2002 the Memory Box Programme trains various NGOs, FBOs and CBOs in the methodology of the memory boxes, mostly in Kwa-Zulu Natal but also in the Gauteng province. More than ten community organisations have signed partnership agreements with the Sinomlando Project.

The overall objective of the Memory Box Programme is to enhance resilience in vulnerable children and orphans affected by HIV/AIDS. The memories of the families are kept in a 'memory box' which contains the story of the deceased parents as well as various objects pertaining to their history. To achieve this objective the Memory Box Programme conducts two types of intervention: family visits and children's groups. In the first case, the programme's 'memory facilitators' encourage the sick parents or the caregivers to tell the history of the family in the presence of their children as a way of facilitating the bereavement process for the children. The methodology of oral history is used for collecting the family's memories. Transcripts of conversations in Zulu are edited and compiled in a booklet that accompanies an audiotape of all the voices. These materials are presented to the interviewed family and placed in a 'memory box' created by the children with the help of memory facilitators.



To complement the work done with the families, the memory facilitators organise children's groups with the assistance of their partner organisations. Ten to 12 children of similar ages, usually orphans, attend 12 sessions, each of two hours, after school. Basic play therapy techniques are used. The Memory Box Programme draws inspiration from the Humuliza Project, an AIDS orphans support programme in Tanzania. Special emphasis is laid on life stories, family trees and bereavement narratives. During the sessions the children create memory boxes which they fill with various artefacts.

The programme has two immediate objectives. The first is to create, revise and test various manuals outlining the methodology of the memory boxes in English and in Zulu. Some of these manuals are accessible on the Sinomlando Project's website. The second objective is to train the staff and volunteers of various community organisations dealing with orphans and vulnerable children affected by HIV/AIDS in the methodology of the memory boxes. The training offered by the Memory Box Programme has three components. Firstly the memory facilitators run training workshops with the staff and volunteers of the partner organisations. These sessions usually last four days. They are followed by one or several evaluation meetings. At a later stage, the memory facilitators assist the trainees in conducting family visits. They also show them how to facilitate children's groups.

The experience of the last three years demonstrates the validity of the methodology of the memory boxes to help children emotionally affected by HIV/AIDS. All the components of the programme – training workshops, children's groups and family interventions – indicate that the children benefit from this work. Particularly encouraging are the closure reports of the family visits. A significant number of children showed signs of improvement after the children's groups and the family intervention. Also encouraging is the feedback received after the training. The volunteers confirm that they have mentioned the possibility of creating memory boxes to the families they visit. In a number of instances, the families produced a memory box almost immediately.

A major challenge for the programme is to transfer skills to community organisations. This is a difficult process given the numerous problems faced by these organisations. The programme's recent experience has showed that apparently simple operations such as organising a children's group or visiting families with community workers take a lot of time. Appointments need to be rescheduled again and again before the desired results are achieved. Various forms of resistance are encountered.

Oral History Journal, <http://www.oralhistory.org.uk/journal>

7.3 Substitute care for children

Family care is the first choice for all children (McKerrow & Verbeek 1995). However, when this is not available, fosterage, adoption and residential projects need to be established.

Institutional care is not recommended for young children. There is consensus among experts that the adverse effects on children's adjustment and development cannot be prevented in institutional environments of any kind (Dunn et al. 2003; Frank et al. 1996). Lessons learned in programmes that support the psychosocial well-being of children affected by armed conflict and displacement support this conclusion. 'We believe that interventions in emergency and refugee situations that automatically provide individualised trauma therapy and recommend establishment of residential treatment centres are most inappropriate, unsustainable and a poor use of resources. They may sometimes even inflict further harm on children' (Save the Children 1996).

The quality of life of children living in institutions may be adversely affected by a number of factors (Dunn et al. 2003):

- Reduced potential to form secure long-lasting attachments, and reduced access to individuals who take a real personal interest in the child's problems and achievements;
- Overcrowding and lack of privacy;
- Reduced or no possibility to maintain contact with family members and friends;
- Stigmatisation in the local community;
- A restricted choice of friends, especially from outside the institution;
- The imposition of religious beliefs;
- A lack of preparation for future life when leaving the institution. There may be inadequate resources to assist young people in finding accommodation and employment, developing relationships, and getting access to services.

Older children, those in senior primary school and beyond, may well benefit from small boarding school environments which ensure their nutrition, maintain children in school, and protect children from abuse. Emergency institutional care is the only option for a number of groups of children until more suitable care can be arranged. These include: abandoned newborns and children in hospital; street and working children; abused children; and as a temporary solution for children for whom alternative care is not yet available (McKerrow 1996; Williamson 1995). However, the programmatic limitation of institutional care is demonstrated by the fact that, worldwide, only about 1-3 per cent of orphans are cared for in orphanages (Subbarao & Coury 2003).

Although institutions have been rejected as an option in Zimbabwe and Uganda, for example, increasing numbers of orphanages are being established in South Africa with donor funds.

Orphanages need to be discouraged for a number of reasons (Grainger, Elliott & Webb 2002; Subbarao & Coury 2003):

- Orphanages are eight (or more) times expensive than home care (Over & Ainsworth 1997). A South African study of care options for children showed that institutional care is ten times the cost of home care (Desmond & Gow 2001; Loening-Voysey & Wilson 2001). In Zimbabwe, institutional care is estimated to be 14 times more expensive than home-care (Subbarao & Coury 2003);
- They are not sustainable in the long term because they are frequently dependent on donor money. When orphanages close down, children are in serious difficulty because they no longer have community ties;
- They are not necessary in the vast majority of cases. For example, a study in Zimbabwe showed that 75 per cent of children in institutions had a known relative (Subbarao & Coury 2003);

- They are not owned by communities and therefore the surrounding population don't take responsibility for the children or the quality of their care;
- Children's emotional and social needs are frequently neglected, and continuity and stability of care is difficult to achieve;
- Children are vulnerable to abuse and poor quality care and supervision;
- Children may be separated from their community, culture and traditions, and they may find it difficult to re-integrate into society;
- Children may suffer discrimination because they are regarded as being without family, in addition to any association this may have with HIV/AIDS.

In almost all countries in Africa it is estimated that the vast majority of children in institutions are not orphans. Instead, institutions are used by very poor families, and by disintegrating families, as a survival strategy. Under these conditions, children enter institutions under both 'push' and 'pull' factors. Responding to push factors, children are loosened from family ties by poverty, familial stress and intra-familial abuse. Pull factors include the relatively high level of material support provided by institutions, including better healthcare, food, educational and housing conditions (MacLeod in Levine 2001)

Foster and adoption care is to be encouraged because family-based care in a child's home community generally offers the best opportunities for positive psychosocial development. Adoption is not common in much of southern Africa for reasons of fear of malevolent forces introduced by non-family members (Parry 1998). However, family-fostering of children by a deceased person's close family is usual in most African families. When financial support is offered, more families are prepared to offer formal fosterage (UNAIDS 2002). In some communities, women or couples take in children as full-time houseparents with financial support from the community, church or an external agency. Financial incentives to take children into fosterage are not necessarily the main drivers of fosterage, however, as most households that formally foster children do not rely on the designated financial support (Bandawe & Louw 1997). Surrogate parents need to be trained in childcare and child management, and they need to be supported and supervised by a cadre of community workers. Another variant of fosterage is 'collective foster care' which, although not suitable for younger children because of their emotional need for a long-term caring relationship with a stable caregiver, is helpful to older children living together.

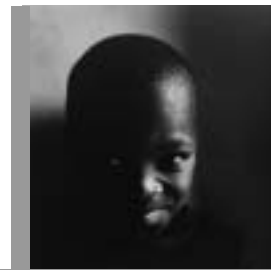
Subbarao and Coury (2003) rank the most desirable living arrangements for children to be, in order: living parent; kin-family care; formal foster care or adoption; foster homes; children villages and community-based centres; and, lastly, orphanages and other forms of group residential care in institutions.

The following good practice guidelines are offered for the care of children (Grainger et al. 2001):

- Children in care should remain within or close to their community of origin;
- Children should maintain contact with their families as far as possible;
- Siblings should remain together;
- Caregivers should be trained in childcare, including health and psychosocial support;
- Institutional care should only be used as a temporary stopgap in the absence of immediate other care solutions for a child;
- All children should have a designated adult who they can trust and who can provide them with affection, supervision and stability;

- The community should be encouraged to get involved in the care of vulnerable children, including the early detection of neglect and abuse;
- Children's health, school attendance and psychological adjustment should be subject to ongoing monitoring.

External agencies can assist to promote the optimal care of children by championing women and children's inheritance rights, sensitising communities to the psychosocial needs of children, and training local people in the detection of abuse and the care of vulnerable children.



8. PROTECTING CHILDREN

8.1 Protecting children from abuse and exploitation

The neglect, harsh treatment, labour exploitation and sexual abuse of orphans and other vulnerable children has been noted under conditions where children are insufficiently protected (Baggaley et al. 1999; Tarantola & Gruskin 1998). Orphan identification and support programmes, as well as home-based care visitors, are well placed to recognise and report children living under abusive conditions. Volunteers, church groups, teachers and community members can be sensitised to abuse and made aware of referral options.

8.2 Protecting children's assets and inheritance

The Convention on the Rights of the Child places a duty on governments to protect children's rights. The impact of HIV/AIDS on families deprives children of many of their rights by removing them from parental care, separating them from family and possessions, and exposing them to abuse and exploitation.

Good practice model: Siywela (crossing over) OVC project of Hope Worldwide, Soweto

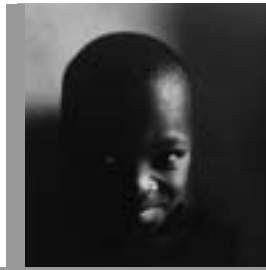
The project aims to increase the capacity of communities to care for OVC and strengthen referral systems to enable a continuum of care through a network of support groups and linkages with the Perinatal HIV Research Unit at Chris Hani-Baragwanath Hospital and surrounding midwifery clinics with Mother-to-Child-Transmission Interventions. Implementation includes:

- Strengthening staff management and technical capacity;
- Participatory research such as community mapping, consensus workshops, disseminating findings;
- Strengthening community network, including OVC committees, developing a partnership/referral database;
- Increased care and support for vulnerable children such as increased capacity of caregivers in child development and the care of children living with HIV, together with referral and support systems);
- Psychosocial support for women and children affected by HIV, including referral systems, support groups, bereavement counselling, and support for disclosure and future planning for children.

In many parts of Africa, children are traditionally the responsibility of the father's family. Especially when marriage rites have not been completed and when kin are not close, the father's family may seize the family's possessions when the father dies and leave the mother and children without a home. This might also occur when the mother dies. External agencies can help local community groups to understand inheritance rights and how they can be protected. It is important that succession planning involves the extended family and traditional leaders to ensure that they will comply with the parent's wishes. Wills might need to be written to protect land and possessions for children and legal action might need to be taken through external agencies to protect children whose assets and inheritance are forcibly removed by extended family.

The protection of children's rights is best tackled multi-sectorally, especially if it contradicts societal norms and traditions. Advocacy, media campaigns, discussions with traditional leaders and extended family are important to ensure that children's inheritance is protected.

9. COMMUNITY MOBILISATION AND MICRO-FINANCE



Donahue and Williamson⁷ have advocated a dual strategy to be supported by external agencies – community mobilisation and the creation of and access to income-earning opportunities including micro-credit or micro-finance systems. This dual strategy is based on the conviction that poor households in communities affected by HIV/AIDS know what they need to be able to deal with crises, and that their capacity to cope should be supported and strengthened. This strategy requires that capacity is developed and supported in community-based participatory interventions and micro-financing institutions.

There have not been any systematic evaluations of the dual strategy although both elements are included in broader mitigation projects. To date, many micro-financing efforts have failed, often as a result of the implementing agency's lack of expertise rather than inherent weaknesses in the model itself (Grainger et al. 2001).

9.1 Community mobilisation

Community mobilisation and capacity building are catalytic processes through which an outside agency can help a community to identify what concerns them most, what they think they should do about it, and assist them to take action. It aims to make as many people as possible in a community aware of the impact of HIV/AIDS and to encourage participation in and ownership of efforts to assist vulnerable children and families through the formation of what are called *community care coalitions* (Lorey & Sussman 2001). 'Effective mobilisation is based on the community's ownership of the problem and a sense of responsibility to address it. It is *not* a matter of convincing people to take action by giving them resources or to work for free in someone else's program' (Williamson 2000a:17). Community mobilisation has been field tested and found to be viable in a wide range of communities.

Community mobilisation is based on participatory techniques and the role of external agencies is to assist communities to move through a succession of loosely, not necessarily consecutive, stages in responding to the needs of children and families (Donahue & Williamson 1999; Grainger et al. 2001).

These stages include, but are not limited to:

- Raising awareness of the impact of HIV/AIDS, particularly on children;
- Recognition by community members that collective action may be more effective;
- The establishment of a sense of ownership and initiative;
- Mapping existing resources in the community;
- Identifying and prioritising needs;
- Planning and managing activities with internal resources;
- Increasing sustainability of activities through linkages with other organisations;
- Monitoring and adjustment of activities in line with changing community needs.

Although community mobilisation has been used to deal with a number of problems in poor rural communities, there is little detail available about such mobilisation. For example, SCOPE-OVC, the Zambian programme, focuses on the *formation* of community committees and networks as well as advocacy, but little information is provided on the

⁷ See references to their individual and joint work.

effectiveness and sustainability of such initiatives (Yamba 2002). There also seems not to have been any evaluation of the suitability of community mobilisation as a mechanism to address the impact 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' (Grainger et al. 2001:57).

Community mobilisation processes for HIV/AIDS need to be integrated into the general approach of delivering social services through community-based approaches. Community-Based Social Care Services (CBSCS) are a fast-growing field, with substantial support from the World Bank. Africa is lagging behind in this field, which typically targets women and children and includes nutrition, maternal and childcare, literacy and vocational training. CBSCS are usually delivered through implementing agencies, mostly CBOs and NGOs.

McLeod and Tovo (2001) summarise lessons learnt to date in CBSCS that are usefully taken into account in community mobilisation to respond to children affected by HIV/AIDS:

- Carefully determine in advance what the project is trying to achieve and at what price;
- Ensure that social care standards (if they exist) are adequate and followed. If not, help the authorities formulate or revise the standards;
- Secure the support and involvement of local authorities, regardless of their financing role;
- Avoid perverse financing incentives by using demand- rather than supply-side financing;
- All projects should plan for recurrent cost financing if they are to be sustainable;
- Accurately determine cost per beneficiary by factoring in time and compare available service providers;
- Reach out to vulnerable groups through well-planned dissemination and publicity activities;
- Plan and budget for informed demand;
- Geographic targeting is seldom as good as self-targeting;
- Build capacity development of project staff into the project cycle and budget;
- Share knowledge and experience with central government so that it can effectively be part of the long-term solution.

Community-based Options for Protection and Empowerment (COPE)

Examples of effective community mobilisation projects are the COPE, Phase 1 and Phase 2 programmes in Malawi. These present a systematic approach to mobilising community-based action aimed at addressing the needs of orphans and families affected by HIV/AIDS.

COPE, a low-cost community mobilisation programme to moderate the impact of the AIDS pandemic on the lives and welfare of AIDS-affected children and families, was first funded by the USAID/Displaced Children and Orphans Fund (DCOF) and was implemented by Save the Children/US. USAID/DCOF funded the initial COPE 1 programme from mid 1995 to Set 1997. COPE 11 was maintained by a second grant from Sept 1997 to Sept 2000. (From Sept 1997 to December 2001 COPE received \$1 619 459 from DCOF.)



In Malawi, close to 60 per cent of its predominantly rural population of 10 million live below the absolute poverty line. The country is in an advanced stage of the HIV/AIDS epidemic. The Malawian National AIDS Control Program estimated that, at the start of COPE, the 15–49 age group HIV prevalence was 14 per cent. It is expected that in the coming years there will be a substantial increase in the number of deaths due to AIDS. Policy guidelines for the care of orphans in Malawi were established in 1992, with an orphan defined as a child under 18 years who has lost one or both parents. By this definition, 15 per cent of Malawian children are orphans. Despite the many psychological and physical needs faced by families affected by AIDS, counselling and HIV testing are not widely available in Malawi, and it was concern over this negative situation that was the impetus for the establishment of COPE in 1995.

The original aims of COPE were:

- To strengthen community capacities to ameliorate the impact of HIV/AIDS on the community;
- To identify, assist and protect orphans and vulnerable children;
- To increase economic opportunities and resources available to especially vulnerable households;
- To strengthen the capacity of government and community organisations to lead and sustain effective responses to needs children and families affected by HIV/AIDS; and
- To advocate policy change at national and district and local levels.

The strategy adopted by COPE was as follows. COPE began their efforts by sensitising religious, business and political leaders to the reality of the impact of AIDS on the community, and to initiate the formation of community care alliances. These alliances jointly assume responsibility for addressing the broad range of problems brought to the community by the HIV pandemic. Part of COPE's approach was to strengthen the capacity of these partnerships – to mobilise internal resources, to access external resources and to organise community involvement.

Initial activities took place in nine villages around the Mangochi town area in Mangochi District. COPE staff worked with government, church, business and NGO personnel. Area AIDS Committees mobilised action at the village level by bringing people together to address their concerns. Community ownership is central to the COPE approach, and their strategy is based on the premise that with the assistance of an external mediator of change, the concept of community mobilisation and ownership can generate community action and involvement that is effective and sustainable.

COPE was reviewed by DCOF in 1996, 1998 and 1999 with a range of recommended changes proposed on each occasion. The first review was undertaken in 1996 and it found that COPE was achieving its main objectives. Initially COPE's focus was on problem solving and service provision, but this proved to be too costly. COPE considered their initial programme activities to be community-based because volunteers carried out many of the activities. However, ongoing participation of volunteers depended on continuing involvement of a large number of NGO staff and material benefits from the programme. Once COPE staff moved on to work in another



part of the district, volunteers did not always continue to implement COPE activities. In addition, COPE employed a complex information gathering and monitoring system that was thorough, but very labour intensive and expensive. After the first evaluation, COPE cut costs by reducing staff, and by redirecting efforts into community mobilisation. Its principal activities were seen in a positive light by communities, their leaders, government personnel and NGO staff. For example, patients in homes with trained caregivers were found to be receiving better care, to be more comfortable, and to live in greater dignity. However, because the COPE activities appeared to be too costly to maintain, alternative approaches had to be introduced. Although most of the interventions were rated as producing positive results, the cost per beneficiary (US\$162) was too high to enable COPE's staff-intensive approach to be taken to scale in Malawi.

As a result, COPE modified its approach in Phase 2. Staff size was reduced and the focus shifted from addressing problem directly to mobilising and building the capacities of communities. COPE started to use the Community AIDS Committee (CAC) concept, an idea that was initially devised by the Malawian Government and UNICEF as the *modus operandi* for implementing their programmatic strategy. CACs co-ordinate both HIV/AIDS care and prevention activities at sub-district level and these, in turn, are supported and monitored by the District AIDS Co-ordinating committee (DACC). CACs are responsible for the mobilisation, monitoring and support of Village AIDS committees (VACs) in all villages in the CAC catchment area. This strategy had been attempted by the National AIDS Control Programme and supported by UNICEF, but did not function beyond the district level due to lack of resources. Through committees, COPE implemented a broad range of interventions. The initial group formed the Namwera AIDS Co-ordinating Committee, which in turn organised the village base committees (VACs) who:

- Identified orphans, ill people and other vulnerable people;
- Assisted the return and reintegration of orphans to school;
- Trained caregivers in the skills required for home-based care;
- Raised community funds to provide material assistance;
- Started youth Anti-AIDS clubs;
- Planned and organised recreation activities to address the psychosocial needs of orphans;
- Developed community gardens to produce food and income for the benefit of vulnerable households. Chiefs and well-to-do members of the community donated land for cultivation, and COPE staff assisted the committees with training in agricultural practices.

In 1997, COPE expanded from 16 VACs to 208 VACs with 4 420 members. More than 12 600 enumerated orphans received material assistance and food; more than 150 woman heads of households were in enterprise networks, 735 youth received vocational skills training, more than 11 000 families benefited from agricultural inputs. In terms of training, 449 people were trained in caregiving and community-based childcare, 807 people received home-based care training, and 6 577 people received HIV/AIDS prevention training. A total of 248 967 people benefited directly or indirectly from the COPE programme at an annual cost of \$317 000.



A significant lesson learned by COPE is that fragmented and compartmentalised programmes are less effective in assisting families affected by HIV/AIDS than programmes that are integrated. HIV- prevention efforts also appear to be more effective if integrated with activities to care for those living with AIDS, orphans and other groups affected by the pandemic. By this view, prevention efforts have not been effective because people living in extreme poverty have no sense of control over their futures. However, the integration of programmes through community mobilisation increases social cohesion, which is believed also to reduce infection rates.

The COPE programme has also established income-generating activities, for example gardening. COPE introduced a micro-credit programme, which makes available small loans for poor households who engage in short-term rapid-turnover trading activities. These have shown potential to increase household food security and to improve the wellbeing of children. Over time this access to credit has enabled some households to even out their household incomes.

Cope is well established in four districts of Malawi, having been replicated in many villages. Subsequently COPE has been evaluated twice, and the following main issues were highlighted:

- The need for further integration and greater community mobilisation efforts;
- A commitment by DCOF (in collaboration with SC-US/COPE and USAID Malawi) to support the micro-credit programme's expansion to other geographic areas where COPE is mobilising VACs and CACs;
- The potential for staff to network further links with other programmes that provide interventions for HIV/AIDS prevention, health and education, as well as microfinancing;
- USAID/Malawi's commitment to address COPE's expansion;
- USAID/Malawi and SC-US/COPE to mount a collaborative effort to request funds to teach their community mobilisation approach to other NGOs and government departments.

9.2 Livelihood support

Many of the problems of AIDS-affected children and households result from their economic problems. For this reason, Donahue has argued that the ability of families to cope with the impact of HIV/AIDS is largely dependent on their capacity to maintain or increase their incomes. The baseline level and stability of household resources is dependent on two factors – existing economic resources and assets, such as savings and livestock, and the ability to generate income from livelihood activities. Support for IGAs can include material assistance (such as tools or seeds), credit to individuals or groups, technical know-how and support, and assistance to set up small-scale enterprises.

It is recommended that livelihood support should be one element of a larger programme framework, rather than a stand-alone intervention, to avoid the goals of the programme from being distorted. In at least one review of an OVC support programme it was noted that, as might be anticipated in conditions of poverty, IGAs tend to dominate over concerns for affected children (Grainger et al. 2001).

9.3 Micro-credit and the targeting of women

Micro-credit, or micro-finance programmes, offer small amounts of credit to individuals or groups, often women, to support and sustain existing livelihood activities. They sometimes include a savings component as a collateral on loans. The credit is often granted for short-term, high-turnover activities such as trading to prevent destitution rather than to build wealth, employment or entrepreneurship. Village banking, or solidarity group lending, is the best-known methodology for micro-credit programmes. Typically, this involves a body that makes loans to self-selected groups, most frequently women. Individual group members use their share as they choose, usually for individual or family-based IGAs, and each is responsible for repaying the group with interest. The group, in turn, repays its collective loan, with interest, to the loan body, through weekly payments over a few months.

Good practice guideline: The Foundation for International Community Assistance (FINCA)

FINCA established a solidarity group lending programme in Uganda initially using funds from USAID intended to benefit orphans. The programme is growing and, in 1999, had 650 village banks with 19 500 members, each representing a different household. The banks were maintaining loan repayment rates above 98 per cent. When members of these banks were asked, three-quarters reported that they were caring for orphans.

The targeting of women is based on evidence which demonstrates differential allocation and expenditure patterns between men and women, with the latter having greater benefits for children (Donahue 1998, 2000). However, credit to women also increases their self-esteem and status in the household and community, it can promote community mobilisation by stimulating solidarity among women, and it can give them access to other institutions in society. Women are also less likely to differentiate between biological and foster children in the allocation of resources (Aspaas 1997), and they have been found to be reliable clients with better repayment records than men (Wright & Mutesasira 2001). However, care should be taken not to add to the existing high burden of work carried by women or to reinforce unhelpful gender stereotypes and confine women's activities to lower paid and less skilled work.

The successful and sustainable provision of funds to vulnerable households through community-based efforts is highly dependent on effective community mobilisation. In addition, there is some concern that programme-implementing agencies have not built up experience and knowledge in the field of micro-credit and that health and social welfare personnel are not effective micro-finance managers. There is general agreement that specialised personnel are required to run these schemes (Grainger et al. 2001; Williamson 2000). Further, problems with micro-credit schemes have not yet been sufficiently addressed. These include the exclusion of the poorest and most marginalised groups, and the exposure of vulnerable borrowers to risks that could drive them further into poverty. Some of the poorest households lack the skills or labour to use the schemes, and many community-based credit and savings programmes will not lend to very high-risk groups, such as young people with inconsistent income or people with life-threatening illnesses

such as HIV/AIDS (Johnson & Rogaly 1997). In addition, loan groups need to be self-selected and not engineered by outside agencies, as this undermines the solidarity among group members. 'While microfinance services are very promising as a way to strengthen family and community capacities, it is necessary to raise some points of caution. Where microfinance programs have become sustainable, they have done so by adhering closely to tried and true operational practices and respecting the economic realities and constraints of the situations in which they work' (Williamson 2000a:19).

Despite concerns with risk, there is in fact evidence of high repayment in severely affected areas of Malawi and Uganda (Williamson & Donohue 2001). Further follow-up is needed to examine whether borrowing benefits children, and whether it benefits all children in the household equally. Despite the difficulties, it is the opinion of some that targeting micro-finance schemes directly towards caregivers in AIDS-affected communities is the most effective way of assisting orphans and vulnerable children (vor der Bruegge 2000).

Micro-finance – Zambuko Trust, Zimbabwe

The Zambuko Trust in Zimbabwe was born out of discussions in 1990 between key trade, industry, community and religious figures. These discussions centred around developing a means of providing economic opportunities for disadvantaged and vulnerable individuals. The Trust itself was created in February 1992 and was the first urban-based micro-finance programme in the country. It is registered legally both as a social welfare organisation (which exempts it from having to pay taxes though being able to collect donations and awards) and a lending institution (which permits it to collect interest on its loans). The Zambuko Trust is a Christian non-banking financial institution that aims to be 'a bridge between the marginalized, the unemployed and bring opportunities for enterprise and income generation in Zimbabwe'. It is now regarded as the premier micro-finance programme in the country. Initial funding came from many sources though a large part of it came from the NGO, Opportunity International.

Zambuko offers three types of loans:

- *Group-based loans* – 9 to 12 month loans are given to individuals who form groups of 5–10 people. Each person in the group stands as a co-guarantor for the other members of the group, having pledged a moveable asset against their own loan. Before loans are granted, applicants have to attend a mandatory workshop dealing with business administration. Loan repayments are made on a monthly basis.
- *Individual loans* – 9 to 12 month loans are awarded to individuals who must have a guarantor and have put up a moveable asset as collateral. Loan repayments are made on a monthly basis and applicants have to attend a mandatory business training session prior to the loan being processed.
- *Trust bank loans* – This loan is designed to assist poorer individuals. Applicants form groups of 10–15 people, with each member serving as a guarantor for the other members of the group. The loans are smaller than the others and are usually allocated six-monthly. The borrowers are required to attend eight weekly hour-long



sessions on business management and to meet with loan officers twice weekly during the period of the loan.

In 2000 the average loan size was US\$185, and interest rates rose to 52 per cent, depending on the loan cycle and repayment record, as a result of Zimbabwe's high rate of inflation.

Zambuko targets women and over 75 per cent of its clients are female. Just under half its clients are involved in trading while approximately 40 per cent of its borrowers are in manufacturing, particularly clothing. Most of the other clients are engaged in agriculture and food production.

The Zambuko Trust has been evaluated in a USAID-funded study of the programme that interviewed both client (338) and non-client (241) individuals involved in micro-enterprise. Two rounds of questionnaires were administered to both groups in 1997 and 1999. Respondents were not questioned directly about their HIV status or their experience with AIDS. Proximate determinants were used in an attempt to gauge whether individuals and households were affected by HIV/AIDS.

The results of the evaluation showed that about 40 per cent of both Zambuko client households and non-client households were affected by HIV/AIDS. Affected households with a Zambuko client found themselves in a better-off position than those affected households with no access to loans and credit. Affected client households who were on the same footing as non-clients in 1997 were found to have more sources of income in 1999. The conclusion here was that the loans had enabled these households to branch into other income-generating activities. HIV/AIDS-affected households with a Zambuko client were also more likely to have their children attending school. The financial and entrepreneurial training that formed part of Zambuko's loan programme was also found to be beneficial since Zambuko clients were much more adept at saving and managing their funds.

In interviews and discussions both Zambuko staff and clients expressed the belief that the political and economic situation in the country had done more harm than the AIDS epidemic. Many believed that a better national economy would alleviate some of the hardships associated with HIV/AIDS. There was also consensus that loans to people in crisis situations were not advisable, as business activities would not be a priority for people in extreme poverty.

Recommendations stemming from the evaluation included the following:

- Lending bodies should adjust their interest rates according to inflation rates so as to protect their capital foundation;
- These bodies should also set in place mechanisms which enable them to assess the impact of HIV/AIDS and poverty on its clients and to assist clients in overcoming the negative economic consequences arising from HIV/AIDS;
- Micro-finance programmes need to provide some HIV/AIDS information. This could be provided by the microfinance programme itself or by partnering with an HIV/AIDS organisation.

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9.4 Vocational training and apprenticeships for young people

Training for adolescents in marketable skills to generate income has been advocated and tried in several areas. There is concern though, that due regard is given to the demand for skills and to protection of children from exploitation. As Grainger et al. conclude, '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 needs to be demonstrated through programme-based research' (2001:63).

9.5 Factors contributing to the success of income-generating activities

A failed project in South Africa (Harber 1998) illustrates some of the difficulties associated with IGAs. The programme was pressurised to introduce IGAs even though it lacked specialised knowledge in the field. In addition, no market research was done and it turned out that there was no market for the products; the most needy groups of women were unable to join the project because they were old, lived in remote areas, and were already overburdened with care responsibilities; and the project did not make use of available skills and resources. In addition to these problems, experience from programmes in other parts of the region suggests that the most socially and economically vulnerable households may have difficulty managing credit (Senkusu 1995).

Hunter and Williamson (1998) argue that the most effective interventions are those that target support to IGAs for which people already have most of the necessary skills and ongoing access to markets and resources. Other lessons learnt to increase the success of IGAs include the following:

- The environment in which commodities and services are going to be offered needs to be stable;
- The implementing agency needs to have knowledge and experience in the field;
- Market research needs to be done and risks estimated and accommodated;
- Household support appears to benefit affected individuals more directly than community businesses to which the most vulnerable groups do not always have easy access;
- IGA activities have to accommodate the burden of care shouldered by those also responsible for generating income.

9.6 Emergency relief

The economic stress HIV/AIDS causes in some families is sometimes so severe that IGAs are not helpful because people do not have the resources to take advantage of them; for example, they have no alternate care for dependants, they have no suitable clothing and money for transport to join a group, and they are driven by the necessity to scrounge a daily living.

In these circumstances, emergency relief is necessary. However, there is a concern that in the long term material assistance detracts from the capacity and motivation of communities to secure needed resources for extremely vulnerable families and children.

Circles of Support, South Africa

The Circles of Support is a key component of the Moving the Nation to Act Campaign in South Africa (Smart 2003) The campaign is built around the concept of a number of circles:

The first circle involves help from family, neighbours and friends who can:

- Give food and clothes if they are able;
- Care for the sick;
- Offer to cook a meal;
- Go shopping;
- Help with food gardens or in the fields;
- Look after children;
- Tell stories to children;
- Take a child to the clinic for immunisations or if they are sick;
- Accept and care for people living with HIV/AIDS;
- Make sure that others do not hurt or exploit vulnerable children;
- Listen to someone's problems; and
- Give help to people who are willing to offer foster care to children in need.

The second circle involves help from the community, particularly through the formation of a Circle of Support Group. The aim is to form a network of people who care for and work with children in some way.

The third circle involves resource people in the wider society, such as:

- Youth, women and church groups;
- Local AIDS support groups;
- NGOs like hospice, NICRO, home-based care or the Street Children's Forum;
- Local business;
- Local authorities and traditional leaders;
- Teachers, schools, nursing staff, clinics, social workers and the local Child Welfare Society;
- South African Police Services;
- The Department of Social Development.

10. THE ROLE OF GOVERNMENT



The role of government is not the focus of this review. However, there are a few key pointers to government actions that are stressed as being essential to supporting families and communities to respond to the needs of vulnerable children. Amongst these is the need for government (Hunter & Williamson 1998) to:

- Take the lead in broadening the response to AIDS beyond the health sector and ensuring a multi-sectoral approach at all levels;
- Expand interventions to the scale required to meet the level of demand. NGOs and CBOs tend to operate small localised interventions, limiting their reach. For example, estimates from Uganda are that only 5 per cent of orphans, that is, 83 100 of 1.7 million orphans, received some sort of assistance from 183 organisations between 1998 and 2000 (Subbarao & Coury 2003). In Malawi, only 4.4 per cent of orphans are estimated to be reached by available services;
- Enact policies to respect and protect children's rights to health, education, inheritance and protection from abuse, including (Williamson 2000):
 - Prohibition of discrimination in health care, schools, employment, or other areas based on actual or presumed serostatus;
 - Placement and guardianship for children who lack adequate adult care;
 - Enactment and enforcement of laws ensuring the inheritance rights of women and children;
 - Protection of children against abuse, neglect and sexual contact with adults;
 - Prohibition of harmful child labour;
 - Elimination of barriers to orphaned children continuing their education;
 - Protection and support for street children.
- Provide support for the care of children through the budgets of line ministries;
- Create infrastructure at the district level to enable local government support for community efforts to respond to the needs of affected children;
- Prohibit the discrimination of affected children;
- Encourage and support men to take responsibility for their families;
- Provide accessible information, services and training on HIV-related issues for all government staff whose jobs intersect with the care of children;
- Encourage and support NGO and private sector involvement in the response to children affected by HIV/AIDS;
- Lead and co-ordinate the activities of donors, NGOs, the private sector and civil society.

Government also needs to give effect to national programmes which benefit children affected by AIDS. These include, for example (Hunter 2000):

- Expanding free education;
- Birth registration to increase children's access to basic services;
- Review and revision of laws to protect children from sexual exploitation.

It is a matter of growing concern that the vast majority of efforts to support children affected by HIV/AIDS in the southern African region are funded, managed and staffed through the assistance of international and national NGOs. Should the donor agenda change or be exhausted by continual overwhelming demand, the situation of affected children will be extremely precarious unless governments start to make provisions for programme support within mainstream departmental budgets. In addition, a donor-driven approach may not be appropriate to the scale of the problem.

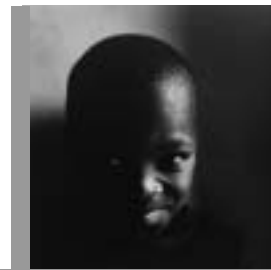
In the developing countries most seriously affected by HIV/AIDS, most mitigation activities have fallen into two categories: the first is NGO programmes whose paid staff deliver direct relief and development services to affected children and families, sometimes with the involvement of community volunteers. Many such programmes have produced good results, but with relatively limited geographic coverage and at a cost per beneficiary that is too high to reach more than a tiny fraction of families and communities made vulnerable by HIV/AIDS ... A second category of interventions is grassroots community initiatives, which have produced good results at a low cost per beneficiary ... The programmatic challenge, then, is to develop ways to systematically mobilise such responses and to help communities sustain them over time. (Williamson 2000a:15)

Government thus has a responsibility to help to support the volunteer networks that form the backbone of home-based service provision and many of the efforts to respond to the needs of children affected by HIV/AIDS (Subbarao & Coury 2003).

10.1 The role of the private sector

There is a notable absence of efforts to include corporate and private sector actors in programmes to support vulnerable children despite the fact that there is good reason to believe that a substantial amount of money is invested by this sector in programmes for vulnerable children through Corporate Social Investment initiatives.

II. MONITORING AND EVALUATION OF SUPPORT EFFORTS



There are very few systematic evaluations of programmes to mitigate the impacts of HIV/AIDS on children. What predominates in the field are anecdotal accounts which draw their legitimacy from their alignment with agreed good practice in the field of social development. There are several reasons for the lack of systematic evaluations. For one, it is difficult to evaluate multi-sectoral initiatives with several aims, but in addition, the HIV/AIDS field has tended not to draw on the conceptual and measurement tools available in child development disciplines for assessing outcomes in children and families. The goals of programmes are also often poorly defined and, in resource-poor settings, it is difficult to differentiate between the impact of HIV/AIDS and poverty.

In general, input factors, such as the number of children who attend a feeding scheme, are more frequently measured than are output factors, such as the number of children whose growth is within the normal range. There are few standard indicators in the field of programmes to assist vulnerable children, and thus it is very difficult to compare different approaches for effectiveness and/or cost. While monitoring and evaluation (M&E) has often been seen to be a function of external experts, participatory M&E approaches need to be encouraged, including the participation of children (Colling 1998).

Programmes to assist vulnerable children need to establish the basic framework for both monitoring and evaluation. Monitoring consists of the regular recording of inputs, outputs and processes related to the targets and goals of a programme. Evaluation is an analytical process, based on qualitative and/or quantitative information, that aims to assess the performance of the programme either mid-stream or at the completion of a project cycle. The purposes of M&E need to be clearly understood by all so that their results can be best used to prioritise actions, allocate resources and improve services. Some of the purposes of M&E include the following:

- To demonstrate impact at the local level to encourage buy-in from communities and further support from external agencies;
- To target resources more effectively;
- To choose amongst options as resources become more constrained;
- To enable the organisation to learn as it goes and improve its practices;
- To develop and disseminate good practice guidelines among organisations and groups working with children affected by HIV/AIDS.

In order to monitor the evolution of the situation over time, Williamson (2000a) suggests that stakeholders need to regularly gather information on the following factors.⁸

Epidemic/war/drought situation and its consequences

- HIV prevalence rate (reported/estimated/projected);
- Child and adult AIDS cases (reported/estimated/projected);
- Number of population displaced/in refugee camps;
- Mortality rate/morbidity rate (by age-group and gender);
- National population (number and growth rate);
- Child population (by age group and gender);
- Number and percentage of orphans (grouped by age, gender, and orphanhood status);
- Number and percentage of OVC (grouped by age and gender);

⁸ When possible, data should be geographically broken down (urban/rural, regions, communities) since situations are very specific to local areas.

- Percentage of vulnerable children less than two negative standard deviations of height for age as measured against the National Child Health Statistics standards;
- Percentage of vulnerable children less than two negative standard deviations of weight for age as measured against the National Child Health Statistics standards;
- GNP per capita and average growth rate;
- Population in absolute poverty;
- Primary/secondary/vocational school enrolment rate (by OVC and gender status);
- Immunisation coverage (by OVC and gender status);
- Data on children's nutritional status (by OVC and gender status);
- Percentage population with access to safe water.

Households and community coping mechanisms' responses

- Evolution of household head;
- Estimated number of children working on the street, living on the street, in institutional care, foster/adopted by alien families, child-headed households, involved in commercial sex activities;.
- Average household family size (by type of household head);
- Household dependency ratio (by type of household head, and OVC status);
- Household per capita poverty level (by type of household head, and OVC status);
- Economic activities of households and main sources of revenue (by type of household head, and OVC status);
- Intra-household allocation of food, education, work;
- Percentage of households who spend more than 75 per cent of total expenditure on food;
- Number of household involved in IGAs, with access to credit and savings schemes (by type of household head and OVC status)
- Number of households benefiting from day-care services, home visits, assistance (food, material, financial, fees, etc.) (by type of household head, and OVC status).

Existing policies and laws

- Child welfare law and policies (education, healthcare, work);
- Law regarding inheritance right of widows and orphans;
- Anti-discrimination laws (access to school, healthcare, work, housing);
- Laws and policies concerning street children.

In addition to monitoring orphans' welfare, it is also important to monitor programme indicators, especially on coverage and progress. These include the coverage of existing services, methods of training and costs. Indicators should be computed on a regular basis at the community/regional/national levels, and should include (Subbarao & Coury 2003):

- Number of programmes supporting OVC and affected families (by type of interventions);
- Percentage of OVC committees started up;
- Percentage of OVC committees with robust multi-sectoral representation;
- Number and percentage of OVC and affected families supported (by type of interventions);
- Number of community initiatives receiving some kind of support;
- Number and percentage of paid/voluntary staff involved (by type of interventions);
- Number and percentage of trained staff (by type of interventions);
- Cost per beneficiary (by type of interventions);

- Measurable results achieved: number, percentages (against the initial objectives set) regarding:
 - Education support (for example, number and percentage of OVC sent to school, OVC provided with technical and vocational skills, OVC provided with education material, with grants, etc.);
 - Health and nutrition support (for example, number and percentage of OVC provided with medicine, vaccination, health visits, food supplement, psychological support, etc.);
 - Abuse control (for example, number and percentage of OVC and families receiving home visits, etc.);
 - Economic assistance provided (for example, number and percentage of families having access to IGAs, to credit and saving schemes, to agricultural inputs, etc.).

Data on other special populations of children, such as street children, child labourers, institutionalised children, should be routinely collected to monitor the shift of children between different types of care or outside of family and community caregiving systems. 'The relative numbers of children in different types of care may be the most robust indicator of overall demographic pressure and social change resulting from increased adult mortality' (Family Health International 2001:14).

The main challenges of these monitoring and evaluation systems are identified as (USAID 2002):

- Avoiding double-counting OVC especially when they receive different types of support, or recurrent supports for the same beneficiary;
- Quality indicators. Counting numbers often clouds quality of care;
- Assessing households'/community's ability to cope with orphans;
- Assessing OVC's unmet needs.



12. INTERVENTION-LINKED RESEARCH

There is general consensus that there is a fundamental and widespread need for more research in the field of programming for vulnerable children. Amongst other things, more 'rigorous evaluation is needed of the various intervention models, including cost; and longitudinal studies to help us understand the long-term effects of the immense growth of the orphan population' (Rosen 2002:3).

A large number of research questions can be linked to intervention research to help improve targeting, programme scope and quality, as well as sustainability. These include:

- The impact of additional childcare on families and the extent to which families are breaking down;
- Methods for understanding and implementing systematic strategies to achieve community mobilisation;
- Barriers to sustainability of community-based care organisations;
- Community incentives needed to provide care;
- Developing and implementing activities to support vulnerable children within a home-based care and support context;
- Participation of adolescents and young people in prevention, care and support;
- Long-term psychosocial impact of AIDS on children and contextual factors which make children more vulnerable;
- Appropriate care for children in different circumstances.

In the course of interventions, it is recommended that much-needed data is collected on issues about which still little is known; for example, the mental and physical health of orphans and vulnerable children, the impact of gender on different aspects of children's lives (Subbarao in Levine 2001); simple and pragmatic approaches to mitigate the impacts of AIDS on children and families; costing studies to maximise the allocation of resources; evaluations of how children of different ages need to be responded to, and longitudinal research to evaluate the impact of different care options on children over time. What is essential for all research in this field is the rapid dissemination of results.

Smart (2003:19) makes the following recommendations with respect to useful information for programming and monitoring:

- Use a set of standardised data and core indicators that form the basis for country-level analyses and assessments. This would improve the potential for comparisons across regions in countries and across countries;
- At the country-level, conduct a baseline and thereafter regularly repeated studies (say every five years). This would serve as a useful way of tracking both trends in vulnerability of children and the effectiveness of interventions;
- Disaggregate data on HIV/AIDS and vulnerable children by age and gender and reflect the situation of children living in different circumstances and of children in need of special protection. Such data should then inform the design of programmes and policies targeted to address the needs of different groups of children;
- Routinely collect data on children not living in households – street children and children in institutions, to monitor trends and possible shifts between different types of care as well as to track those children outside of recognised care systems;
- Use tools to model future scenarios, upon which planning and resource allocations can be based;

- Capture the voices of children themselves, with due regard for ethical principles and practices governing child participation in research;
- Be aware of and pre-empt the possibility that studies raise expectations through the identification of needs that subsequently remain unmet.



13. GENERAL PROGRAMME APPROACH

The general programme approach endorsed by the UNAIDS Committee of Co-sponsoring Organizations was spelled out at the beginning of this document. A satellite session at the XIV International AIDS Conference in Barcelona gave further form to this approach by identifying the key factors required to foster effective local responses, which is agreed to be the optimal way to support children affected by AIDS (Smart 2003):

- Factor 1: Communities are taking ownership of the problem and the solution.
- Factor 2: As they are assuming ownership of the problem, communities mobilise for its solution. They rally the support they require for effective responses from the providers of services in their local environment – the teacher, the primary care nurse, the environmental officer. Effective local responses hinge on local partnerships.
- Factor 3: Effective and sustained local responses often require facilitation. Facilitation starts with helping communities to assess how HIV/AIDS is affecting their lives and to take appropriate action to tackle the issues.
- Factor 4: Effective country-wide responses result from three concomitant, interdependent processes:
 - Sharing of AIDS-related competence. This represents a horizontal expansion (scaling out). Effective local responses grow because they multiply and adapt. Facilitation can nurture these processes; but forcing them into mechanistic representations and planning instruments kills them;
 - Scaling up of the supply, in the local environment and the whole country, of the information, money and commodities that people require to take action;
 - The development of a supportive environment for effective responses country-wide; in particular, through political and spiritual leadership, mass communication, supportive taxation and subsidisation, and the adoption and implementation of supportive legislation, including human rights.

Multi-sectoral approaches, including sectors beyond health and education, and greater collaboration between NGOs in the same region and nationally, and between NGOs, government and donors, are recommended as general programming principles.

Good practice model: The Community-Based Options for Protection and Empowerment (COPE) programme in Malawi

The objective of the programme in Mangochi 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 programme involved two aspects: firstly, to stimulate the formation of a broad-based coalition of groups in a community concerned to respond to the impact of HIV/AIDS and, secondly, to train and build capacity to undertake initiatives to benefit HIV/AIDS-affected children and families and to mobilise internal and external resources. There is strong community ownership and motivation. Activities include orphan identification, community fundraising, home-based care programmes, youth clubs, recreational activities and childcare, and training of teachers to respond to the needs of vulnerable children. The programme is structured in a pyramid framework, cascading upwards from voluntary village-level activities to district-level structures. The programme has been externally evaluated and scaled up.

Programme principles reiterated in document after document reporting on experience in this field are:

- Work within a rights-based approach;
- Consult and enlist a wide range of stakeholders;
- Co-ordinate with other donors, NGOs and community groups working in the area;
- Conduct local needs assessment through participatory approaches to reach agreement on programmes to assist children;
- Ensure participation, including by children;
- Build on local capacity and increase existing strengths through community mobilisation;
- Work through existing groups;
- Conduct baseline assessments and use them to mobilise communities;
- Set up monitoring systems;
- Support families and communities to care for children rather than provide services directly to children;
- Respond to children before a parent dies;
- Respond to children's psychosocial as well as their material needs.

There is widespread advocacy for integrating care and prevention in what is called the *prevention-care-mitigation continuum*. Grainger et al. (2001) describe the potential synergy of integrating care and prevention as follows:

'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.' (2001:91)

South Africa has much to learn from countries with HIV/AIDS epidemics more advanced than our own, and with greater resource constraints. For example, a 1999 review of orphan programming in Tanzania listed the following as lessons learned for best practices with respect to families and communities:

- Emphasis on development, not charity;
- Preference for absorbing families in extended family and foster family settings;
- Systematic registration, needs assessment, and monitoring of orphans and other vulnerable children;
- Creation of daycare centres to provide protection, stimulation, nutrition and education for vulnerable children;
- Emphasis on income generation and self-reliance;
- Interest in access to loan and credit programmes;
- Creation of communal gardens to support vulnerable families;
- Fund raising at community level;
- Volunteer provision of vocational training;

- Participation of women, children and youth in decision making and committee affairs;
- Promotion of counselling to ease problems between guardians and children;
- Involvement of traditional leaders and use of traditional councils;
- Support for and recognition of community volunteers;
- Village headmen donate land use by Village Orphan Committees;
- Protection of women and children's property through changes in local by-laws.

APPENDIX



Responses developed by stakeholders to meet OVC's needs for OVC living in family-like settings

Level of intervention		
Community/household	NGOs	Government
Basic needs		
General		
	<ul style="list-style-type: none"> Home-visits to monitor the well-being of the child Raise awareness of OVC's needs 	
Improve income		
<ul style="list-style-type: none"> Labour sharing Communal gardens Resort to less work-intensive and more resistant crops Resort to less risky/less productive activities Savings club (ROSCAs) Income generating activities Marketable skills training for out-of-school youth 	<ul style="list-style-type: none"> Cash/in-kind transfer to affected families Micro-finance (formal savings and credit schemes, in-kind revolving credit) Income generating activities Helping product marketing Agricultural assistance (in-kind and technical) Marketable skills training for out-of-school children 	<ul style="list-style-type: none"> Cash/in-kind transfers to affected families (Grants to foster families) Agricultural assistance to communities (in-kind and technical) Marketable skills training for out-of-school youths
Shelter		
<ul style="list-style-type: none"> Community house-repairing 	<ul style="list-style-type: none"> Provide inputs 	<ul style="list-style-type: none"> Grants for the most needy households
Food		
<ul style="list-style-type: none"> Improving access and availability of food (Communal gardens, improved agricultural production and its marketing) Enhance effective nutrition practices, supplementary food programmes, nutrition counseling (especially for child-headed households) Food rations for the most needy children School feeding programmes and school gardens 	<ul style="list-style-type: none"> Technical assistance (seed selection, irrigation, natural resources management) Provide agricultural inputs Training of nutrition counselors Provide food for feeding programmes 	<ul style="list-style-type: none"> Technical assistance for better farming practices Training in nutrition by public health workers Food basket to foster families
Health care		
<ul style="list-style-type: none"> Distribution of medicines to the most needy household Rural pharmacies Day care centers, youth-clubs (to address adolescent's specific needs, HIV/AIDS prevention) 	<ul style="list-style-type: none"> Distribution of medicines to the most needy household Provide inputs for rural pharmacies Training of health counselors Provide material for basic hygiene practice (soap) 	<ul style="list-style-type: none"> Health subsidies for OVC Training in health issues by public health workers Immunisation campaigns for all children



Level of intervention		
Community/household	NGOs	Government
Clothing		
	<ul style="list-style-type: none"> • Collection of used clothing to hand over to needy children 	<ul style="list-style-type: none"> • Grants for OVC
Education		
<ul style="list-style-type: none"> • Community fundraising to send OVC children to school • Bear school-related expenses • In-kind support for schools that admit OVC • Collection of used uniforms, shoes, books to hand over to OVC in need • Enable OVC to attend school without uniform • Promote alternative form of education: distant learning, community schools, interactive radio education • Training in marketable skills for out-of-school youths (especially for child-headed household) • Pre-school programmes for 3–6-year-old children 	<ul style="list-style-type: none"> • School subsidies (fees, books, uniform) • Cash granted to the most needy guardian tied to child's attendance at school (conditional cash-transfers) • Promote alternative form of education: distant learning, community schools, interactive radio education • Vocational training and non-formal education for youths • Pre-school programmes for 3–6-year-old children 	<ul style="list-style-type: none"> • Elimination of school fees and uniforms • Fee/uniform waivers for OVC • School subsidies (fees, books, uniform) • Cash granted to guardian tied to child's attendance at school (conditional cash-transfers) • Promote alternative form of education: distant learning, community schools, interactive radio education • Improve quality of education • Vocational training and non-formal education for youths • Pre-school programmes for 3–6-year-old children
Safety needs		
General		
Raising awareness on OVCs safety needs		
Prevent verbal/physical/sexual abuses		
<ul style="list-style-type: none"> • Home visits to monitor OVC's well-being 	<ul style="list-style-type: none"> • Training volunteers to recognise children abuses and direct them to adequate services 	<ul style="list-style-type: none"> • Law against child abuse and its enforcement • Reprisal against child abuses
Prevent work exploitation		
<ul style="list-style-type: none"> • Home visits to monitor OVC's well-being • Home helper to reduce vulnerable children workload 	<ul style="list-style-type: none"> • Training volunteers to recognise children abuses and address the issue 	<ul style="list-style-type: none"> • Law implementation and enforcement • Reprisal against household exploiting OVCs



Level of intervention		
Community/household	NGOs	Government
Legal needs		
General		
Promote advocacy and raise awareness around property and inheritance rights		
Property inheritance right		
<ul style="list-style-type: none"> Facilitate written will, birth and death registration Allocation of land by traditional leaders to landless households (those who experienced property grabbing or do not have access to their land because of displacement or insecurity) 	<ul style="list-style-type: none"> Support OVC and widows Facilitate wills Facilitate transition/guardianship 	<ul style="list-style-type: none"> Establish legal support to enforce children's right Reprisal actions against offenders Establish the practice of written will, birth and death registration
Psychological and emotional needs		
<ul style="list-style-type: none"> Counseling via home visits by volunteers (especially for children living with dying parents) Favour recreational activities, such as sport and art Promote youth clubs Prepare the family for planning when parents are dying 	<ul style="list-style-type: none"> Train community volunteers to provide adequate emotional and psychological support 	<ul style="list-style-type: none"> Inclusion of psychological support in teacher training programmes Home visit by trained public health personnel

Source: Subbarao & Coury (2003: 25-27)

Interventions to improve the financial situation of families fostering OVC

Intervention	Advantage	Drawback
Labour sharing	<ul style="list-style-type: none"> • Free caregivers and children for performing other tasks • Enhance community cohesion (especially valuable in post-conflict settings) • Ownership of the initiative by the community 	<ul style="list-style-type: none"> • May not be sustainable in high prevalence areas because HIV/AIDS epidemic depletes human resources • May overburden some community members
Communal gardening	<ul style="list-style-type: none"> • Restoration of ancient tradition • Enhance community cohesion • Source of resources for landless households (important for displaced/refugee households) • Ownership of the initiative by the community 	<ul style="list-style-type: none"> • May overburden some community members (especially as the HIV/AIDS epidemic depletes human resources)
Develop less work-intensive and more resistant crops (like cassava)	<ul style="list-style-type: none"> • Improve income as well as food security • Improve individual skills 	<ul style="list-style-type: none"> • Dependency on external assistance regarding seed provision and technical assistance
Agricultural assistance (use of new crops, of natural pesticide, irrigation)	<ul style="list-style-type: none"> • Improve community members' skills 	<ul style="list-style-type: none"> • External assistance dependency
Micro-finance	<ul style="list-style-type: none"> • Improve access to credit and savings schemes • Reduce vulnerability to loss • Enable to avoid irreversible coping strategies • Enable to set up IGAs 	<ul style="list-style-type: none"> • Need skills to manage money (may lead to unsustainable level of indebtedness) • Do not reach the most needy household (not appropriate for destitute households) • Requires follow-up and marketing supports
In-kind revolving credit (cattle, poultry)	<ul style="list-style-type: none"> • Easy to implement • Enhance also food security 	<ul style="list-style-type: none"> • May create more vulnerability if the animal dies, since it is an 'indivisible good'
Income generating activities	<ul style="list-style-type: none"> • Diversify sources of income 	<ul style="list-style-type: none"> • Need adequate skills and market opportunities • Rely on external assistance to help find markets and to get adequate training
Marketable skills training for out-of-school youths	<ul style="list-style-type: none"> • Improve skills, particularly adequate for adolescent household head and youths living with sick or old caregivers 	<ul style="list-style-type: none"> • Rely on external trainers
Cash/in-kind transfers to needy households	<ul style="list-style-type: none"> • May be particularly adequate for destitute households (child-headed household, OVC living with sick parents or old caregivers) 	<ul style="list-style-type: none"> • May be difficult to manage as the number of potential beneficiaries increase substantially • Household may become dependant on such aid relief • May not directly improve the OVC's well-being • May not be financially sustainable over the long-run (especially as the AIDS/HIV epidemics increases the number of needy households) • Limited resources of government to provide for all the destitute

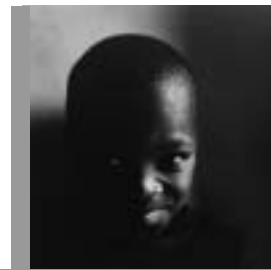
Source: Subbarao & Coury (2003: 25-27)

Risks and interventions to help families meet OVC's basic needs

Main intervention taken	Drawbacks/risks	What interventions are more relevant?	
Risk of dropping out of school (education)			
<ul style="list-style-type: none"> Abolition of school fees School subsidies (fees, books, uniform) for OVC Cash granted to the guardian tied to child's attendance at school 	<ul style="list-style-type: none"> May create stigma May not be financially sustainable over the long-run if not well targeted May create dependency-behavior 	Sectoral approach more relevant Yet some OVC still may require some special assistance: <ul style="list-style-type: none"> Conditional transfers (on the ground that the child attends school) should then be provided to the most vulnerable children targeted in their community Liaise with school officials to improve access of the OVC through fee waiving 	
<ul style="list-style-type: none"> Promote alternative forms of education: distant learning, community schools, interactive radio education 	<ul style="list-style-type: none"> Require specific training, input and strong community commitment 		
<ul style="list-style-type: none"> Community fundraising to send OVC children to school Community grants by governments/donors Collection of used uniforms, shoes, books to hand over to OVC in need 	<ul style="list-style-type: none"> Require a strong mobilisation of community members 		
<ul style="list-style-type: none"> Enable OVC to attend school without uniform 	<ul style="list-style-type: none"> May create stigma if targeted only to orphans 		
<ul style="list-style-type: none"> Vocational training and non-formal education for youths 	<ul style="list-style-type: none"> Require trainers, initial inputs 		
<ul style="list-style-type: none"> Pre-school programmes for 3–6-year-old children 	<ul style="list-style-type: none"> Require teachers to be trained, external subsidies. 		
<ul style="list-style-type: none"> Home helper to perform house chores 	<ul style="list-style-type: none"> May overburden volunteers 		
Risk of exposure to health risks or missing immunisations			
Health subsidies for OVC Immunisation campaign	<ul style="list-style-type: none"> May create stigma May not be financially sustainable over the long run if not well-targeted 		Sectoral approach more relevant Yet some OVC still may require some special assistance: <ul style="list-style-type: none"> free health care and immunisation should then be provided to the most vulnerable children targeted in their community Liaise with basic health care centers officials to provide the most vulnerable children with free medical visits and medicines
Distribution of medicines to the most needy households	<ul style="list-style-type: none"> May create stigma May not be financially sustainable over the long run if not well targeted 		
Rural pharmacy	<ul style="list-style-type: none"> Require initial input Require training (management) May not reach the most needy 		
Home-based care, day-care center, youth club	<ul style="list-style-type: none"> Require initial training, medical input, and commitment of volunteers 		
Risk of nutritional shortfalls			
Improving agricultural production	<ul style="list-style-type: none"> Require technical and material (agriculture input) assistance 	Sectoral approach more relevant Yet some OVC still may require some special assistance, such as free food assistance	
Enhance effective health and nutrition practices	<ul style="list-style-type: none"> Require external agencies training 		
Feeding programmes, food baskets	<ul style="list-style-type: none"> Rely on external assistance May create stigma May not be financially sustainable over the long-run 		



Main intervention taken	Drawbacks/risks	What interventions are more relevant?
Risk of abuse		
Home visits to monitor the general well-being of the child by community members (volunteers)	<ul style="list-style-type: none"> • May overburden volunteers • Home-visitors need to be adequately trained to monitor the OVC's well-being and provide material relief when needed • Insufficient qualified volunteers 	Community-based care provided by volunteers is most cost-effective. Yet the sustainability of their motivation over the long term raises many concerns. Some kind of remuneration, either in kind or in cash, needs to be introduced at a point.
Home visits to monitor the general well-being of the child by NGO or public health staff	<ul style="list-style-type: none"> • Insufficient qualified staff 	
Raise awareness on OVC's needs	<ul style="list-style-type: none"> • Need leaders' involvement: traditional community leaders, religious group leaders and political leaders 	
Appropriate legal laws and practices	<ul style="list-style-type: none"> • Insufficient qualified staff • Need leaders involvement: traditional community leaders, religious group leaders and political leaders 	
Risk of trauma: psychological and emotional support		
Home visits to monitor the general well-being of the child by community members (volunteers)	<ul style="list-style-type: none"> • May overburden volunteers • Home-visitor's need to be adequately trained • Insufficient qualified volunteers 	Community-based care provided by volunteers are the most cost-effective. Yet the sustainability of their motivation over the long term raises many concerns. Some kind of remuneration, either in kind or in cash, needs to be introduced at a point.
Home visits to monitor the general well-being of the child by NGO or public health staff	<ul style="list-style-type: none"> • Insufficient qualified staff 	



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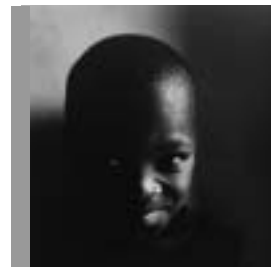


SECTION TWO

AN ANNOTATED BIBLIOGRAPHY FOR
FAMILY AND COMMUNITY BASED
APPROACHES TO SUPPORTING
CHILDREN AFFECTED BY AIDS



ANNOTATED BIBLIOGRAPHY



Adams, J. (2002). *An evaluation of the Department of Social Development's response to the HIV/AIDS crisis*. Cape Town: Budget Information Service, IDASA.

This paper is divided into three sections. The first describes some dimensions of the HIV/AIDS scenario in South Africa as it pertains to developmental social services. Next, it describes how the Department of Social Development has responded to the challenges issued by the disease thus far. Finally, it discusses the implications and appropriateness of these responses.

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Ainsworth, M. (1996). Economic aspects of child fostering in Côte d'Ivoire. In T. P. Schultz (Ed.), *Research in population economics* (8th ed.). Greenwich, CT: JAI Press.

Ainsworth, M., Beegle, K., & Koda, G. (2000). *The impact of adult mortality on primary school enrollment in Northwestern Tanzania*. Development Research Group of the World Bank, Rand Corporation, University of Dar es Salaam.

As adult mortality rates rise due to AIDS, there is increasing concern over the fate of orphans. In this study we explore one dimension of this impact – their schooling. Schooling is an important investment in children's future productivity and well-being. However, the schooling of orphans (and other children in homes with an adult death) is threatened because families affected by an adult death may be less able to afford direct and indirect costs of schooling, and the child's opportunity cost of time may rise in household and farm activities. In this paper, we assess whether orphans or children in households with an adult death are less likely to be enrolled in primary school.

Ainsworth, M. & Filmer, D. (2001). *Poverty, AIDS and children's schooling: A targeting dilemma*. Powerpoint presentation.

Ainsworth, M. & Filmer, D. (2002). *Poverty, AIDS and children's schooling: A targeting dilemma*. (World Bank Policy Research Working Paper 2885). Washington DC: World Bank, Development and Research Group and the Human Development Network, Education and Social protection teams.

This paper analyses the relationship between orphan status, household wealth, and child school enrolment using data collected in the 1990s from 28 countries in sub-Saharan Africa, Latin America, the Caribbean, with one country in Southeast Asia. The findings point to considerable diversity – so much so that generalisations are not possible. While there are some examples of large differentials in enrolment by orphan status, in the majority of cases the orphan enrolment gap is dwarfed by the gap between children from richer and poorer households. In some cases, even children from the top of the wealth distribution have low enrolments, pointing to fundamental issues in the supply or demand for schooling that are a constraint to higher enrolments of all children. The gap in enrolment between female and male orphans is not much different than the gap between girls and boys with living parents, suggesting that female orphans are not disproportionately affected in terms of their enrolment in most countries. These diverse findings demonstrate that the extent to which orphans are under-enrolled relative to other children is country-specific, at least in part because the correlation between orphan status and poverty is not consistent across countries. Social protection and schooling policies need to assess the specific country situation before considering mitigation measures.

Akukwe, C. (1999). HIV/AIDS in African children: A major calamity that deserves urgent global action. *Journal of HIV/AIDS Prevention and Education for Adolescents and Children*, 3: 5–24.

In Africa, HIV/AIDS affects children and deserves urgent global action. According to the UN Global Program on HIV/AIDS, Africans account for 70 per cent of all global HIV infections despite representing only 10 per cent of the world's population. In 1998 more than 80 per cent of global AIDS mortality occurred in Africa. However, the fate that confronts African children is far more ominous: in 1998, nine out of ten new global HIV infections among children 15 years or younger occurred in Africa, and over 95 per cent of all AIDS orphans

worldwide are African children. Since the start of the pandemic, nearly 2.9 million African children have died of AIDS-related diseases. This paper discusses the HIV/AIDS epidemic among African children and concludes with recommendations on how to organise an urgent global response to save these children.

Alliance (2003). *Education: Building Blocks Series*. Africa-wide briefing notes – Resources for communities working with orphans and vulnerable children. Alliance.

These briefing notes are part of a set of six, comprising five topics and an overview:

- Education
- Health and nutrition
- Psychosocial support
- Social inclusion
- Economic strengthening.

These briefing notes have been developed through a highly participatory process, guided by an international advisory board. During their development in English, French and Portuguese, they have been reviewed by more than 80 people across Africa. These people have read and commented on the papers, and have added examples and case studies from their own countries. One part of the review took place at a meeting in Uganda, attended by 20 people from Uganda, Malawi, Zambia, Zimbabwe, Kenya, Burkina Faso, Senegal, Mali, Mozambique and Angola. The people who attended this meeting then took the papers back to their colleagues in their home countries, who undertook a further process of review. Examples and case studies from this process have been noted in the text as coming from a 'Member of the Building Blocks Development Group'.

The notes are divided into four sections:

- Introduction: An overview that explains why programmes need to strengthen the skills and resources of families and communities to provide psychological and emotional support to children.
- Issues: An outline of the psychosocial impact of HIV/AIDS on children.
- Principles: Guidelines for programmes aimed at providing psychosocial support to orphans and vulnerable children.
- Strategies: Possible ways of taking action to strengthen support for orphans and vulnerable children. There is a growing evidence base for strategies that are effective in supporting orphans and vulnerable children. As the evidence base is not yet comprehensive, strategies in the briefing notes include both those that have been implemented together with suggestions for strategies based on the experience of people working with orphans and vulnerable children. As such, strategies are not given in any order of priority or relative effectiveness.

Most programmes for orphans and vulnerable children focus on material support and meeting children's physical needs. Relatively few consider the psychosocial effects on children of having HIV, caring for a sick parent, living in a household affected by HIV/AIDS, or losing one or both parents. The loss of a parent is a traumatic and stressful experience. Early intervention is vital, and we should not assume that children can always cope. They should be given plenty of opportunity to express their feelings. Different approaches to counselling for children need to be explored further. Caregivers also need care and support. Those caring for orphans and children in households affected by HIV/AIDS have psychosocial needs too. Meeting these needs is essential to help them go on to provide the best possible care and support for orphans and affected children. 'When people came to visit me after the loss of my mother, they all brought me food and more food but they never noticed how depressed I was. I could not even eat the food they had brought for me. All I needed was someone to listen to me and tell me I could still be loved even after my mother had died'. (Masiye Kids Club)

Trauma is an emotional shock, producing long-lasting, harmful effects on the individual. Stress is an emotional condition, experienced or felt when an individual has to cope with unsettling, frustrating or harmful situations. It is a disturbing sense of helplessness, which is uncomfortable and creates uncertainty and self-doubt. Caregivers also need care and support. Children should be given plenty of opportunity to express their feelings.

Alliance (2003). *Building Blocks Series: Africa-wide briefing notes – Resources for communities working with orphans and vulnerable children*. Alliance.

HIV/AIDS is associated with taboo subjects such as sex, death and blood, and with behaviours such as commercial sex, drug use and homosexuality. This leads many people to stigmatise and discriminate against anyone with HIV or affected by HIV. Since AIDS was first recognised as a fatal disease, it has caused widespread fear, ignorance and denial, which have resulted in discrimination, abuse and violence not only against people with HIV but also their families.

Denial when a parent is dying and the sense of shame linked to an AIDS death is particularly harmful for children. They are especially sensitive to the damaging psychological effects of stigma. Stigma and discrimination can affect children with or without HIV in many ways. Even if they do not have HIV themselves, children may be stigmatised because a parent has HIV or has died from AIDS. Stigmatisation and discrimination create and reinforce the social isolation of those affected by the epidemic, including children. They engender rejection, hostility, isolation and human rights violations; for example, reduced access to healthcare, education and employment. Stigma and discrimination can affect children if one or both parents has HIV or has died from AIDS. Sometimes children have to cope with hearing their sick and dying parents insulted by neighbours and relatives. Community members who fear that the orphans may also have HIV or think their families have shamed the community often discriminate against the children and deny them social, economic, emotional and educational support. This intensifies the harmful effects of HIV/AIDS on children. HIV/AIDS also worsens the stigmatisation of already marginalised children; for example, the children of sex workers, street children, refugee children, children in detention and children using drugs. Some of these children, however, may be most at risk of HIV infection because of problems such as lack of information and emotional support, powerlessness and potential vulnerability to sexual exploitation and abuse. Stigma also prevents people with HIV disclosing their status and getting access to available support and care services, as well as to information about HIV prevention that would help people (with or without HIV) to adopt safer behaviour. Stigma can suggest to people from discriminated groups that they are social outcasts and deserve to be punished.

Orphans, vulnerable children and their caregivers are often unaware of their rights and the laws intended to protect them from discrimination. Sometimes they are aware of their rights but are not able to demand better treatment from their caregivers or community. They may have no one to advocate on their behalf and lack access to legal advice.

Defining stigma and discrimination:

- Stigma is an attribute that singles out an individual or a specific group of individuals as different. They are regarded in a negative and judgmental way because they possess this attribute.
- Discrimination is one of the ways in which stigma is shown. It occurs when a person or group of people is treated unfairly or unjustly on the basis of their belonging, or being perceived to belong, to a particular group. Stigmatised people are often discriminated against in laws, policies and social relations.

Alliance (2003). *Economic Strengthening: Building Blocks Series*. Africa-wide briefing notes – Resources for communities working with orphans and vulnerable children. Alliance.

This section considers the effects of increased poverty and lack of economic opportunities on children's lives. Orphans and children from affected families are more likely to be poor because of *reduced household income* while parents are too sick to earn money, and after their death. This leads in turn to reduced access to healthcare, food and education for the children, and even in some cases the loss of their home and property. Usually, sick parents cannot remain as productive, so less income or food is produced for the family. *Increased expenditure on healthcare:* Households with a family member who has AIDS-related illnesses use a high proportion of their income for medical expenses. *Funeral costs:* In some areas where death rates due to AIDS are high, communities may no longer contribute towards funeral costs, leaving bereaved households to meet all the expenses themselves. Funeral

costs are usually high: there is a long period of mourning, with large number of mourners to be fed, and many families have to deal with several funerals in close succession. *Debt*: Sometimes parents die leaving unsettled debts. *Depleted resources*: Common coping strategies used by households in times of economic difficulty deplete the family's resources and compromise the children's futures. They include:

- Spending savings
- Seeking wage labour
- Switching to lower maintenance subsistence crops
- Selling possessions, livestock and land
- Borrowing food and money
- Reducing consumption and expenditure on food
- Resorting to cheaper medication
- Withdrawing children from school
- Children resorting to paid labour

Life chances: Children in affected households or who have lost their parents may have to earn money to contribute to household income. Such children start work earlier than their contemporaries and often either leave or miss school, affecting their chances of achieving functional literacy. In extreme cases, girl children may sell sex to support themselves and younger siblings. Sometimes girls may get married for economic security. A study in Cote D'Ivoire found that in urban households affected by AIDS, average income is halved and health care expenditure increases by 400 per cent (UNAIDS/UNICEF 1999).

The Community-based Options for Protection and Empowerment (COPE) programme in Malawi found the severest economic stress in households headed by a grandparent, adolescent or a single, ill parent. Children in those households lacked food, clothes, shoes and bedding

Alliance (2003). *Nutrition: Building Blocks Series*: Africa-wide briefing notes – Resources for communities working with orphans and vulnerable children. Alliance.

HIV/AIDS affects children's health and nutrition both directly and indirectly. Children living with HIV have specific health and nutritional needs. At the same time, children who do not have HIV but are orphaned or living in families affected by HIV, have a higher risk of poor health and nutrition largely because of poverty and lack of care. In many African countries, infant and child morbidity and mortality rates are increasing as a result of the HIV/AIDS epidemic and its effects on children's health and nutrition. The US Census Bureau estimates that, in the countries worst affected by the HIV/AIDS epidemic, the infant mortality rate could increase by 76 per cent and the under-five mortality rate double by 2010. Good nutrition can help reduce morbidity and mortality, and increase the quality of life of children with HIV.

Mother-to-child transmission from an HIV-positive mother during pregnancy, birth or breastfeeding is responsible for most HIV infection in children. Without intervention, one in three positive mothers will pass on the virus to her children. Research is controversial, but it is likely that the risk of transmission can be significantly reduced by a combination of three interventions: antiretroviral drugs, caesarean section and exclusive breast-feeding or replacing breast milk with a suitable formula, soy or animal milk. HIV can be transmitted to children through transfusions with infected blood or injections using equipment contaminated with infected blood. The risk of transmission can be significantly reduced by using sterile or disposable instruments, needles and syringes, and screening blood for transfusion services.

Sexual abuse of children may expose them to HIV infection. Community action to prevent child sexual abuse and support abused children can work to reduce the number of children infected in this way. Many orphans and vulnerable children have poor health and are malnourished because they have inadequate:

- environmental and sanitary living conditions
- food/nutrition
- access to quality health care when they are sick.

This occurs when households cannot afford their basic survival needs, such as quality food and health services, and where these children are stigmatised within the household and/or at health centres.

Children living without parents or with sick parents are also likely to be malnourished. Many poor households, especially those caring for many children, cannot afford enough good food, and so eat cheaper and less nutritious foods. HIV/AIDS is causing less food to be produced in areas where many young people and adults are sick or have died. When less food is produced, families have less income also for other families who cannot find food to buy.

All children should have access to adequate health care services and programmes. These should include adequate preventive education and treatment for HIV/AIDS, when necessary.

Orphans and vulnerable children should receive special protection from economic exploitation and from performing any work that is likely to be hazardous or harmful to their health, or physical, mental, moral and social development.

Data from the AIDS Outreach Project of Child Advocacy International (CAI) show that 74 per cent of children enrolled in the programme (most of whom have HIV) were underweight and/or malnourished, but once food was provided the majority put on weight and reached their expected weight-for-age within a few months of enrolment. The Mothercare Project (also run by CAI) looks after abandoned children in Mulago Hospital. The majority of these children are sick and malnourished when they arrive, but after a few weeks they improve and gain weight.

Half the children interviewed in a study in Kenya did not get enough to eat. Some just had tea or water for breakfast; a third had no lunch. There have been similar reports from elsewhere of children only having one meal a day – often just maize porridge with a few vegetables and little or no protein. In Rakai, an area of Uganda badly affected by HIV/AIDS, a quarter of families have had to reduce land use, crop and livestock production. Similar effects have been seen on agriculture in areas of Tanzania and Rwanda.

Alliance (2003). *Overview: Building Blocks Series*. Africa-wide briefing notes – Resources for communities working with orphans and vulnerable children. Alliance.

There is a growing evidence base for strategies that are effective in supporting orphans and vulnerable children. As the evidence base is not yet comprehensive, strategies in the briefing notes include both those that have been implemented together with suggestions for strategies based on the experience of people working with orphans and vulnerable children. As such, strategies are not given in any order of priority or relative effectiveness.

The HIV/AIDS epidemic has vastly increased the number of orphans and other vulnerable children, particularly in Africa. Most programmes aim to meet the basic material requirements of these children. But children need – and are entitled to – a wide range of other forms of support. Without this, the future for these children, their families and the communities in which they live lies in jeopardy. These briefing notes are intended to help governments, non-governmental and religious organisations meet the severity of this challenge and provide more effective, holistic support to children within their families and communities. The overview outlines important issues involved in working with orphans and other children made vulnerable by HIV/AIDS, and summarises principles for programming support for them.

Alwang, J., Siegel, P. B., & Jørgensen, S. L. (2003). *Vulnerability: A view from different disciplines*. (Social Protection Discussion Paper No. 0115). Washington, DC: World Bank.

Practitioners from different disciplines use different meanings and concepts of vulnerability, which, in turn, have led to diverse methods of measuring it. This paper presents a selective review of the literature from several disciplines to examine how they define and measure vulnerability. The disciplines include economics, sociology/anthropology, disaster management, environmental science, and health/nutrition. Differences between the disciplines can be explained by their tendency to focus on different components of risk, household responses to risk and welfare outcomes. In general, they focus either on the risks (at one extreme) or the underlying conditions (or outcomes) at the other. Trade-offs exist between simple measurement schemes and rich conceptual understanding.

Anarfi, J. (1997). Vulnerability to sexually transmitted disease: Street children in Accra. *Health Transition Review*, 7, 281–306.

The study confirmed the findings in earlier studies in Ghana and elsewhere that street children are a vulnerable group of young people whose lifestyles place them at high risk for the contraction and transmission of HIV and other STDs. They are exposed to elements of the physical and social environment which may adversely affect their health. They are among the known high-risk groups for the spread of HIV/AIDS. Most eat irregularly and under unhygienic conditions. There is evidence of repeated illness and infections which receive inadequate treatment and, therefore, may facilitate HIV infection. There is further evidence of drug use which may also increase their vulnerability to HIV infection by weakening them physically and reducing their capacity to make rational decisions. Under the influence of drugs they tend to be reckless in their sexual practices. Most of the street children are sexually active and most had their first experience on the street and with prostitutes. Some of the girls engage in sexual activity for money in order to survive. Most of them have multiple sexual partners and there is evidence that some experiment with unconventional sexual practices including homosexual acts. Some of them think sex is pleasurable and is a biological necessity which must be engaged in as often as possible. Street children are aware of AIDS and regard themselves as in danger of contracting it.

Nevertheless, the level of their condom use is very low and the use patterns are inconsistent. Generally, they are not doing much to protect themselves from contracting HIV, which is also influenced by the kind of misconceptions they have about the disease. The children appear a little more ignorant of other STDs than AIDS. A few of them had been infected by some kind of STD. Self medication is the general practice for the treatment of STDs and there is evidence of inadequate treatment. Such a situation increases their chances of contracting HIV.

Anderson, B. A., Phillips, H. E., van Zyl, J. A., & Romani, J. H. (2001). *Estimates of orphans in South Africa, 1995–1998*. Paper presented at a workshop on children, HIV and poverty in southern Africa, organised by SARP, HSRC and Save the Children, 2002 [Available online: <http://www.sarpn.org.za>]

Andvig, J. C. (2001). *Family-controlled child labor in Sub-Saharan Africa. A survey research* (Social Protection Discussion Paper no. 0122). Washington, DC: World Bank.

This is a review of research on child labour in Sub-Saharan Africa. It focuses on child labor taking place in the household and controlled by relatives of the children since this is the most extensive form of child labour in African countries. It is also the form of child labor that is the most difficult one to appraise from a normative point of view. Subtle trade-offs between schooling, leisure and poverty across generations may be involved. Hence, the paper emphasises welfare economics issues pertaining of child labour.

Another feature of this study is that it seeks to survey not only the economic research, but also research from other social sciences, particularly social anthropology. The social anthropological studies deal with an aspect of child labour so far less adequately dealt with by economists – the relationship between their labour and their socialisation; how certain types of labour and education may give rise to different preferences to the children as adults. A major, but tentative conclusion of this survey is that the relationship between poverty and child labour is less close than normally assumed in the policy debate.

Ansell, N. & Young, L. (2002). *Enabling households to successfully support young AIDS migrants in Southern Africa*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>]

Background: Most southern African orphans are cared for by extended families, but the implications of the spatial dispersal of southern African families are seldom recognised: orphans migrate to new homes and communities. This paper compares orphans' migration experiences to assess how successful migration might best be supported. *Methods:* Research was conducted in urban and rural communities in Lesotho and Malawi. Qualitative and quantitative methods were employed with 822 10–17 year-olds, and 40 guardians. In particular, focus groups and storyboards were used to elicit children's AIDS-related migration

experiences. *Results:* Most children found migration traumatic in the short term, but over time many settled into new homes and communities. Although much AIDS policy in southern Africa stresses the role of communities, in practice communities were found to have little involvement in caring for incoming children. Instead the burden lay with extended family households. Failed migrations, which resulted in renewed migration and trauma, were attributable to one of two household-level causes: a change (often economic) in guardians' circumstances; or orphans feeling discriminated against in their new families, including through harsh punishments, hard work and withdrawal from school. Sometimes this treatment was rooted in economic necessity. In other cases it reflected resentment of their presence in the household. Regardless of the cause, many such children chose to leave, moving either to other relatives or onto the streets. *Conclusions:* Policy interventions to reduce disruption and trauma for young AIDS migrants should focus on enabling households to provide care. Reducing the economic costs of caring for children, particularly school-related costs, would help: allow children to stay with those relatives best able to meet their non-material needs; reduce the resentment of foster children in impoverished households; diminish the need for multiple migrations.

Are, S. K. (2003). *Helping AIDS orphans through supporting extended families*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

Thailand could have up to 500 000 AIDS orphans by the year 2005. Most of the AIDS orphans in Thailand tend to be cared for by surviving parents and relatives. Extended families are still prevalent in Thailand though this has been weakened by rapid urbanisation during the past half century. The social and institutional infrastructure for supporting family life has been steadily eroded by rural-urban migration, industrialisation and commercialisation of agriculture. When the AIDS epidemic hit Thailand, its social and institutional infrastructure was found to be inadequate to cope with the crisis. AIDS morbidity and mortality rose sharply.

A comprehensive program to strengthen extended families in Thailand is badly needed to enable AIDS orphans to survive within their home communities by:

- providing educational support to attend local primary school
- providing psychological inputs in healthcare and AIDS prevention
- helping surviving parents/guardians with income generating schemes
- creating opportunities for skill training to integrate AIDS orphans into society
- promoting community participation in caring for local AIDS orphans.

AFXB Thailand is setting up programs in Chiangrai province, along the above lines to succour AIDS orphans and promote children's rights. Supporting extended families have proven to be a humane and cost-effective approach to caring for AIDS orphans compared to running orphanages.

Aspaas, H. R. (1997). AIDS and orphans in Uganda: a geographical and gender interpretation of household resources. *The Social Science Journal*, 36, 2, 201–226.

Ugandan households are providing crisis fostering for the orphans of relatives who have died of AIDS. Findings are reported from a study conducted to determine how the gender of household heads and locational differences among households are associated with resource outlays for AIDS orphans. Education is used as an indicator of resource outlays in order to better assess how household cash resources are distributed relevant to AIDS orphans. Findings are based upon field surveys conducted in Jinja district during October–November 1993. The survey identified the location of households in the district caring for orphans by rural areas, market centres, or towns; the gender of the household head; and the resource base of the household and its implications for investing in orphans' education. Analysis of the data indicates that decisions about the welfare of orphans may be a function of the gender of the household head and the location of that household on a rural to urban continuum.

Awate, R. V. (2002). *Sustainable community-based care support programme for the orphans of HIV/AIDS -suburb of Dar Es Salaam, Tanzania*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>]

The number of orphans has increased significantly over the years due to the HIV/AIDS pandemic in sub-Saharan Africa. It is becoming quite unrealistic technically and financially to cater for increasing demands of this underserved population (orphans of HIV/AIDS). An ongoing project has been launched in the village Tegeta, a suburb of Dar Es Salaam (Tanzania) with the help of local village development council, government dispensary and IMTU. The ambitious project 'Sustainable Community-Based Care and Support Programme for HIV/AIDS orphans' envisages to explore the magnitude of orphans and associated problems, social support that is in place for orphans and to implement appropriate interventions to improve quality of life of orphans. Approximately 250 orphans of both sexes have been identified. Preliminary interviews with the orphan, the guardians, and community leaders and clinical examination every orphans has been done. Clinico-social profile and interventions adopted/planned are presented in this paper: Malnutrition (60 per cent), anaemia (45 per cent), worm infestation (40 per cent) and skin infections (35 per cent) are the major clinical morbidities. Sense of segregation, discrimination, insecurity and stigma are the psychological problems faced by most of them. Lack of access to school (secondary 70 per cent), inadequate shelter and privacy, poor quality and quantity of food, lack of clothes and foot-wares and learning materials are socio-economic hurdles in development. Health examination, treatment of prevalent morbidities, follow up and counselling are the immediate interventions adopted. The guardians/foster parents, caretakers, community and religious leaders are involved, counselled and motivated to improve the care and support to orphans. It is planned to establish a multi-purpose facility centre funded and managed by the local community for sustainable activity: clinic, counselling, education, entertainment, etc.

Ayieko, M. A. (1998). *From single parents to child-headed households: The case of children orphaned by AIDS in Kisumu and Siaya Districts* (Study Paper No. 7). New York: UNDP.

The socio-economic consequences of the HIV/AIDS epidemic are felt in a growing number of countries. Increasing mortality rates among adults are threatening economic and social well-being. Women and children are bearing the heavy burden of nursing the sick, and managing households with over-stretched resources. Observations show that when a husband dies of AIDS in a family, the mother is also often living with HIV/AIDS and dies shortly thereafter, leaving children as orphans.

Most parents, even if they are aware of their terminal illness, do not attempt to make any alternative living arrangements for their children before their death. Children are left in the household with limited, or no, resources. As the epidemic spreads, these child-headed households are becoming more and more frequent in rural areas.

Children in such conditions are deprived of their childhood and the opportunity to go to school. Economic hardships lead them to look for means of subsistence that increase their vulnerability to HIV infection, substance abuse, child labour, sex work and delinquency. This study looks at the status, needs and skills of orphans, especially those orphaned by AIDS. The study documented available family and community resources with the intention of facilitating future development of community-based interventions for children affected by HIV/AIDS in Kenya.

Badcock-Walters, P., Desmond, C., Dorrington, R., Ewing, D., Giese, S., Gow, J., Johnson, L., McKerrow, N., Motala, S., Smart, R., & Streak, J. (2001). *The long term socio-economic impact of HIV/AIDS on children and the policy response* (DRAFT IN PROGRESS) Durban, South Africa: Health Economics and HIV/AIDS Research Division (HEARD) University of Natal, Durban, South Africa.

UNICEF has embarked on a Global Impact and Policy Study aimed at analysing the medium- and long-term impact of HIV/AIDS on children and the policy and programmes responses in the fields of prevention, treatment and mitigation of HIV/AIDS in order to sustain child well-

being over the long term in countries affected by HIV/AIDS. South Africa is one of eight countries for which a case study is being undertaken in respect of the global study and HEARD at the University of Natal, Durban, has been commissioned to facilitate the South African component of this study. The study aims, in line with the global study terms of reference, to develop a country-specific analytical framework of the interaction between AIDS, welfare and policy, in doing so to provide a detailed evaluation of the expected long-term impact on child welfare in SA. The study aims to identify best practice responses to the impact of HIV/AIDS on children's welfare. Moreover the study aims to identify gaps in existing responses and possible measures and policies to respond to them.

- Badcock-Walters, P., Desmond, C., Dorrington, R., Ewing, D., Giese, S., Gow, J., Johnson, L., McKerrow, N., Motala, S., Smart, R., & Sreak, J. (2001). *The long term socio-economic impact of HIV/AIDS on children and the policy response*. (VERSION 2) Durban, South Africa: Health Economics and HEARD, University of Natal, Durban, South Africa.

This paper aims to highlight the plight of South Africa's children in the face of HIV in an effort to identify ways and means to alleviate the many impacts. It examines the nature of the epidemic and its likely course, assessing the impact on mortality for adults and children. The paper goes on to discuss the impact on mortality for adults and children. The paper goes on to discuss the impact of increased illness and death from HIV/AIDS on the health, welfare and education of children and on children already living in poverty. These areas are examined in terms of household-level economic strain and the damage to the systems designed to provide services to children. Attention is given to interventions which currently exist in terms of mitigation and prevention. Family, community and state responses are outlined and critiqued. This information is used to identify key concerns and areas of action.

- Bandawe, C. R. & Louw, J. (1997). The experience of family foster care in Malawi: A preliminary investigation. *Child Welfare*, LXXXVI, 535–547.

This preliminary investigation into family foster care in Malawi set out to provide information on the Malawi government family foster care structure primarily through the qualitative experience of foster caregivers. A semi-structured interview schedule was used to interview 24 foster parents, who were selected from a government family foster care register, in two regions of Malawi. The study revealed that cultural factors influenced various aspects of family foster care, ranging from the caregivers' decision to foster children to the caregivers' determination not to disclose to the children that there were fostered. Social and economic factors also played a role, particularly with regard to shortcomings in service delivery.

- Barnard, A. (2002). *Sibambisene. An integrated response to HIV*. South African National Conference on Children Affected by HIV/AIDS, 2–5 June, 2002.

- Bedri, A., Kebede, S., & Negassa, H. (1995). Sociodemographic profile of children affected by AIDS in Addis Ababa. *Ethiopian Medical Journal*, 33, 227–234.

A survey was conducted in Addis Ababa between October 2 and December 10, 1993, to assess the extent of orphanhood due to AIDS mortality. Only 1 047 AIDS cases could be traced among residents. During the survey 59 per cent of cases and 16 per cent of their spouses were already dead. There were 2 186 children born to the index cases, of whom 883 were below 15 years of age. 280 of these 883 children had lost either one or both parents. 3.9 per cent of the 10.5 per cent were in poor health, were abandoned or displaced, and had a lack of medical care at the time of their illness. Reliance upon the extended family is an important coping mechanism in this setting. The authors point to the need to raise the level of community awareness and strengthen the system to enhance efforts to protect and support children affected by AIDS.

- Beers, C. (1988). AIDS: The grandmother's burden. In A. F. Fleming (Ed.), *The global impact of AIDS*. New York: Liss.

- Bekunda, R., Foex, J. M., Kibalya, W., & Alimuwa, A. (2002). *Sustainable community based approaches to address the needs of AIDS orphans and their guardians in Uganda*. Presented at the XIV International AIDS Conference held in Barcelona, 7–14 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

Luweero district population is faced with the vulnerability of AIDS orphans. This vulnerability partially arises from poverty, lack of knowledge, skills and start-up capital for income generating activities (IGAs). As a result of the above, there are high levels of school drop outs, early marriages and increased incidence of STDs and HIV/AIDS. AFXB AIDS orphans programme was started in 1991 to address the needs of AIDS orphans and their guardians. The goal of the programme is to empower the people of the Luweero district to develop community-based solutions and acquire the capability to adequately meet the basic needs of the AIDS orphans under their care on their own. *Lessons learned:* The programme has enabled up to 4 630 orphans to enrol in primary and secondary schools respectively. The income generating component has enabled 1 240 out of 1 556 guardians to earn sufficient incomes to enable them to meet other household needs of the orphans. Due to the success of this programme, AFXB replicated it in two other sub counties and one region in Rwanda, while Alliance for the Youth Achievement replicated it in another district. Orphans, unable to continue their studies, were offered an apprenticeship program. Twenty of them learned carpentry and have already established their own workshops.

Community-based initiatives in addressing the needs of orphans are much more sustainable and affordable. This approach helps orphans grow up within the community and enables them to learn how to survive on their own in the long term. The provision of in-kind materials, rather than cash, is a good strategy for minimising loss of funds before the beneficiaries gain anything. It is possible to motivate volunteers in the community to continue performing their roles. AFXB is planning to strengthen the AIDS care component by introducing antiretroviral therapy in order to have the impact of the IGAs sustainable on a long term basis.

Bhargava, A. & Bigombe, B. (2003). Public policies and the orphans of AIDS in Africa. *British Medical Journal*, 326, 1387–1389.

The AIDS epidemic is wreaking havoc in sub-Saharan Africa. The HIV seroprevalence among young adults is nearly 40 per cent in some countries, and millions of children have lost their parents. Although the extended family can alleviate these children's plight, it is unrealistic to assume that the children can escape from poverty without massive support from agencies such as the World Bank and the United States Agency for International Development. The article reports on a visit to Ethiopia, Malawi and Tanzania in March 2002 which undertook an assessment of ongoing programmes and made suggestions for strategies for improving child welfare. It also outlines findings of a visit to over 20 NGOs and national ministries responsible for caring for AIDS orphans.

Bhargava, A. & Bigombe, B. (2002). *Formulating policies for orphans of AIDS and vulnerable children in African Countries: Report from a mission to Ethiopia, Malawi and Tanzania*. Washington: World Bank.

Bhatt, P., Saba, J., Reeler, A., Richardson, J., & Moser, R. (2003). *Developing a framework to support and analyze the potential to increase the coverage and quality of orphans and vulnerable children programs through government, NGO, and university facilitated mechanisms in Tanzania, Burkina Faso, India, and Romania*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

To meet the needs of the growing numbers of orphans and vulnerable children (OVC), different implementation mechanisms reaching OVC require analysis and adaptation for large-scale use. Limited documentation exists on the comparative advantage, potential reach, and effectiveness of OVC interventions delivered by different mechanisms.

The Step Forward Program of the Abbott Laboratories Fund, uses a framework to support and analyse OVC models with the potential for large-scale adaptation. Models in Romania, India, Burkina Faso, and Tanzania are categorised based on: 1. delivery mechanism – government, NGO, or university; 2. implementation approach – local capacity building or direct service delivery; and 3. interventions – VCT, healthcare, education, and basic needs. Using quantitative and qualitative indicators, a monitoring and evaluation framework will capture the

reach, effectiveness and sustainability of each model to explore the potential for large-scale adaptation. *Lessons learned:* Developing a framework to capture the potential for increased coverage requires an assessment of past experiences and future potential of a broad range of mechanisms. Given the diversity of interventions in OVC support, defining common output parameters across models is essential to assess the large-scale replication potential of each approach. Best practice indicators for various sectors should be used to determine program effectiveness of multisectoral OVC programs.

Future OVC policies and strategies to increase coverage and quality should consider frameworks analysing diverse mechanisms to support OVC. To increase the coverage of OVC programs, delivery mechanisms need to be supported with an understanding of their comparative advantages. A synthesis of approaches in similar geographic areas should be considered in developing future programme support.

- Bicego, G., Rutstein, S., & Johnson, K. (2002). *Dimensions of the emerging orphan crisis in Sub-Saharan Africa*. Calverston, MD: Macro International.

This study uses recent Demographic and Health Survey (DHS) data to examine levels, trends, and differentials in orphan prevalence in sub-Saharan Africa. The first part of the analysis presents direct estimates of orphan prevalence in 17 countries during the period 1995–2000. We find a strong correlation between orphanhood prevalence and national adult HIV prevalence estimates, lending support to the interpretation of the orphan crisis as, in large part, AIDS-related. The second part of the analysis consists of an in-depth study of trends and age-patterns in orphan prevalence and welfare in the 1990s for five countries that have had widely divergent HIV prevalence levels (Zimbabwe, Kenya, Tanzania, Ghana, and Niger). The vulnerability of orphans with respect to their situation in households and educational opportunities is evaluated in relation to non-orphans' experience. The results of the analysis indicate that losing one or both parents is significantly associated with diminished chances of being at the appropriate grade level for age. Our results are interpreted in the context of societal responses to the crisis, and potential recommendations for intervention.

- Black, M. (2003). *Growing up alone: the hidden cost of poverty*. New York: UNICEF.

- Bledsoe, C. H., Ewbank, D. C., & Isiugo-Abanihe, U. C. (1988). The effect of child fostering on feeding practices and access to health services in rural Sierra Leone. *Social Science and Medicine*, 27, 627–636.

In Sierra Leone, where infant and child mortality rates are quite high, a large proportion of small children (1–5 years) are fostered, living away from their mothers. This paper examines the relationships between fosterage and child feeding practices and children's access to western medical care. Ethnographic data from field studies in Sierra Leone are combined with quantitative data from Serabu Hospital, which show that fostered children are under-represented in hospital admissions and that young fosters present more problems of nutrition. (Fostered girls appear to be at more risk in both these categories than boys.) Unlike young fosters, however, older ones do not appear to be at more risk than children with mothers. We draw connections between these results and patterns of intra-household discrimination in food allocation and access to medical treatment for young fostered children: especially those sent to elderly rural caretakers. Finally, we examine the implications of the findings for applied issues, arguing that fostered children may slip through the cracks of maternal-child healthcare programmes.

- Blunch, N.-H., Dar, A., Guarcello, L., Lyon, S., Ritualo, A., & Rosati, F. (2002). *Child work in Zambia: A comparative study of survey instruments*. (Social Protection Discussion Paper No. 0228). Washington, DC: World Bank.

We analyse child work in Zambia applying two recent surveys, the LCMS 1998 (World Bank) and the SIMPOC 1999 (ILO). The analysis aims at contrasting and comparing findings on the incidence and characteristics of the two surveys. The extent to which the findings are survey-dependent is assessed and implications for the design and implementation for future surveys for the analysis of child work is discussed.

Bor, R. & Elford, J. (1994). *The family and HIV*. New York: Cassell.

Bowsky, S., Nnamdi-Okagbue, R., Tembo, S., Sangiwa, G., & VanPraag, E. (2003). *Psychosocial support for orphans and other vulnerable children within the continuum of care: What's possible?* Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

Children and adolescents affected by HIV/AIDS face unique emotional challenges brought on by poverty and/or the illness and death of parent(s) or guardian. A significant factor in how a child deals with death is the type of care the child receives before and after the death. Without sufficient psychosocial support, children can experience severe developmental, behavioural, social, and emotional problems. Processes and activities exist to allow children who have experienced death or extreme loss to live healthy emotional lives. One of the current challenges lies in providing adequate care including psychosocial support to OVC.

OVC and comprehensive home care programmes in Nigeria and Zambia have identified medical, psychological and social needs of OVC. This presentation will elucidate elements of comprehensive HIV/AIDS care and support for families and communities affected by HIV/AIDS to address the needs. Specific emphasis will be given to the technical and programmatic considerations for the provision of psychosocial support based on recent survey data and pragmatic field experience primarily in Africa. A synthesis of psychological vulnerabilities and corresponding interventions will be explored.

The provision of psychosocial family support should begin at the diagnosis of HIV of the parent(s). Psychological vulnerability of OVC can be detected early on and programmes adapted over time to include practical and low-cost psychosocial interventions as part of the continuum of care. Approaches that are community-driven and child-centred with essential monitoring and technical support offer the most promise for sustainability.

Accumulated experience and recent survey data on psychosocial support for orphans and other vulnerable children suggest culturally appropriate, family-centred and comprehensive care programming and collaboration are needed to strengthen the psychosocial well-being of OVC.

Bradshaw, D., Johnson, L., Schneider, H., Bourne, D., & Dorrington, R. (2002). The time to act is now. *AIDS Bulletin*, 11, 20–24.

Brink, P. (1998). *Adoption practice in the AIDS era: A South African perspective*. Conference on 'Raising the orphan generation' organised by Children In Distress (CINDI), Pietermaritzburg, 9–12 June, 1998.

Adoption as a model of care for children who cannot be cared for by their families of origin has unique advantages. However, the current SA adoption system is regarded as inadequate for children expected to require parental care as a consequence of the AIDS epidemic. This paper is an attempt to discuss some of the complex factors associated with the development of a South African model of adoption that could meet the needs of an increasing number of children available for adoptive placement.

Caldwell, J., Caldwell, P., Ankrah, E. M., Anarfi, J. K., Agyeman, D. K., Awusabo-Asare K., & Orubuloye, I. O. (1993). African families and AIDS: Context, reactions and potential interventions. *Health Transition Review*, 3 Suppl., 1–16.

There is a concentration of HIV-positive cases in sub-Saharan Africa (about 66 per cent of all cases) and, specifically, in countries south of Uganda which contain only 3 per cent of the world's population. Discussion focuses on aspects of the African family which pertain to the epidemic, the impact on individuals and families, family care, possible interventions, and future research needs. There is a paucity of social science research on the challenges posed by the AIDS crisis; much of the available literature is based on a few studies. This paper, in fact, is based on the Makerere University and Case Western Reserve research on 22 urban and 24 rural Ugandan families, 30 AIDS cases from Ghana, and 38 Ghanaian households with at least one AIDS case. The orphan research pertains to a study of 60 households. Other research came from the Barnett and Blaikie book which reports on a Rakai, Uganda, study of

14 AIDS households among 69 households and eight AIDS households among 129 households in a family area. Basic social and demographic characteristics of African society must be understood before transmission and social structures for carrying out interventions can be discussed. Women are viewed as property; a reduction in non-marital sexual relations will impact deleteriously on the economic status of women. The notion that a man cannot be satisfied by one woman is promoted by the practice of polygamy. The practice of sexual abstinence after childbirth for long periods and traditional African systems where men do not have sexual access to women put men in the position of seeking sex from other sources. Marital instability is considerable and sexual relations are not openly discussed among partners. Sex is considered healthy. The long latency period and the high incidence of sexually transmitted diseases pose other problems. The family typically absorbs the burden of an AIDS-affected member. The economic impact on families is in terms of loss of income and increased expenditures of care. Advocating monogamous relationships has decided advantages, but anti-sex campaigns are destructive. Condom campaigns and community education are also needed. Women need to be empowered and given greater economic opportunity.

Calver, V. (2000). *AIDS orphans in Africa: Lessons learned and possible strategies for the local church and world relief*. Nairobi, Kenya.

Carey, F. (1995). AIDS and orphans. *Africans on Africa*, 3, 18–22.

Case, A., Paxson, C., & Ableidinger, J. (2002). *Orphans in Africa*. Center for Health and Well-being, Research program in Development Studies, Princeton University.

In the midst of the AIDS epidemic, nations struggling to find a cure for the disease must also find a way to mitigate its widespread effects. In sub-Saharan Africa, where AIDS is most prevalent, this means providing care for a growing population of orphans left in the wake of many AIDS deaths. Because orphans tend to live in poorer households and have less schooling than their non-orphan counterparts, the growth of the orphan population could have a lasting, detrimental impact on the demographic outlook of many African countries. Governments wishing to ameliorate this situation may implement policies targeted toward orphans. But which policy tools would prove most effective? Will transfers of income to households caring for orphans be enough to solve this problem? In 'Orphans in Africa' the authors recognise the magnitude of the orphan problem, analyse the conditions under which orphans currently live and explore policy options, including why income transfers may not be the most effective solution. The orphan population is large and growing. Data from 19 Demographic and Health Surveys (DHS) collected between 1992 and 2000 show that, in many African countries, nearly 15 per cent of children under the age of 15 have lost one or both parents. In all of the countries analysed, the orphan rate is nine per cent or more and, within these countries, the orphan rate seems to be correlated with the presence of AIDS. For example, in the western African countries of Ghana and Niger, where the AIDS rate is lower, the orphan rate is likewise lower. A common characteristic across all countries studied is that orphan rates increase with age, so that school age children are at higher risk of orphanage than younger children. In Mozambique (1997), Uganda (2000), Zambia (1996), and Zimbabwe (1999), a quarter or more of 14-year-olds had lost one or both parents. In many countries, children are more likely to be paternal orphans. In Kenya, Namibia, Tanzania, Uganda, Zambia and Zimbabwe, for example, the fraction of children who have lost a father is markedly larger than the fraction who have lost a mother. Case, Paxson, and Ableidinger use data from the DHS surveys to address how parental deaths affect the living arrangements and the schooling opportunities of children in sub-Saharan Africa. The ten countries studied account for 27 per cent of the children living in sub-Saharan Africa and 50 per cent of all AIDS orphans. Orphans are considered as a group as well as in three mutually exclusive categories: paternal orphans, children who have lost a father but not a mother; maternal orphans, who have lost a mother but not a father; and double orphans, who have lost both parents. The authors find that, on average, orphans live in poorer households than non-orphans. When this tendency is examined for each mutually exclusive type of orphan, the authors find that paternal orphans are significantly more likely to live in poor households

relative to non-orphans, while double orphans are not. Orphans are less likely to be enrolled in school than non-orphans. However, contrary to recent reports from the World Bank and UNAIDS, the lower school enrolment rate of orphans cannot be accounted for solely by their poverty. In fact, it is not the poorest group – paternal orphans – who are the least likely to attend to school. Rather, it is double orphans, who are no poorer on average than non-orphans, who are the least likely to go to school. These authors find that even between children living in the same household, and thus living with the same level of household resources, orphans are less likely to go to school than are the non-orphaned children in their households. Double orphans, for example, are on average 15.7 percentage points less likely to go to school than are the non-orphaned children with whom they live. This tendency does not diminish even in relatively wealthy households.

These authors also examine whether girls who are orphaned face a greater risk of not attending school than do boys who have lost a parent. Recent World Bank and UNAIDS publications suggest that girl orphans are more likely to be pulled out of school to care for a dying family member and that when household resources contract with illness and death, girls' schooling is more likely to suffer. However, Case, Paxson and Ableidinger find no significant difference in school enrolment among girl and boy orphans in 18 of the 19 country-years they analyse. If poverty does not explain the lower school enrolment of orphans, what does? The authors find that the lower school enrolment of orphans is largely accounted for by the nature of the relationship between the orphan and the decision-making adult in the household. Children who live in households headed by their parents or grandparents are more likely to attend school than are children who live in households headed by other, more distant, relatives. Moreover, children who live with non-relatives are even less likely to go to school than are those living with distant relatives. Orphans are at risk not because they are poor, but because they are more likely to live with adults with whom they are not closely related. This evidence supports the idea that household decision-makers allocate resources towards children with whom they have closer relationships, and discriminate against children whose ties are more distant.

Given that the DHS data point to a difference in household resource allocation, in the form of lower investments in schooling for orphans, and that this difference does not depend solely on household income, government transfers of income to households caring for orphans would not necessarily increase school enrolment of orphans. Case, Paxson and Ableidinger propose that governments may employ a more effective policy tool of providing non-transferable goods such as school vouchers or medical care for orphans if they want to improve orphans' living conditions.

Case, A., Paxson, C., & Ableidinger, J. (2003). *The education of African orphans*. Center for Health and Well-being, Research program in Development Studies, Princeton University.

We examine the impact of orphanage on the school enrolment of children in sub-Saharan Africa, using data from 19 Demographic and Health Surveys conducted in ten countries between 1992 and 2000. We find that orphans in Africa are significantly less likely than non-orphans to be enrolled in school. However, although are on average poorer than non-orphans, orphans' lower school enrolment is not explained by their poverty: orphans are equally less likely to be enrolled in school relative both to non-orphans as a group and to the non-orphans with whom they live. Consistent with the predictions of Hamilton's Rule, the theory that the closeness of biological ties governs investments in children, we find that outcomes for orphans depend largely on the degree of relatedness of the orphan to the household head. Children living in households headed by non-parental relatives fare systematically worse than those living with parental heads, and those living in households headed by non-relatives fare worse still. Much of the gap between the schooling of orphans and non-orphans is explained by the greater tendency of orphans to live with more distant relatives or unrelated caregivers.

Cassiem, S. (2002). *Key findings of the study 'Budgeting for socio-economic rights'. A focus on child social security and the need for child poverty alleviation*. Presented at a Workshop on Children, HIV and Poverty in Southern Africa, organised by SARP, HSRC, and Save the Children, 9–10 April, 2002.

This paper presents the key findings of the study 'Budgeting for child socio-economic rights – Government obligations and the child's right to social security and education in SA'. The study:

- Uncovers the obligations on government to budget for delivery of child socio-economic rights;
- Pilots a methodology that evaluates government's performance in budgeting for child socio-economic rights in SA. It examines whether government has been budgeting – as it is obliged to – for the delivery of the child's right to social security and basic education in SA;
- Provides new, and the most contemporary results on the level, depth and provincial distribution of child poverty in SA. This data informed the study's investigation into the need for allocations and spending for programmes that target children.

Child Support Unit, Ministry of Health, Jamaica. (1997). *National policy on children: We must care for them and guide them*. Kingston, Jamaica: UNICEF.

Cohen, D. (1999). *The HIV epidemic and the educator sector in sub-Saharan Africa*. (Issues paper No 32). United Nations AIDS and Development Program.

A functioning and effective educational system is seen as central for achieving the goals of sustainable human development. In part because an educated population which embodies the skills and capacities needed for development is essential if production levels are to be increased, and in part because one, possibly the most important, of the benefits of development is an educated society. To achieve these outcomes countries have everywhere invested in education – in teachers, administrators and other service personnel, and in children. Even in the poorest region of the world – sub-Saharan Africa – there has been extensive investment in human capital over many decades. This can be measured in various ways; some 20 per cent of total public expenditure is spent on education. This is equivalent to almost 6 per cent of GNP for the region as a whole – year in and year out. This represents an enormous cumulative investment over many years in institutions and in human resources.

These investments by countries, by the often very poor citizens of many countries in Africa, are now increasingly threatened by the HIV epidemic. Not only is much of the previous investment in education – in literacy, vocational and professional skills and qualifications – at risk, but so also is current and future investment in young men and women. Human resources are being lost at an alarming rate in many African countries, representing losses of investments which poor countries can ill afford to bear.

It follows that in a world where resources (financial and human) are scarce, and where the HIV epidemic is systematically eroding the capacity for development, that urgent actions are needed to ensure that socio-economic sectors do not collapse. Not the least of the sectors which is threatened is education where factors are operating which are systematically destroying what can be achieved. But a functioning education sector is both fundamental to achieving sustained development and eradicating poverty and to an effective response to the HIV epidemic.

The foregoing discussion has identified some of the more important and urgent actions that are needed and there is no need to summarise what these are. On the other hand it is worth emphasising what is required for effective policy and programme response. It is to think in terms of systems, and to analyse and respond in ways that are themselves systemic. To understand that the educational sector is an integrated process for ensuring that citizens possess appropriate capacities – embodying the human qualities required for sustainable development. But unless sectoral capacity as a whole is protected it is hard to see how the objectives of development can be met.

Colling, J. (1998). *Children living in a world with AIDS: Guidelines for children's participation in HIV/AIDS programmes*. Geneva: The Children and AIDS International Non-Governmental Network (CAINNN).

These guidelines show how children and young people can be involved in education, prevention and care programmes related to HIV/AIDS. These guidelines provide a framework

for local projects to develop ways of working with children and young people that respect their rights and enable their voices to be heard.

Collins-Jones, T. L. (1997). AIDS orphans: The psychological adjustment of children with multiple family members with a terminal illness. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 58, 2659.

Connelly, M. (2003). HIV/AIDS, orphans and other vulnerable children: The crisis, consequences, and responses. Powerpoint Presentation. ICROSS.

Presents a global picture of the impact of AIDS on children worldwide. Indicates prevalence rates by continent, and by means of graphs, of epidemic curves, compares HIV prevalence with the accumulative impact of AIDS, and the increase in number of orphans. Presents data on double orphans, orphan school attendance, and orphans in prostitution and living on the streets. Highlights that the problem is increasing, and that the increase is steep and of long duration. The responses to the crisis are inadequate, development gains are being reversed, and there is a myth of coping and sustainability.

Cook, M. R. (2002). *Beyond borders. Migration and the affects of HIV/AIDS on Southeast Asian children and youth*. Canada: National Library of Canada, Cataloguing in Publication Data.

The community guidelines presents the rights-based approach to children affected by HIV/AIDS and migration; tools for promoting children's participation and ideas for exploring the role of culture in supporting vulnerable children. The last part of the guideline discusses ways of putting the guidelines into action. The guideline objectives are to 1. Assist agencies in developing holistic responses to the affect of HIV/AIDS on children and youth; 2. Empower community field workers, local government representatives, and young people to support children and youth; 3. Provide field workers with the tools and strategies to engage children; 4. Outline methods to build on cultural values supporting children; and 5. Create a 'continuum of care and support' that develops a stronger civic response in supporting vulnerable children and youth.

Cook, M. R. (2002). *Filling the gaps: Using a rights-based approach to address HIV/AIDS and its affects on South African children, youth, and families*. Canada: National Library of Canada Cataloguing in Publication Data (co-published by: Interagency Coalition on AIDS & Development).

These community guidelines were developed in response to needs of South African practitioners to better understand a rights-based approach to programming in the area of HIV/AIDS. The community guidelines are designed to: 1. Create a continuum of care and support; 2. Assist agencies in developing holistic responses to the affects of HIV/AIDS on children and family; 3. Empower community field workers, local government representatives and young people; 4. Provide field workers with the tools and strategies to engage youth; and 5. Outline methods and approaches to build on cultural values supporting children.

Cook, P. H., Ali, S., & Munthali, A. (2002). *Starting from strengths. Community care for orphaned children in Malawi*. Final report submitted to the International Development Research Centre (IDRC).

The 'Starting from strengths: Community care for orphaned children' research project was initiated in 1995 as a partnership project linking universities, NGOs, government ministries and UN Agencies in Canada and Malawi. The initiative was undertaken in response to Malawi's rapidly rising population of children who have lost one or both parents to the HIV/AIDS pandemic sweeping sub-Saharan Africa. The research used a participatory action approach drawing on a methodology grounded in the UN Convention on the Rights of the Child. Twelve communities across Malawi were selected based on cultural and economic variation. Focus group and key informant information was then collected in these communities in partnership with local leaders, women, orphan guardians, and children. The research was carried out from 1996–1998 by local community facilitators who helped participants assess local issues, then analyse some of the key themes emerging from this assessment, before engaging the community in discussion aimed at developing action that could support children orphaned by HIV/AIDS. Research findings addressed issues of the

long-term effects of HIV/AIDS on communities and children, community capacity, local perceptions of AIDS, and children's survival and psychosocial needs, and local perceptions of children's rights. Findings revealed the predominance of local cultural definitions of, and responses to, HIV/AIDS. The extended family and other traditional support structures continue to support most of the children orphaned by AIDS, however, the research also underscored the strains of this system and the increasing number of vulnerable children whose rights are not recognised. The research suggests more attention be focused on developing locally designed responses to protecting the rights of vulnerable children. These responses must be placed in the context of some of the broader issues of poverty and vulnerability resulting from HIV/AIDS. In doing this, policy and programmes should place a first call for vulnerable children and their guardians, and build on locally identified strengths. The research concludes by making a number of recommendations promoting greater local, national, regional, and international collaboration in supporting children affected by HIV/AIDS. These recommendations suggest specific strategies falling under the strategies of: building on traditional cultural strengths; addressing poverty alleviation; promoting a continuum of care; integrating services; counteracting property grabbing; supporting children's psychosocial needs; advocating for a rights-based approach.

- Coombe, C. (2000). Keeping the education system health: Managing the impact of HIV/AIDS on education in South Africa. *Current Issues in Comparative Education, e-journal of Teachers' College Columbia*.

HIV/AIDS not only attacks individuals. It also attacks systems. Until recently, HIV/AIDS has been perceived primarily as a health problem, which can be contained by effective health education programs. But the deadly virus has not been contained and continues to spread so widely that it is now having a profound adverse impact on communities and institutions. Government's health-focused HIV/AIDS plans have failed to consider what must be done when the disease is out of control and state systems are themselves threatened. This article suggests that while working to limit the spread of the disease, it is necessary to recognise and manage the pandemic's impact on the education system.

- Coombe, C. (2001). *HIV/AIDS and trauma among learners: Sexual violence and deprivation in South Africa*. University of Pretoria, Faculty of Education.

- Coombe, C. & Kelly, M. J. (2001). *Education as a vehicle for combating HIV/AIDS*. Presented at Conference on HIV/AIDS and the education sector: The Education Coalition Against HIV/AIDS held at Midrand, Gallagher Estates, 30 May–1 June 2002.

Education systems, already fragile, are being severely threatened by the HIV/AIDS pandemic. If business is allowed to continue as usual, these systems will become increasingly incapable of delivering their mandated services. But with HIV/AIDS it can no longer be business as usual. The need now is for bold and decisive actions that go beyond anything that the world has hitherto experienced, even in crisis situations.

Some governments and ministries of education are committed to action, although slow in giving practical effect to their intentions has been slow. In addition, the international community is giving voice to its commitment through such instruments as the International Partnership Against AIDS in Africa. But it is people at local level, private individuals working through community organisations, who are making the most evident practical contribution to alleviating the suffering HIV brings in its wake.

However, a greater sense of urgency is needed, more commitment and more action. It is clear that education systems are under threat. What must be done to stabilise and restructure them so that they can respond proactively to the AIDS pandemic, protect themselves, and offer protection to all who use their services, is also clear. The steady deterioration and ultimate destruction of education and school systems can be reversed through determined and well-planned activities directed at stabilising education provision and quality, reducing the impact of the disease on learners and educators, and responding creatively to the new learning needs cast up by the pandemic.

If these steps are taken, the returns will be enormous, since education and schooling provide almost the only known antidote to HIV infection. Making this antidote universally available

implies making education universally available. It implies education for all, with the provision of educational opportunities so that every person – child, youth and adult – can meet their basic learning needs. Commitments to this were made at Jomtien. They were renewed repeatedly throughout the 1990s. They have been reaffirmed at Dakar. They are given renewed urgency by the need to get ahead of the HIV/AIDS pandemic. There is no longer any time for delay. The survival of millions depends on what is done *now* to deliver on these commitments. In the words of Nelson Mandela at the close of the XIIIth International HIV/AIDS Conference in Durban, the time for action is now and right now.

Dane, B. O. (1993). Mourning in secret: How youngsters experience a family death from AIDS. In C. Levine (Ed.), *Orphans of the HIV epidemic*. New York: United Hospital Fund.

Dane, B. O. & Levine, C. (1994). *AIDS and the new orphans: Coping with death*. Westport, CT: Auburn House.

The cataclysmic but still largely hidden impacts of AIDS on America's children is examined carefully and constructively in the chapters of this book. The authors have collaborated skilfully to create a knowledge base drawn from what we know about the development of children, about bereavement, and about HIV/AIDS. The integration of this knowledge allows the reader to develop a fresh, albeit sobering, perspective on the scale and nature of problems faced by orphaned children.

The Center for Disease Control and Prevention is quoted in the first chapter as stating that 'the recognition of a disease and its emergence as a leading cause of death within the same decade is without precedent'. The slowness of our response to the effects of this disease has contributed to its impact on children, 80 per cent of them from minority families. While coping with parental loss has always strained the capacity of family members and community institutions, children orphaned by AIDS present new and greater challenges.

Daniel, M. (2003). Children without parents in Botswana: The safety net and beyond. Unpublished report.

In Botswana the AIDS epidemic creates enormous stresses. These stresses are both psychological and increasingly, as the epidemic takes its toll, manifest in socio-economic disorder. Though virtually every family in the country has now been affected in some way by AIDS, the response at individual, family and community levels, is denial. Denial at the individual, household and community levels defines the onset of a culturally distinctive and progressive process of involution. Because of stigma many families feel forced to remain silent about the true nature of their loved one's illness. As men and women seek options for responding to the stresses, people turn a blind eye to expedient behaviour and use witchcraft to explain anti-social responses. These responses further wound children who make up the dependent generation. Expediency in the context of a culture of silence will enable the hidden wounds to proliferate to the extent that, over time, 'community' is destroyed or dramatically altered. Although the government's intervention programme attempts to address the physiological stress caused by the AIDS epidemic, it has not yet begun to address psychological and sociocultural stress on the scale needed to prevent cultural collapse.

dart@sai.co.za. *AIDS Orphans time bomb*. Available online: <http://news.hst.org.za/view.php3?id>

DCOF (1999). *Community mobilization for orphans in Zambia: An assessment of the orphans and vulnerable children program of Project Concern International*. New York: USAID.

An estimated 78 per cent of Zambia's current orphans are the result of the HIV/AIDS epidemic. As the number of the disaffected, undereducated, inadequately nurtured and socialised young people grows because of the HIV/AIDS epidemic, Zambia and other countries in the Southern Africa region may face serious threats to their social and political stability and economies. Finding effective ways to mitigate the impacts of HIV/AIDS on children and families must become a top national priority. Fundamental strategies involve strengthening the capacities of the two primary social safety nets on which people in the region depend: the extended family and the community. Although these two may not in themselves be sufficient, they can reduce the number of vulnerable children that government and NGO social services assist to a manageable level. Strategies to combat the problem of

AIDS orphans should also involve government ministries, bilateral development bodies, international organisations, religious networks, the private sector, NGOs and community-based groups. To be effective, USAID must actively seek ways to collaborate with other organisations and to help mobilise prospective participants that are not yet engaged.

- De Beer, J. (1998). *An overview of welfare policy: Raising the orphan generation*. Presented at the conference on 'Raising the orphan generation' organised by Children in Distress (CINDI), Pietermaritzburg, 9–12 June, 1998.

I will give an overview of the approach to developmental social welfare in order to serve and build a self-reliant nation in partnership with all stakeholders through an integrated social welfare system which maximises its existing potential and is also equitable, sustainable, accessible, people-centred and developmental. I will also address the way forward within a social welfare framework, to address the AIDS epidemic, especially focusing on care and support services regarding children. I will also give examples of current projects which will enable welfare to be well equipped in raising the orphan generation.

- Deininger, K., Garcia, M., & Subbarao, K. (2002). *AIDS-induced orphans as systemic shock: Magnitude, impact and program interventions in Africa*. Washington, DC: World Bank.
- Deininger, K., Crommelynck, A., & Kempaka, G. (2002). *Long-term welfare and investment impact of AIDS-Related changes in family composition: Evidence from Uganda* (Social Protection Discussion Paper No. 0207). Washington, DC: World Bank.

Although availability of quantitative information on the extent of AIDS in Africa is improving, the socio-economic implications of the epidemic remain poorly understood. This paper explores this issue for Uganda focusing on households who received foster children between 1992 and 2000, a phenomenon that affected more than 15 per cent of households. We find that addition of a foster child resulted in significant reductions of per capita consumption, income, and household investment which were more pronounced for the poor. Initial disadvantages in foster children's access to education for this group were overcome in the course of UPE implementation while new inequalities have emerged in access to health services. Foster children's ability to access services will thus be affected by the broader policy environment as well as programmes more specifically targeted at this group.

- De Jong, J. (2001). *A question of scale*. Washington DC: Horizons.

As the HIV/AIDS epidemic continues its rapid spread, bringing individual tragedies and social upheaval, the inadequacy of existing programmes is increasingly a subject of debate. This publication has asked the question whether organisations active in the HIV/AIDS arena, and perhaps most particularly NGOs, have done enough in thinking about scaling up their activities. It explains, however, that scaling up in the context of HIV/AIDS is a challenging and complicated process.

The extent to which NGOs can be proactive in scaling up, with sufficient time for reflection and planning in order to maximise impact and safeguard their organisational mission is critical. Not all NGOs should scale up and nor should NGOs scale up all of their activities simultaneously, and thus choices as to which aspects of NGOs' work to scale up with maximum impact have to be considered carefully. To the extent that it is possible, organisations need to prepare their own structures and staff for the scaling up process. If they are merely responding to donor demands or the evolution of the epidemic, they will command little control over the scaling up process and ultimately perhaps have less effect. At the same time, however, NGOs may need to sacrifice some elements of the quality of the programmes they run for the sake of broader coverage. This in turn points to the need for more information on the quality and impact of NGO programmes. While definitions of scaling up vary according to the perspective of the individual and organisation, consensus exists over the need to define objectives in terms of impact on either preventing the epidemic or mitigating its effects. A narrow understanding of impact, however, based only on reducing the number of new infections, without looking at the synergies between prevention, care and support and the broader social change needed to address HIV/AIDS, is misleading. NGOs – based on the many successful but often undocumented experiences of scaling up – need to

express their own notions of the impact of their efforts, and to communicate these to a broader audience.

In both effectiveness and efficiency terms, integrating HIV/AIDS efforts into development processes and institutions more broadly is desirable to address the structural and social determinants of the epidemic and take advantage of existing infrastructure. Yet such efforts should not lose sight of the experience accumulated by specialised AIDS-service organisations (O'Malley et al. 1996).

Scaling up the programmes of NGOs in HIV/AIDS entails much more, however, than finding avenues for reaching wider coverage. If scaling up is seen as a process, as described here, the dynamic relationships between impact, coverage and quality of programmes mean that at different stages of the process, different objectives become paramount. Moreover, scaling up that is sustainable in social, as well as financial and programmatic terms necessitates understanding, strengthening and catalysing the existing response of individuals and communities to the complexities of the epidemic.

Finally, truly scaling up will require that NGOs do not work in isolation but forge much stronger and workable alliances with other NGOs, research institutions and with government. To do so will inevitably require compromises and conflicts of institutional culture, but will be well worth the effort in the broader aim of stemming the epidemic and mitigating its devastating effects.

Delany, A. (2001). *A critical reflection*. Pietermaritzburg: The Children in Distress (CINDI) network.

The purpose of this study is to document the experience of the CINDI network and to share the valuable networking lessons that can be learnt from this local network with others. The CINDI network is used as a case study to identify and explore the factors that influence networking dynamics. It is not intended as a step-by-step guide but should be adapted to suit each individual context.

De Marco, R., & Sussman, L. (2003). *Overview of USAID Strategies and Supported Actions to Assist Children and Adolescents made vulnerable by HIV/AIDS*. USAID.

HIV/AIDS is causing unprecedented threats to the well-being and safety of millions of children and adolescents, including orphaning, by intensifying poverty, increasing stigma and psychosocial distress, and increasing vulnerability to exploitive labour, abuse, and HIV infection. Families, communities, and governments responsible for protecting and caring for these children are taking action to mitigate these threats. USAID recognises that programmes supporting children and adolescents affected by AIDS (CAABA) are most effective when they build on local capacity to support the greatest number of children possible.

The foundation of USAID's response to CAABA is centred on the following strategic components:

- Strengthen and support the capacity of families and communities to care and cope;
- Mobilise and strengthen community-based responses;
- Fortify the capacity of children and adolescents to express and meet their basic needs;
- Build on the ability of government to protect the most vulnerable children and provide essential services;
- Create a supportive environment for affected children and their families.

USAID funds numerous projects, primarily in Africa, that embrace these strategic components. Types of activities supported by USAID include: community-based interventions, organisational and community capacity building, policy, research, and information exchange. Approaches and accomplishments from these projects are summarised in the recent publication, USAID Project Profiles: Children Affected by HIV/AIDS. (http://www.usaid.gov/pop_health/aids/Publications/index.html)

To stimulate further strategic actions benefiting children and adolescents affected by AIDS, highlights from USAID-supported projects in Africa and from other regions with transferable approaches will be shared. Trends in facilitating community mobilisation and implementing multi-sector activities will be discussed.

Drawing on its historical involvement with displaced children and orphans, and boosted by increased funding allocations from the US Congress for children affected by HIV/AIDS, USAID is a global leader in addressing the enormous challenges posed by the situation confronting CAABA. The Agency is currently funding over 60 activities in 22 countries. Lessons learned from these activities will guide priority setting and strategic direction of future efforts for CAABA

Department of Population and Development (2001). *The impact of HIV/AIDS on South African children*. Report for Dr Z. S. T. Skweyiya, Minister of Social Development.

Department of Social Welfare (1994). *Orphans and children in need: A situation analysis of Masvingo and Muenzezi District*. Report produced by the Department of Social Welfare, Masvingo Province, Zimbabwe.

Department of Social Development. (1999). *National guidelines for social services to children infected and affected by HIV/AIDS*. Pretoria: Department of Social Development.

A guideline document that provides the following discussions on the problem of service for children infected and affected by AIDS:

- Chapter two provides information about community-based care and support models;
- Chapter three presents guidelines on how to establish a home-/community-based care and support service;
- Chapter four discusses options for child care – foster care, adoption and residential care;
- Chapter five investigates types of financial assistance for the care of children – child support grants, foster grants, care dependency grants and social relief grants.
- Chapter six gives guidelines for the reporting of child abuse; and
- Chapter seven provides an evaluation tool for monitoring the performance of the programme.

Derbyshire, M. & Derbyshire, L. (2002). *Friends in need: A handbook for the care of orphans in the community*. Oxford: Viva Network.

'Friends in Need' is the fourth in the Viva Network series of training handbooks based on good practice in child care. This handbook profiles three projects that have established community-based care programmes for orphaned children in Zimbabwe, and draws out important issues and general recommendations of use to others. It shows how volunteers can be mobilised within local communities to take care of children who have been orphaned due to HIV/AIDS, and others in especially difficult circumstances.

Desmond, C. & Gow, J. (2001). *The cost-effectiveness of six models of care for orphans and vulnerable children in South Africa*. Health Economics and HIV/AIDS Research (HEARD), University of Natal, and UNICEF, Durban, South Africa.

By the year 2010 it is estimated that SA will have an orphan population close to 2 million, mainly as a result of the HIV/AIDS epidemic. Planning for their care has commenced by families, communities, NGOs and government. A number of different models of care currently exist in SA. These vary both in the quality of care offered and the cost of providing it. This paper is one part of a two-part study dealing with these differences. This study concentrates on the cost of providing care in each of six identified models ranging from the formal children's homes to community based structures, utilising cost effectiveness analysis. The other paper deals with the quality of care in the same six models. The study is directed toward policy makers, but also provide valuable information to NGOs and other community organisations working in the field. To allow for a meaningful comparison the cost analysis was conducted using two effectiveness measures: The cost of care per month per child and the cost of providing a minimum standard of care per month per child in each of the six models. This was necessary as the quality of care varied substantially and conclusions based on comparing only the current cost per month would be misleading and show differences in quality rather than just differences resulting from the structure of care. The cost of providing minimum care allowed for comparison between the models which provide more than the minimum of care and those which are unable to achieve even this minimum. The results show high costs associated with formal models of care, but also the difficulties of providing

care in the informal models due to lack of access to resources. The conclusion of the paper is that resources should be concentrated on the more informal community-based structures, for the most cost-effective care of orphaned vulnerable children while recognising the need for more formal organisations as a last resort.

Desmond, C. (2002). *The economic evaluation of models of care for orphaned and vulnerable children*. Arlington: Family Health International.

Desmond, C. & Gow, J. (2002). The current and future impact of the HIV/AIDS epidemic on South Africa's children. In G. A. Cornia (Ed.), *AIDS, public policy and child well-being*. New York: UNICEF.

In this chapter we had three main aims. One, to investigate the impacts of the HIV/AIDS epidemic upon the children of South Africa, with a focus on the health, welfare and education implications. Two, to examine the responses of families, communities, civil society and especially governments to the crisis confronting the children. Third, to critique those responses and offer alternatives which may assist in ameliorating the impacts on children. *The impacts*: infant and child mortality rates will double over 15 years; life expectancy will dramatically decline as more children acquire HIV; millions of orphans will be created as adults die and these children will be kept in poverty and be less likely to attend school and receive the normal socialisation of childhood. *The responses*: the national AIDS plan has a focus on prevention of HIV transmission, with existing health services expected to treat HIV-infected and affected children; information and education about HIV have been effective in raising awareness of the disease; government has pushed orphan care onto the community, however, the existence of a welfare system is helping some children and their carers cope. *Alternatives*: existing health services are not coping with the increased demand, extra resources are needed; government is denying Nevirapine and ARVs to people, this needs to be changed; community capacity in coping with orphans is near breaking point and government needs to look at reconfiguring the welfare system to reach those children and provide for their care

Desmond, C., Gow, J., Loening-Voysey, H., Wilson, T., & Stirling, B. (2002). Approaches to caring, essential elements for a quality service and cost-effectiveness in South Africa. *Evaluation and Program Planning*, 25, 447–458.

By 2010 there will be close to 2 million orphans in South Africa, mainly as a result of HIV/AIDS. The paper assesses different approaches to care and support of children orphaned by AIDS and other vulnerable children, as well as the cost-effectiveness of each approach. Using a typology of care and essential elements of care, six approaches are evaluated: informal, non-statutory foster care; community-based support; home based care; unregistered residential care; statutory adoption and fostering; and statutory residential care. A cost-effectiveness analysis assessed actual programmes and the costs of providing a minimum standard of care for the six approaches. High costs are associated with formal models of care. Informal approaches may lack the resources to meet children's rights. Resources should be largely allocated to the more cost-effective, informal, community-based structures, but formal models will still be needed for those children who cannot be placed elsewhere.

Development Gateway (2003). *Nyumbani village: Serving children and the elderly impacted by AIDS*. Available on line: <http://www.noelgroup.com/vision/nyumbanivillage.aspx>

The village project is a self-sustaining community to assist elders and AIDS orphans. It will provide a family-like setting for orphaned children and elderly people. Housing, health care, counselling, education and training for children and adults will be provided. Children will learn traditional customs in a family-like environment. The project is partnered by UNOPS and UNICEF, and has been pledged operational funding by USAID.

Diakonia Council of Churches AIDS Programme (2001). *HIV/AIDS challenges Durban churches to care for children*. Diakonia Council of Churches.

Dickson-Tetteh, K. & Ladha, S. (2000). Youth health. In *South African Health Review 2000*.

The world today is experiencing an unprecedented increase in the number of young people. In SA, there are currently about 18 million people under the age of 20 years (approximately

44 per cent of the total population). Young people are at risk of a broad range of health problems. Sexual and reproductive health behaviours are among the main causes of death, disability, and disease amongst young people; among these health problems are STDs, HIV/AIDS, unwanted pregnancies, and pregnancy-related complications. Between 1997 and 1998 alone HIV infection rates amongst young people almost doubled. One-third of all teenagers have been pregnant or had a child by the age of 19. Young people are also at risk of physical and psychological trauma resulting from sexual abuse, gender-based violence, and other forms of physical violence and accidents. Policies and programmes have been developed to address the problems and challenges facing the youth in SA. The rapid spread of the HIV epidemic especially amongst adolescents has also meant that programmes have had to focus their attentions on interventions that aim to raise awareness and influence positive behaviour change among adolescents. (media campaigns, lifeskills and peer education). These interventions need to be supported by services that are both accessible and acceptable by adolescents. NAFCI and the Y-centre models are examples of this. This chapter aims to bring together information from a wide range of sources to provide a picture about the health status of young people in SA. The major health problems and needs of young people are highlighted. Also provides a summary of national policies and programmes for young people in SA.

- Dijkstra, L. (1997). Suffer the little children – conviction or compassion? Hospice care for HIV. *AIDS Bulletin*, 6, 39–40.

Using her own funds, a woman bought a 24-hectare farm in 1995 and converted the homestead into a private hospice for orphaned children with HIV-infection and AIDS. The stigmatisation and social isolation endured by AIDS patients is particularly traumatic for children. While some may consider caring for children with AIDS in hospices to be a compassionate approach, it must also be understood that the children are socially and physically isolated from others because of their disease. During her three months with the children at the homestead in Kwa-Zulu Natal, the author, however, did not get the impression that the hospice was a place for children afflicted with a terminal disease. It instead functioned almost as an extended family within a normal household. The children were developing well within the limitations of their illness, and were happy and well adjusted, suffering little anxiety or distress. Pending registration as a children's home, the home can only house ten children. There are therefore now two children per caregiver. This high child-to-caregiver ratio together with the casual, loving care and cuddling provided by the caregivers from a similar cultural background as that of the children make the home so warm and the children so content. It also helps that primary healthcare is provided in the hospice and more complex treatment is provided by physicians to the children as outpatients at the local state hospital. This hospice is a fine example of a practical, cost-effective, and suitable concept.

- Dippenaar, S. M. (2002). *Being a child, a victim and a survivor*. Presented at a Workshop on Children, HIV and Poverty in Southern Africa, organised by SARN, HSRC, and Save the Children, 9–10 April, 2002.

Child sexual abuse is a well-recognised problem in Namibia and other countries in the region. The rise of HIV infection rates add an horrific dimension to this in that abused children now, in effect, face a potential death sentence in addition to the other traumatic experiences, consequences and sequels to the sexual abuse. Additionally, the weakening, by the HIV epidemic, of the protective structures which would normally support children, leave them even more vulnerable. This paper seeks to shed some light on the phenomenon of child sexual abuse and, in particular, to present mechanisms which will allow abuse to be identified at an early stage and to suggest ways in which abused children and children at risk of abuse, can be supported.

- Donahue, J. (1998). *Community-based economic support for households affected by HIV/AIDS*. Washington, DC: USAID.

Because the burden of HIV/AIDS is felt first by the families of those stricken, the first line of response should be to mitigate the impact on those households, in particular, by improving

their income-earning capacities. When families are no longer able to cope, however, they turn to members of their community, and projects that strengthen communities' coping mechanisms will become increasingly significant as an epidemic continues. Planners should therefore consider a two-pronged approach to mitigating the socio-economic consequences of HIV/AIDS on affected communities: building the economic resources of households, primarily through microcredit programmes; and supporting the creation of community safety nets.

Donahue, J. (2000). *HIV/AIDS and economic strengthening via microfinance*. Washington, DC: Displaced Children and Orphans' Fund and War Victims' Fund Contract.

Donahue, J. (2000). *Economic strengthening of household and community safety nets to mitigate the impacts of AIDS*. Washington, DC: USAID.

The documents the minutes and objectives of the Town Hall meeting on topics relevant to children affected by AIDS.

The objectives were to:

- Provide a forum for learning and exchanging information between micro-enterprise and HIV/AIDS practitioners;
- Provide information on how households cope economically in times of stress;
- Examine strengths and weaknesses of different micro-enterprise services in supporting economic coping strategies;
- Present programmatic responses to the HIV/AIDS pandemic and examine them in relation to economic strengthening needs of households affected by HIV/AIDS;
- Explore options for fostering strategic alliance and creating new and utilising existing modes for information exchange and dialogue.

The document highlights the conclusions reached and the resolutions reached in this regard.

Donahue, J. (2002). *Children, HIV/AIDS and poverty in Southern Africa*. Presented at a Workshop on Children, HIV and Poverty in Southern Africa, organised by SARP, HSRC, and Save the Children, 9–10 April, 2002.

The paper discusses ways in which the economic scaffolding of families and communities can be strengthened to support children affected and infected by AIDS. It goes on to propose a combined community and household strategy for economic strengthening. Families and communities are not only on the frontline of the impacts of HIV/AIDS, but also at the forefront of the response to the impact that children encounter. Communities are seen as prepared to take leadership and ownership and devise ways of sustaining the activities they initiate. Development professionals are implored to find innovative ways to show solidarity and support of communities and households.

Donahue, J. (2003). *HIV/AIDS care and support initiatives via community mobilisation*. Washington, DC: DCOF.

Donahue, J. (2003). *Discussion papers on HIV/AIDS care and support*. Health Technical Services Project.

Because the burden of HIV/AIDS is felt first by the families of those stricken, the first line of response should be to mitigate the impact on those households, in particular, by improving their income-earning capacities. When families are no longer able to cope, however, they turn to members of their community, and projects that strengthen communities' coping mechanisms will become increasingly significant as an epidemic continues. Planners should therefore consider a two-pronged approach to mitigating the socio-economic consequences of HIV/AIDS on affected communities: building the economic resources of households, primarily through micro-credit programmes; and supporting the creation of community safety nets.

USAID seeks to develop and promote effective strategies for providing basic care and support to those affected by HIV/AIDS. This series of discussion papers on HIV/AIDS care and support represents a first step in this effort. HIV/AIDS care and support mitigate the effects of the pandemic on individuals, families, communities, and nations. Such interventions are an important component of the overall response to HIV/AIDS because they increase the impact of prevention strategies and mitigate the negative consequences of the epidemic on the prospects for sustainable development.

This series of discussion papers covers several key issues related to care and support:

- Human rights and HIV/AIDS;
- Palliative care for HIV/AIDS in less developed countries;
- Preventing opportunistic infections in people infected with HIV;
- Psychosocial support for people living with HIV/AIDS;
- Community-based economic support for households affected by HIV/AIDS;
- Responding to the needs of children orphaned by HIV/AIDS;
- Systems for delivering HIV/AIDS care and support.

Each paper provides a preliminary review of some of the current thinking and research on these broad and complex topics. It is important to note that the papers are not meant to be comprehensive – time and resource constraints prevented the authors from reviewing all the relevant literature and from contacting all the people who have valuable experience in these and related fields. Nor have they been subject to technical or peer review. Their purpose is to stimulate a broad conversation on HIV/AIDS care that can help USAID define its future programme activities in this area. We welcome your participation in this process.

Donahue, J., Hunter, S., Sussman, L., & Williamson, J. (1999). *Children affected by HIV/AIDS in Kenya: An overview of issues and action to strengthen community care and support*. New York: DCOF/USAID & UNICEF.

An estimated 1.5 million Kenyan children, 12 per cent of all the children in Kenya, have already lost one or both parents. AIDS is the major cause. By 2010, this number is projected to increase to 2.3 million, 20 per cent of all children in the country (children on the brink). Kenya's only realistic hope of avoiding a serious deterioration of the already precarious welfare of these and other vulnerable children is to strengthen the capacities of its families, communities, and fundamental child protection structures. Concern about this situation led USAID and UNICEF to conduct a joint assessment of children affected by HIV/AIDS in Kenya in March 1999. The objectives of the assessment were as follows:

- Provide an overview of the extent to which HIV/AIDS is contributing to the vulnerability of orphans and other children and where the resulting problems are greatest;
- Examine the nature and adequacy of community, organisational, and governmental responses to these problems, with particular attention to such issues as community-based efforts, income-generating activities, and the role of institutional care;
- Review the legal and policy framework relevant to both problems and responses; and
- Recommend ways to identify and scale up effective responses (See Appendices 1 and 2 for respective scopes of work).

The assessment team included staff or consultants from UNICEF Headquarters' Child Protection Section, USAID's HIV/AIDS Division, and USAID's Displaced Children and Orphans Fund. The team reviewed available documentation, conducted interviews, held discussions with key informants, and participated in a stakeholders' meeting to identify and discuss recommendations on addressing the needs of families and children affected by HIV/AIDS (See Appendices 3, 4, and 6 for further details).

Donahue, J. & Lorey, M. (2000). *Displaced children and orphans fund & Patrick J. Leahy war victims fund*. DCOF Technical Assistance Report: Pretoria and Johannesburg, South Africa/Washington: USAID.

The USAID Displaced Children and Orphans Fund began as a series of trips to Pretoria, South Africa in July 1999, at the invitation of the South African USAID mission. The first trip explored how USAID could best contribute to mitigating the impacts of HIV/AIDS on children and families. The second trip included attending a workshop to discuss the Department of Welfare's National Strategic Framework for children and families affected by HIV/AIDS. After the workshop, USAID/South Africa and DCOF met with staff from the Department of Welfare and the Nelson Mandela Children's Fund (NMCF) respectively. Staff from both institutions expressed interest in further developing their respective approaches to mitigate the impact of HIV/AIDS on families and children. USAID/South Africa and DCOF offered technical assistance for this purpose.

This report summarises the work done during a third trip to provide specific technical assistance to the Department of Welfare and Nelson Mandela Children's Fund. Jill Donahue, the DCOF technical advisor on community mobilisation and economic strengthening activities, served as team leader. Mark Lorey, a former staff member of Save the Children's COPE programme in Malawi and a visiting lecturer and researcher at the University of the Western Cape, participated as a technical resource advisor. USAID/SA provided two other technical resource advisors for the team: Caroline Brokenshire, a monitoring and evaluation specialist, and Felicity Young, an organisational development specialist with experience in supporting HIV/AIDS projects.

Donahue, J. & Sussman, L. (1999). *Building a multi-sectoral response: Follow-up assessment of programming for children and families affected by HIV/AIDS in Kenya*. Washington, DC: USAID.

How can the social, health, and economic needs of those affected by HIV/AIDS be addressed? The paper presents a USAID/Kenya and UNICEF/Kenya assessment of the situation of families, children, and communities affected by HIV/AIDS. The paper states that the social, health, and economic needs of those affected by HIV/AIDS can be addressed through two operationally separate projects: one that specialises in mobilising community support for families affected by HIV/AIDS; the other that fortifies household economic resources by providing microfinance services. Based on the assessment, the paper says that USAID/Kenya projects should:

- build local capacity to address the needs of children affected by HIV/AIDS;
- integrate orphan and vulnerable children issues into other development programmes and sectors;
- link prevention, care, and support activities;
- incorporate comprehensive adolescent programmes.

Donahue, J. & Williamson, 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*. Washington DC: USAID.

The introduction to this document portrays the general situation in Malawi. The country is in an advanced stage of the HIV/AIDS epidemic. It also has 60 per cent of its predominantly rural population of 10 million living below the absolute poverty line. The Malawian National AIDS Control Programme estimates that in the 15–49 age group HIV prevalence reaches 14 per cent. It is expected that in the coming few years there will be a substantial increase in the number of deaths due to AIDS. Policy guidelines for the care of orphans in Malawi were established in 1992. These define an orphan as a child under 18 years who has lost one or both parents. It is estimated that 10–15 per cent of Malawi's children fall into this category. Despite the many psychological and physical needs faced by families affected by AIDS, counselling and HIV testing are not common in Malawi. Concern about this negative situation led to the establishment in 1995 of a programme entitled 'Community-based Options for Protection and Empowerment' (COPE).

Initially, COPE activities were implemented in Mango and later were extended to Mangwera. The review found that the programme appeared to be on track for achieving its main objectives. Its principal activities were seen in a positive light by communities, their leaders, government personnel and NGO staff. However, because the COPE activities appeared to be quite costly, alternative approaches had to be introduced.

The principal areas of intervention were in the areas of care, income generation, and children's well-being. The programme supported home-based care activities and the training of household members in the giving of care (and administration of medicines). Patients in homes with trained care-givers were found to be receiving better care, to be more comfortable, and to live in greater dignity. To address the challenge of increasing the household incomes of families economically stressed by AIDS deaths, the programme strengthened community-based groups to create a sustainable safety net for the most vulnerable households; it also strengthened village banking schemes through a Group

Guaranteed Lending and Saving Service. This makes small loans to groups of 15–20 women for training and small enterprises. A single loan is given per group, with the group lending small amounts to each member. Collectively, the group is responsible for the repayment of the loan before any subsequent loan can be disbursed. These loans enable the women to obtain the inputs needed for use in the wetland gardens to which they have access. Almost all of the income this enables them to earn is used on the welfare of their families. Children's well-being is fostered by meeting the secondary school expenses of children from target families, and by encouraging recreational activities that will increase these children's social integration and allow those who have suffered losses to express their pent-up emotions in a positive way.

COPE has played a key role in advocacy on behalf of Malawi's orphans, feeding into the government's orphan care programme for 1996–1998 and participating in the national task force on orphans. It has also sensitised the business community and politicians to the problems of orphans in communities, one outcome being considerable support for its school scholarship component.

The review noted the success of the programme to date and recommended modifications and adjustments that would facilitate it in achieving its objectives. It noted key implications in any programming directed at mitigating the orphans crisis: 1. no single intervention can be expected to benefit all who are in need; 2. there is an ever-present need for ongoing community-based monitoring so as to identify the most vulnerable children and households in order to direct assistance to these; 3. as the orphan crisis grows and needs increase, attention must be paid to the sustainability of activities, particularly through the involvement of genuinely committed community-based groups; and 4. communities should be encouraged to identify their own problems and how to deal with these.

Donahue, J. & Williamson, J. (1998). *Community mobilization to address the impact of AIDS a review of the COPE11 program*. Available online: http://www.usaid.gov/pop_health/dcofwvf/dcwvprogs.html

Malawi is among countries most severely affected by HIV/AIDS, and its growing number of orphans is one of the epidemic's most apparent and troubling impacts. The health, development, education, and social integration of these children is already at serious risk. Their number can be expected to continue to increase, and their problems, already severe, can be expected to become much worse. However, the COPE program of Save the Children Federation of the United States (SC-US) offers reason for hope. It deserves careful attention in Malawi and throughout the region, because it is demonstrating a systematic approach to mobilising community-based responses to the needs of orphans and other people made vulnerable by the impacts of HIV/AIDS. If this approach can be scaled-up effectively, it may provide a cost-effective, sustainable way to address the crisis.

By the year 2000, 1.2 million children in Malawi, over 27 per cent of all children in the country, will have lost one or both parents due to AIDS and other causes. This estimate appears in 'Children on the brink: Strategies to support children isolated by HIV/AIDS', a report released in December 1997 by USAID. This document presents estimates of the number and proportion of children who will lose one or both parents in 23 countries heavily affected by HIV/AIDS. The report also presents USAID's view that solutions can be found only through co-ordinated efforts to support, strengthen, and multiply coping strategies among the families and communities on the front lines of the pandemic. The COPE program is a promising example of how this can be done.

The DCOF of USAID funded the initial COPE program (COPE I) for the period July 1995–September 1997 and provided a second grant for the period September 1997–September 2000 (COPE II). DCOF sent a team to collaborate with COPE staff in reviewing the programme in October 1996 and again in January 1998. This is the report of the team's second visit.

In Mangochi District's Namwera area, COPE has mobilised district, community, and village AIDS committees. This structure for community-based action was devised by the National

AIDS Control Program in 1994 with UNICEF support, but due to a lack of resources, for the most part it did function below the district level. COPE has brought the structure to life in Namwera. This effort began with a workshop in late 1996 that sensitised religious, business and political leaders and local line ministry personnel to the impacts of AIDS in their community. To take action participants decided to form the Namwera AIDS Co-ordinating Committee (NACC). With the support of COPE, NACC, in turn, organised 16 village AIDS committees (VACs) that have identified orphans, people who are ill, and other vulnerable individuals; helped orphans return to school; trained care givers in home-based care; raised funds and provided material assistance; started youth anti-AIDS clubs; and organised structured recreation activities to respond to the psychosocial needs of orphans.

Community ownership is the essential element in COPE's approach and the key to the potential sustainability of the community action that is generated. In Namwera, at both the area and village levels, participants in the sensitisation and training have assumed responsibility for addressing the broad range of problems caused by HIV/AIDS.

NACC includes government health, community development, agriculture, and education personnel; business persons; and representatives of religious groups. It has been successful in continuing to mobilise VACs even without the support of COPE, organising five additional VACs on its own. It is also playing a linking role between the district and village levels. NACC has supported VAC activities by raising funds through special events and monthly contributions of its members. COPE provided bicycles to help ease NACC's transportation difficulties. Problems with transport were cited frequently at village and district levels, as well.

Each VAC decides which problems it will address and the approaches it will use. Using its own criteria, each identifies the most vulnerable individuals in the village. The most active members of VACs have been chiefs and their counselors, Muslim religious leaders, clan heads, and families caring for orphans. All of the VACs have raised funds to provide limited material assistance to orphans and their guardians, home-based care patients, and/or isolated elderly people. Most collect monthly contributions from members. Activities carried out by VACs include:

- identifying and monitoring orphans and other vulnerable individuals;
- intervening with guardians and schools to return orphans to school;
- community fund raising;
- providing material assistance to orphans and home-based care patients;
- training care givers in home-based care;
- developing community gardens;
- forming youth anti-AIDS clubs;
- organising structured recreation activities for children.

Through linkages with other organisations COPE could significantly increase the scale of responses to the problems of vulnerable children and families in Malawi. For example, COPE personnel expressed interest in training other NGOs in their approach to community mobilisation. COPE may also be able to increase the impacts of its own program by selective linkages with such bodies as the Malawi Social Action Fund, the World Bank, and the Episcopal Conference of Malawi's home-based care programme.

COPE I focused primarily at the community and village levels, achieving encouraging results. COPE II seeks to make an impact over a much wider geographic area. Stimulating and strengthening district AIDS co-ordinating committees to take the lead in mobilising community and village AIDS committees will be a particular challenge for COPE and perhaps the most difficult test of whether this model can be implemented effectively at scale.

Donahue, J. & Williamson, J. (1999). *Community mobilization to mitigate the impacts of HIV/AIDS*. New York: Displaced Children and Orphans Fund (DCOF).

The HIV/AIDS pandemic is unravelling years of hard-won gains in economic and social development. The scale and severity of the social and economic impacts of the pandemic, already large, will continue to increase for many years. By next year in five countries, an estimated one of every four children will be orphans, and the proportion will be one in five

in an additional four countries, with others not far behind. Life expectancy will drop to 40 years or less in nine sub-Saharan Africa countries by 2010, and AIDS-related mortality will substantially reduce gains made in child survival in many countries. HIV/AIDS is not only an increasing cause of death among adults, infants and young children, it is also slowly impoverishing and dismembering families, leaving growing numbers of orphans in its wake. At all stages of the epidemic, families bear most of the social and economic consequences of HIV/AIDS. The pandemic is an evolving, slow onset disaster, and no country can assume it has seen the worst of it.

Recommendations: The problems caused by HIV/AIDS are too great for any government, donor, or organisation to be effective as a unilateral actor. Just as people are doing on the frontline in affected communities, donors and those who would intervene must define common strategies and collaborate closely. They must also give much more serious attention to cost-effective strategies and interventions. Fundamental strategies include building the capacities of:

- families to care for vulnerable children;
- communities to support vulnerable children and households;
- children affected by HIV/AIDS to support themselves and younger siblings;
- the government to protect vulnerable children and provide essential services;

Build an enabling environment

Find ways to make it easier for vulnerable families and communities to cope. This includes increasing the awareness and commitment of leaders and the public concerning children who are especially vulnerable, establishing laws and policies that protect children and widows, reducing stigma and discrimination associated with HIV/AIDS; monitoring the epidemic's impacts and the effectiveness of interventions; and increasing awareness, effectiveness, and co-ordination among key government bodies, international organisations, donors, NGOs, and CBOs. In addition, governments have critical roles to play in the protection and placement of children who are abused or neglected, establishing and monitoring compliance with policies to guide action, and delivering such essential services as health care, education, and access to clean water. Work through organisations that already exist in communities. Considering scale, cost, and potential sustainability, there are advantages to working through organisations or structures already active in a community. Examples include churches and other religious bodies; health services; neighbourhood health committees; schools; civic organisations; women's associations; and co-operatives.

Promote state-of-the-art participatory development techniques

Skill in participatory techniques that spark genuine community ownership cannot be acquired by reading a book, or by a one-shot training workshop. While these may help, mobilisation is learned through participation, observation, and dialogue. Just as the process itself is iterative and incremental, so too is the development of participatory skills for mobilisers. This takes patience and commitment, but once a foundation of genuine community ownership is established, progress is often very rapid. In addition to developing their own skills, catalysts must also strengthen mobilisation and participation skills at the community level. Creating design and methodological innovations to scale up project outreach. In order for community mobilisation programs to scale up, there must be effective links between communities and external structures and resources. Catalysts (whether NGO or extension agents) must promote genuine commitment to the participation from the community level up through each higher level of administration and organisational co-ordination. Financing training activities may be even more important than providing external grants for project operations. Training can include enabling more experienced community members to take part in mobilising and training counterparts from neighbouring areas and to exchange lessons with them. Similarly, ensuring that there are periodic 'retreats' during which staff review and analyse their progress will allow them to better identify their support needs and plan future strategies.

Promote a two-pronged technical assistance approach

Strengthening household economic resources and community safety nets are two critically important aspects of HIV/AIDS impact mitigation. Since the two types of services involved –

microfinance services and community mobilisation around HIV/AIDS care and support issues – require specific expertise, it is preferable to involve an organisation that specialises in microfinance services along with those with expertise in generating and supporting community-based action around HIV/AIDS and children's issues. Although the two technical approaches should be operationally separate, they must be conceptually joined.

Recommended areas for joint planning would be 1. the desired impact of microcredit; 2. monitoring and evaluating impacts; and 3. packaging loan products to reach target clients.

- Draimin, B. (1993). Adolescents in families with AIDS: Growing up with loss. In C. Levine (Ed.), *Orphans of the HIV Epidemic*. New York: United Hospital Fund of New York.
- Drew, R. S., Foster, G., & Chitima, J. (1995). *Economic status and cultural practices of orphaned families in the North Nyanga District of Zimbabwe*. Presented at IXth International Conference on AIDS and STDs in Africa. [Poster Abstract TuD678]
- Drew, R. S., Foster, G., & Chitima, J. (1996). Poverty – A major constraint in the community care of orphans: A study from the North Nyanga District of Zimbabwe. *SafAIDS News*, 4, 14–16.
- Drew, R. S., Makufa, C., & Foster, G. (1998). Strategies for providing care and support to children orphaned by HIV/AIDS. *AIDS CARE*, 10 Suppl. 1, 9–15.

In sub-Saharan African countries such as Zimbabwe, where 25–30 per cent of the adult population is HIV-infected, a steadily increasing number of AIDS orphans are in need of care and community support. A study conducted in Zimbabwe's Manicaland province in 1992, found that 1 in 5 households contained orphaned children. The tradition of incorporating orphans into the extended family has broken down as HIV-infection rates have risen. Community-based orphan support programmes that use volunteers to visit the most needy children have the potential to complement existing coping mechanisms in a cost-effective manner. Through a programme operating in four rural sites in Manicaland (Families, Orphans and Children Under Stress), 88 volunteers made 9 634 visits to 3 192 orphans in a six-month period in 1996. The total cost of this programme in 1996, was US\$26 000 (\$1.55/visit), 51 per cent of which was spent within the affected communities. Key steps in establishing a community-based orphan support programme include an organisational analysis, identification of catchment areas, selection and training of volunteers, client identification and registration, and programme monitoring and evaluation. Despite the efficacy of community-based orphan programmes, new childcare institutions without links to the community continue to be established in sub-Saharan Africa and to attract scarce resources. Among the obstacles to more widespread implementation of a community-based strategy are the low priority given to problems that affect children, the sheer magnitude of the problem, a reluctance to acknowledge AIDS as a cause of death, and a lack of awareness on the part of politicians and the planners of the potential such programs.

- Dunn, A., Jareg, W., & Webb, D. (2003). *A last resort: The growing concern about children in residential care – Save the Children's position on residential care*. London: International Save the Children Alliance.

In the West, abuse of children in residential homes continues to be reported and has long-term consequences for the affected children. In sub-Saharan Africa the use of residential care appears to be increasing because of the deaths of parents from HIV/AIDS. Asia is beginning to face similar issues. Armed conflict kills parents, separates children from families and necessitates urgent solutions to childcare problems. In former socialist countries, the new governments have to overcome the legacy of large, resource-consuming institutions that are not an answer to childcare and child protection problems.

This paper sets out the International Save the Children Alliance's position on the residential care of children and highlights concerns about its growing use. Its aim is to draw attention to an area that has largely been ignored as a rights issue for international attention and action.

The reasons for so many children – over 8 million worldwide – living in residential care are multiple and complex. At a macro level, socio-economic problems, globalisation, poverty, migration, HIV/AIDS and armed conflict affect the ability of families to raise their children. Social protection systems to support families facing these problems are failing, and the result

is that many children are growing up outside the family. These children need care and protection, but it is social policy influenced by culture, history, politics and many other contextual factors that determines the type of support a child will receive. In many countries, residential care is the main strategy for helping children in need of care and protection. Save the Children argues that many features of residential care are an abuse of children's rights and is concerned that the issue of children living in institutional care is escaping international attention and needs placing on the international agenda. A parallel concern is that the search for good community-based childcare alternatives is not being given sufficient attention by governments and donors. Through working with children themselves, we need to find better solutions for helping children affected by poverty, conflict and HIV/AIDS. This paper brings together the learning of Save the Children and other bodies, examines the issues, and provides advice and guidance for Save the Children and other agencies working with children living outside of family care. It is hoped that other agencies and partners can use this document as a basis of shared work, dialogue and action. For the purposes of this paper Save the Children uses the following working definition of residential care: 'a group living arrangement for children in which care is provided by remunerated adults who would not be regarded as traditional carers within the wider society'. This definition implies an organised and deliberate structure to the living arrangements for children and describes a professional relationship between the adults and the children rather than one that is parental.

Editorial (2002). AIDS orphans are the real challenge. *Aids Analysis Africa*, 10, 2.

Many of the articles in this issue focus on children, particularly orphans. Throughout Africa the effects of AIDS are being felt in the form of rising infant and child mortality and a decrease in life expectancy. Children born HIV-positive are likely to live for only a few years before they die. But it is not just HIV which is killing the children of Africa. It is well documented that the death of primary caregivers means that children are likely to have poor nutritional status and suffer more ill-health. This in turn will result in higher mortality rates among the young. This issue examines the situation in Nigeria, Kenya and South Africa. In Kenya an increase in infant and child mortality is being seen across the country, correlated with higher HIV prevalence. In Nigeria the scale and scope of the epidemic are still to be realised, but even here it is clear that children are suffering. The impact is not just on health. Children who are orphaned, or under stress because of the illness and death of their parents, are less likely to be in school or socialised. The socio-economic consequences of this will run on from generation to generation. South Africa is a prime example: during the 1970s and 1980s it suffered a 'lost generation' of children who did not attend school because they were involved in the struggle against apartheid, lost much of their economic and social potential, and consequently provide greater potential for poverty, crime and unrest. While increased mortality and morbidity due to HIV/AIDS are inevitable, there is some hope. One article in this issue suggests that with imaginative and considered responses we could develop new ways of dealing with AIDS. The argument is simple: there will be huge numbers of AIDS orphans; there is a need to care for them; there are high rates of unemployment; and one of the goals of many development programmes is to create employment, particularly for the disadvantaged and for women. Taken these as givens, the article suggests that we ought to try to develop a way of providing care for orphans, which is employment-creating for women. It will cost money, of course, but the choice between doing this and not doing it will be even more costly for our states and societies in the long run. This constitutes a potentially invaluable response to the epidemic, and it is to be hoped that policy-makers will read and consider this suggestion.

Ellis, C. (2001). *The impact of HIV/AIDS on South African children*. Department of Social Development, SA. Powerpoint presentation.

Elmore-Meegan, M., Conroy, R., & Tomkins, A. (1999). *AIDS orphans study*. Presentation at the Collaborative Symposium on AIDS research, Nairobi.

Elmore-Meegan, M. (2003). *Aids orphans and vulnerable children: An evidence-led response*. Powerpoint presentation.

- Elmore-Meegan, M., Conroy, R., & Tomkins, A. (2003). Comparison study of children orphaned by AIDS. ICROSS.
- Eveillard, R. B. & Shields de Leiva, J. (2003). *Strengths and weaknesses learned from two approaches to care for HIV/AIDS orphans in Haiti*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].
- The number of orphans related to the AIDS epidemic in Haiti is currently estimated at 200 000. Two organisations, CARE/HAITI and Maison Arc-en-Ciel, have developed unique programmes for family and community care for HIV/AIDS orphans.
- This presentation will delve into strengths and weaknesses of two different approaches used in Haiti to address CAAs. CARE/HAITI's community-based care approach encourages families to maintain CAAs by giving them training and efforts are made to prevent stigmatisation. CARE/HAITI also introduces income-generating activities to economically support the host families. Maison Arc-en-Ciel was established as a CAA orphanage and currently is home to close to 40 children. These children are provided meals and education and receive healthcare on-site. Maison Arc en Ciel also provides support to more than 100 children in the outside community who live with families. *Lessons learned*: Community-based care programmes are accepted and encouraged by the community and extended families are willing to accept orphans from their community. Partnerships with credit co-operatives are feasible and are one of the guarantees of success of these programmes. Conversely, fixed-site programs (like orphanages) have high operational costs, which limit their sustainability. Providing support to orphans and other vulnerable children while living in their communities, among family or other caregivers, is the most appropriate choice.
- Based on these two experiences, it is necessary to promote the community-based approach in designing programs for CAAs. Community-based programmes should take into consideration issues of cost-effectiveness and seek to link with micro-credit programmes. Further, appropriate education for host families regarding the care of HIV/AIDS orphans and other vulnerable children and issues surrounding stigmatisation are essential components of a successful program for CAA.
- Ezalé Gnahué, J., Ahondjo Okou, L., Dablé, O. T., Lauri Bilé, P., Meyé Offossé, D., Zan, J. Y., & Kakou, A. J. (2003). *Care and support to orphans and vulnerable children*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].
- SidAlerte is an NGO which provides care and support (C&S) to children infected and affected by HIV/AIDS and living in precarious and rural areas. The age of these children varies from 4–15 years. They receive nutritional, medical, psychosocial and financial support. SidAlerte collaborates with a religious congregation of Catholic sisters called 'les missionnaires de Sainte Therese de L'Enfant Jesus de Koumassi' in Abidjan. The identified orphans referred by the sisters are supported from private, public institutions and individuals. The children receive appropriate C&S based on their identified need. Help comes under various forms: food; clothing; school supplies; and payment of school fees, medical care. Infected children are oriented toward the university hospital and the maternal and child health centre in Yopougon for provision of anti-retroviral treatments. In addition, the French Co-operation built a lunch stall and provides food supplies for the children.
- Collaborating with religious organisations to provide C&S to orphans and vulnerable children (OVC) enhances the capacity of local NGOs to better identify the needs of communities and to provide an adequate response. The logistical and material support provided by the religious order also help to facilitate the actions of the NGO within the community. In addition, this type of partnership helps establish the credibility of the project and the NGO and facilitates the mobilisation of donor funds.
- Although all these actions have been successful in providing assistance to OVC, it is noted that a portion of these children are overlooked. In particular, older children and adolescents are not taken into account by these activities. Consequently, a vocational training centre needs to be established in order to address the social reinsertion of marginalised young people who cannot receive training through the formal training system.

Family AIDS Caring Trust (FACT) (1995). *Practical steps to starting and implementing community-based orphan support programmes*. Family AIDS Caring Trust.

This report of a clinic bringing together staff and volunteers of three orphan support programmes covers areas such as questions people ask when trying to start a programme, enumeration, defining an orphan, record systems and report forms, selection of volunteers, guidelines for needs assessment, the role of social welfare and external agencies, monitoring, involving the local community in the programme, keeping volunteers motivated and bible teaching on orphans.

Family AIDS Caring Trust (FACT) & International HIV/AIDS Alliance (2001). *Expanding community-based support for orphans and vulnerable children*. United Kingdom, (Zimbabwe): International HIV/AIDS alliance, (Family AIDS Caring Trust (FACT)).

In order to provide support to increasing numbers of OVC, there is a pressing need to scale up effective community-based care initiatives. In October 2001, a workshop was co-hosted by FACT and the international HIV/AIDS Alliance in Mutare, Zimbabwe. The workshop was attended by representatives of 17 intermediary NGOs from nine countries, mostly from east and southern Africa. The aim of the workshop was to understand the proliferation of OVC initiatives throughout the region and the ways in which NGOs and their partners can expand the impact and coverage of OVC programmes. This report is largely the result of discussions by workshop participants. Case studies of participant groups and organisations are included throughout the report. Participants focused on three levels at which change is required to achieve scale-up: community, facilitation, and policy/resource. At each of these levels, workshop participants agreed that successful scale-up efforts should pay attention to the focus, coverage, quality and sustainability of programmes. For each level, participants analysed the respective roles of five groups concerned with scaling-up: community groups and CBOs; intermediary NGOs; government; international NGOs; and donors. The key conclusions of the workshop were that stakeholders must be aware of their respective 'niche roles', act appropriately and work together. Policy/resource organisations should make greater commitments to the development of supportive OVC policy and commit more funding through intermediaries. The provision of both technical support and appropriate funding by intermediary NGOs to community level organisations could go a long way to helping such groups to reach more vulnerable children and perhaps expand their response into areas such as home care, income generation and effective HIV prevention.

Family AIDS Caring Trust (FACT) (2002). Orphan care in Zimbabwe - a community response. *Aids Analysis Africa*, 10, 14–15.

Family Health International (2001). *Care for orphans, children affected by HIV/AIDS and other vulnerable children: a strategic framework*. Arlington: Family Health International.

One measure of the massive social change still to come is the number of orphans, children affected by HIV/AIDS, and other children made vulnerable by the pandemic. According to revised 2000 estimates, there are currently 34.7 million children under the age of 15 in 34 countries who have lost their mother, father, or both of their parents to HIV/AIDS and other causes of death. By 2010, that number will be 44 million. The human and social costs these estimates represent are staggering. Although the overwhelming majority of orphans and vulnerable children are living with surviving parents or extended family, many of them are being cared for by a remaining parent who is sick or dying, elderly grandparents who themselves are often in need of care and support, or impoverished relatives struggling to meet the needs of their own children. Children living in these situations are at increased risk of losing opportunities for school, healthcare, growth, development, nutrition, and shelter; in short, their rights to a decent and fulfilling human existence. When the family and community capacity to absorb children has been reached, increasing numbers of children must look after themselves. Often the eldest child takes responsibility as the head of the household. Some of these children are left with no other option than to live on the streets, exposing them to even greater medical, social, and psychological difficulties. The growing demand for care and support of orphans and vulnerable children at the community level has strained traditional

coping mechanisms to a crisis stage in the most heavily affected countries. An increasing number of communities and government structures are struggling to deal with the impact of AIDS on children and their families. In the absence of support there will be long-term developmental impacts on children and the future of these countries. Failure to support children to overcome this trauma will have a very negative impact on society and might cause dysfunctional societies, jeopardising years of investment in national development.

Care and support for orphans and vulnerable children has primarily focused on addressing their material needs. The secondary focus of programmes has been to address the needs for skill transfer and education for children. Even fewer programmes have been able to adequately address the medical, social welfare and psychological needs of children affected by AIDS.

Although African and Asian countries have responded with comprehensive policies and plans of action for these children, (Malawi, Zimbabwe, Thailand), most countries have national plans still in development. At the community level, various community groups have developed a wide range of responses. The extent of these responses is not known, but there is general agreement that geographic and programmatic coverage of existing programs is insufficient. The challenges faced by children, families, communities, and their governments in managing the impact of HIV/AIDS are and will continue to be enormous. Therefore, comprehensive and cost-effective approaches, coupled with co-ordinated partnerships and community mobilisation, are needed. It is also imperative to replicate, scale-up, and sustain these approaches to meet the short- and long-term care and support needs of orphans and other vulnerable children.

This document provides a strategic framework to assist national and local planners, implementers, and donors in setting priorities, and outlines the steps necessary to develop responsive care and support programs for orphans, children affected by AIDS and other vulnerable children. It also elaborates on the role that FHI can play in this effort.

Fekadu, Z., Guralnick, M., Klein, P. S., Melese, F., Rye, H., & Teferra, T. (2001). *Seeds of Hope. Twelve years of early intervention in Africa*. Oslo: Unipub.

'Seeds of Hope' summarises the main results of 12 years of child development research, focusing on the long term effects of family-based intervention in a slum area of Addis Ababa, Ethiopia. The early intervention approach was based on the MISC-program developed by Pnina Klein, Bar-Ilan University, Israel. The results presented document a successful way of working with disadvantaged families and children applicable in Third World countries as well as economically more advanced countries. The project was directed by Professor Tirusew Teferra, Addis Ababa University and Professor Henning Rye, Oslo University.

Fogarty Foundation (2000). *Proceedings of a Fogarty Maternal and Child Health Workshop. Research priorities in Early Childhood Development for Southern Africa*. Workshop held 14–18 August 2000, at the Rob Roy Hotel and the Valley Trust, Durban South Africa

Forehand, R., Armistead, L., Morse, E., Simon, P., & Clarke, L. (2003). *HIV-infected mothers: Parenting skills and stress-related adjustments of their children*. Presented at the XIth International Conference on AIDS, Vancouver, 7–12 July, 1996. Abstract No: We.D. 375.

Foster, G. (1998). Today's children – challenges to child health promotion in countries with severe AIDS epidemics. *Aids Care*, 10 Suppl. 1, S17–S23.

Recent declines in infant and child mortality rates (IMR and CMR) are being reversed due to AIDS. Greatest impacts are in southern African countries with severe HIV epidemics and lower non-AIDS IMR/CMR. Zimbabwe and Zambia's IMR were estimated to be 40 per cent and 30 per cent higher in 1996; CMR by 2010 was projected to increase fourfold in Zimbabwe, threefold in Botswana and to double in Kenya and Zambia due to AIDS. HIV indirectly impacts children through orphanhood, TB and poverty. By 1996, life expectancy fell to 36 in Zambia, 42 in Zimbabwe and 40 in Uganda. One-third of children may become vulnerable after maternal orphanhood since elderly and juvenile caregivers are frequently uninformed about nutrition, oral-rehydration, immunisation and diagnosing serious illness. Resurgence of adult and paediatric TB affects children through increasing orphanhood and

increased child mortality. AIDS-induced poverty among survivors leads to deterioration in children's health and increased vulnerability of adolescent survivors to HIV infection. The situation is set to worsen, especially in communities experiencing the cumulative impact of repeated parental deaths. Reducing the number and vulnerability of children and adolescents becoming HIV infected and increasing support to affected children are important strategies to improve child health in countries with severe epidemics.

Foster, G. (2000). Responses in Zimbabwe to children affected by AIDS. *SafAIDS News*, 18.

Foster, G. (2001). Proliferation of community initiatives for orphans and vulnerable children. *AIDS Analysis Africa*, 12, 4–5.

Foster, G. (2001). *Expanding support to orphans and vulnerable children*. Oak Foundation.

During 2000, Oak Foundation embarked on a Scaling-up OVC Programmes Initiative through which additional resources would be made available to partners to enable scaling up OVC programmes. In January 2001 Oak sponsored a workshop which was attended by 25 people, representing 16 Zimbabwean NGOs. The workshop was designed to provide the critical tools necessary for planning and designing expanded programmes and to lead to the development of project proposals. Participants identified the need for ongoing collaboration amongst NGOs engaged in similar programmes, as well as for future workshops on specific themes. The effectiveness of the Initiative will be evaluated by participating organisations after 12–15 months.

Foster, G. (2003). HIV and AIDS: *Orphans and sexual vulnerability in sexually exploited children: Working to protect and heal*. Monrovia: MARC.

Foster, G. (2002). *Understanding community responses to the situation of children affected by AIDS – Lessons for external agencies*. Draft paper prepared for United Nations Research Institute for Social Development (UNRISD) project HIV/AIDS and Development, Geneva.

This article analyses community, NGO and international agency responses to the impact of AIDS on children in sub-Saharan Africa. Reports of the social and economic impacts of AIDS in children appeared in the late 1980s. Large-scale international responses to the situation of children affected by AIDS did not occur until the late 1990s. The circumstances surrounding the development of international responses are reviewed.

Community coping responses that are occurring in response to the deteriorating situation of orphans and vulnerable children are hardly known outside their immediate locale. They have been little studied or documented and few external organisations have sought to foster their development. Yet community initiatives are a robust, sustainable and widespread community-owned response to cope with growing numbers of orphans and vulnerable children. Using examples, the characteristics of community initiatives are described and compared to existing forms of community coping. The ease with which such responses are becoming established suggests that outside agencies should seek to strengthen community initiatives. This must be done in ways which avoid undermining community coping. Implications of community coping responses for external agencies are discussed. Partnerships between local organisations, community initiatives and local researchers and strengthening the development of intermediary organisations are proposed strategies.

Foster, G. (2003). *Study of the responses by faith-based organizations to orphans and vulnerable children: preliminary summary report*. New York: World Conference of Religions for Peace/UNICEF.

Foster, G. & Germann, S. (2000). The orphan crisis. In M. Essex (Ed.), *AIDS in Africa*, 2nd Edition. New York: Kluwer Academic Publishers.

Foster, G., Makufa, C., Drew, R., Mashumba, S., & Kambeu, S. (1995). Perceptions of children and community members concerning the circumstances of orphans in rural Zimbabwe. *AIDS Care*, 9, 391–406.

Focus group discussions and interviews were held with 40 orphans, 25 caretakers and 33 other community workers recruited from a rural area near Mutare, Zimbabwe. Orphan concerns included feeling different from other children, stress, stigmatisation, exploitation,

schooling, lack of visits and neglect of support responsibilities by relatives. Many community members, while recognising their limitations due to poverty, volunteered or were already actively helping already involved in activities to help orphans and caretakers. Extended family networks are the primary resource for orphans, though some relatives exploit orphans or fail to fulfil their responsibilities. Interventions are suggested which support community coping mechanisms by strengthening the capacities of families to care for orphans. Outside organisations can develop partnerships with community groups, helping them to respond to the impact of AIDS, by building upon existing concern for orphan families. They can help affected communities who are at an early stage of the epidemic to develop setting up committees and developing orphan support activities. Such activity encourage caring responses by community leaders and relatives and which discourage property grabbing and orphan neglect. Material support channelled through community groups to destitute families at critical times can strengthen family coping mechanisms. Income generating activities should build upon communities' existing capabilities and benefit the most vulnerable orphan households. Some communities are responding to the AIDS disaster by adoptions to cope with devastating changes taking place in their communities.

Foster, G., Makufa, C., Drew, R., Kambeu, S., & Saurombe, K. (1996). Supporting children in need through a community-based orphan visiting programme. *AIDS Care*, 8, 389–404.

There is an urgent need for programmes to be established to support the growing number of orphans in countries severely affected by AIDS. Most orphans are being cared for by extended families under difficult circumstances. Few descriptions of community-based orphan support programmes exist. The authors describe one such program established in Zimbabwe in 1993. 25 volunteers identified 300 orphan households. During one year, volunteers made 1 725 home visits and 123 households received an average of \$11 in material support or school fees. In 292 orphan households there were 702 orphans, 14.7 per cent of children under 15 years in the area. The rate of parental deaths was increasing, with 3.5 per cent of households in the area having a parental death in 1994. Forty-five per cent of caregivers were grandparents and 33 per cent of caregivers were over 60 years. Three per cent of orphans were cared for by adolescent siblings. The poorest orphan households were those in receipt of school fees, with out-of-school children, or with an older sibling as caregiver. Community members initiated activities to help orphans. The program described is targeted, effective and replicable. Community-based organisations such as local churches and women's groups can be mobilised to administer programmes which provide support to the poorest orphan households.

Foster, G., Makufa, C., Drew, R., & Kralovec, E. (1997). Factors leading to the establishment of child-headed households: The case of Zimbabwe. *Health Transition Review*, 7, 155–168.

This study presents findings from interviews with 27 child- and 16 adolescent-headed households in Manicaland, Zimbabwe, on the factors associated with the formation of these households. In these 43 households, there were 15 adults aged over 24 years, 23 adolescents aged 18–24 years, and 146 children aged under 18 years. The median age of respondents was 16 years. 27 households consisted of children or adolescents caring for younger children. 13 households had adult members, of whom seven were grandparents who were very ill or handicapped. One household had a mentally retarded mother. Two households had aunts who were unable to care for the children. Only one household was in an urban area. Ninety-five per cent were orphans who had lost a parent. Both parents had died in 30 orphan households. Eighty-four per cent of maternal deaths and 74 per cent of paternal deaths occurred during 1993–96. 25 households had female heads, and 18 had male heads. 25 female heads were older sisters. 14 male heads were older brothers. Heads were as young as 9–11 years old. Seventy-five per cent of households were established during 1995–96. Most households were established in the same year as the parent's death. Twenty-one children or adolescents became heads during or following the death of a parent. One child assumed the headship after a mother deserted. In 14 households, children or adolescents became heads after the death of grandparents, aunts, or unrelated household heads. The young age of heads is reported as being due to a lack of known relatives to care for the family, relatives'

disinterest in caring for orphans, and a lack of means to care for the children. 17 children left 13 households during the study to live with other relatives. 16 households received regular visits from relatives. 14 households received material support from relatives. 10 households with known relatives did not receive any support. The households reflect new coping approaches to HIV/AIDS.

Foster, G. & Makufa, C. (1999). *Community mobilization best practices: The Families, Orphans and Children Under Stress (FOCUS) programme*. Mutare, Zimbabwe: Family AIDS Caring Trust.

Foster, G., Shakespeare, R., Chinemana, F., Jackson, H., Gregson, S., Marange, C., & Mashumba, S. (1995). Orphan prevalence and extended family care in a peri-urban community in Zimbabwe. *AIDS Care*, 7, 3–17.

An orphan enumeration survey of 570 households was conducted in and around Mutare, Zimbabwe in 1992; 18.3 per cent (95 per cent CI 15.1-21.5 per cent) of households included orphans; 12.8 per cent (95 per cent CI 11.2-14.3 per cent) of children under 15 years old had a father or mother who had died; 5 per cent of orphans had lost both parents. Orphan prevalence was highest in a peri-urban area (17.2 per cent) and lowest in a middle-income high-density urban suburb (4.3 per cent). Recent increases in parental deaths were noted; 50 per cent of deaths since 1987 could be ascribed to AIDS. Orphan household heads were likely to be older and less educated than non-orphan household heads. The majority of orphaned children are being cared for satisfactorily within extended families, often under difficult circumstances. Caregiving by maternal relatives represents a departure from the traditional practice of caring for orphans within the paternal extended family and an adaptation of community-coping mechanisms. There was little evidence of discrimination or exploitation of orphaned children by extended family caregivers. The fact that community coping mechanisms are changing does not imply that extended family methods of caring are about to break down. However the emergence of orphan households headed by siblings is an indication that the extended family is under stress. Emphasis needs to be placed upon supporting extended families in the community by utilising existing community-based organisations. Orphan support programmes may need to be established initially in high-risk communities such as low-income urban areas and peri-urban rural areas.

Foster, G., Webster, J., Stephenson, P., & Germann, S. (2002). *Supporting community initiatives is crucial to scaling up orphan support activities in Africa*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.aspl>].

Communities in Africa are coping with increasing numbers of orphans and vulnerable children. Community Initiatives (CIs) are associations of people involved in OVC activities. CIs vary in size and structure and were undocumented. The study aims to understand the nature, development and potential of CIs and make recommendations for external support agencies. A workshop was organised by a Zimbabwe network supporting 30 CIs. Findings were tabulated during group sessions and discussed in plenary. In 19 CIs from urban (nine) and rural (ten) sites, the lead agency was a Pentecostal (eight), independent (seven) Baptist (three) or Methodist church. CIs started in 1993/4 (three), 1996/7 (four), 1998/9 (four), 2000/1 (eight). CIs involved 247 volunteers (77 per cent women) from 67 churches. Pastors (13) or other church members (six) started initiatives after seeing OVC hungry (nine), without school fees (seven), lacking clothes (five) or exploited (four). Services for 3 462 OVC included: home visits (16 CIs), spiritual support (14), school fees (14), clothing (13), food (11) and income generating projects (eight). Compared to new CIs, older CIs involved more volunteers (18 vs eight), more OVC (315 vs 63), more activities and volunteer training. CIs wished to expand the area covered (eight), number of OVC (six), volunteers (four) and funding base (two). Greatest needs of CIs were training (administration, psychosocial support) (13), finances (12) and volunteer management (six). Few CIs received external resources.

Conclusions: Faith-based organisations are a widespread, robust and sustainable response to cope with increasing OVC in Africa. Scaling up support to OVC requires intermediary organisations (e.g. local NGOs) to partner CIs and build their capacity with training, advice and small grants. This requires new skills and a deeper appreciation of the resilience of African communities.

Foster, G. & Williamson, J. (2000). A review of current literature of the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS 2000*, 14, S275–S284.

Long-term solutions will need to be crafted for children affected because the impact of HIV/AIDS will linger for decades after the epidemic begins to wane. Even if rates of new infections were to level off in the next few years, the long incubation period means mortality rates will not plateau until 2020. Thus, the proportion of orphans will remain unusually high at least through 2030. For a variety of reasons, little attention has been paid to the situation of children affected by HIV/AIDS. Greater understanding of the impact of HIV/AIDS on children is important in the design and evaluation of programmes to support children living in difficult circumstances. This paper reviews epidemiological characteristics of children affected by HIV/AIDS, coping mechanisms and current knowledge of the impact of HIV on children. Areas where important gaps in knowledge exist are highlighted.

Fox, S. (2002). Hidden needs of children: psychosocial support for children affected by HIV/AIDS. *International AIDS Conference, 14 (abstract number WePeF6871)*.

Fox, S., Fawcett, C., Kelly, K., & Ntlabati, P. (2002). *Integrated community-based home care (ICHC) in South Africa: A review of the model implemented by the Hospice Association of South Africa*. Pretoria: National Department of Health, South Africa.

Hospice has, in a relatively short space of time, been required to develop a response within the context of a burgeoning need for home-based care for AIDS patients in South Africa. In many respects, whilst the broad ethos of the hospice approach has been maintained, the challenge has been to extend existing approaches into new territory. In some hospices, existing systems and structures have been retained and underpin emerging response, whilst in others, systems, structures and infrastructure have been considerably realigned. As a whole, hospices are being transformed and expanded as a direct result of the emerging needs of the HIV/AIDS epidemic. Transformation is never easy, especially where new ground is being charted and where human resources need to be managed, but the value of developing and working with models is that this allows transformation to be well-considered and systematic. At the same time, the ICHC model is flexible, and any part of it can be adapted to an individual home-based care need or situation.

Within hospice, new models of operation are evolving which incorporate diverse human resources and capacities, and in social and community contexts that are themselves changing, and in circumstances that are constrained by poverty and hardship. However, the underlying ethos of care provision – caring for individuals and their families in all aspects – combined with an understanding of the community contexts, is maintained within the ICHC model. Hospices are integral to the developing response to HIV/AIDS, and the organisation has risen to the emerging challenges. However continued support is required from other role players in relation to both its internal development and transformation, and in relation to its reach into the community.

Fox, S. & Götestam, R. (2002). *Redirecting resources to community-based services: A concept paper*. (Social Protection Discussion Paper No. 0311). Washington, DC: World Bank.

A legacy of the command economy in Central and Eastern Europe and the former Soviet Union is a social protection system that emphasises institutional care for vulnerable individuals. It has been well established that in many cases institutionalisation can be more expensive per client served and produce inferior welfare outcomes than more inclusive approaches designed to support individuals within their families and communities. But countries seeking to change the model of services face a number of financial constraints, including redirecting resources away from institutions. How can countries develop the new programmes in an affordable manner? How should they change the financing flows to support the new options, without putting the burden of financing on the vulnerable themselves? The objective of this paper is to provide a framework to help countries re-orient their financing systems for social care. The paper first reviews key concepts in social care financing and then applies them to the problem of changing social care models in ECA countries.

Fransman, D. & Hussey, G. (1999). *Paediatric AIDS home-based care project, Khayelitsba, Cape Town*. Cape Town: Child Health Unit, UCT.

In Africa AIDS is contributing to rising infant and child mortality rates, thus negating progress made in improving child survival in recent years. The effect will soon be as evident in South Africa if concerted efforts to slow down the epidemic's progress are not made. Children infected with HIV in sub-Saharan Africa account for 90 per cent of all infections among children in the world. Half of all new infections occur among young people in the 15–24 age group. It is estimated that South Africans currently account for one in seven new infections on the continent. In South Africa, the right to healthcare has not yet been achieved for many children. The need for special attention to be given to the rights of HIV-infected children attests to this reality. Although a child has the right to basic healthcare services conferred by the State through the Constitution, this is subject to available resources. These constraints within the health care services provide a challenge to healthcare workers, who have an obligation to ensure that the 'best interests' principle of the Convention is applied to all children whom they serve, including those with special needs such as HIV.

Fraser-Moleketi, G. J. (1998). *Address by Ms Geraldine J. Fraser-Moleketi, Minister for Welfare and Population Development* at the Southern African regional conference on 'Raising the Orphan Generation', organised by CINDI, Pietermaritzburg, 9–12 June, 1998.

Gainullin, S. (2003). *Nyumbani Village*. [Available online: www.noelgroup.com/vision/nyumbanivillage.aspx]

A unique project is unfolding in Kenya that will focus on serving the needs of children orphaned by the AIDS pandemic, and the elderly who have lost grown children to the disease. The project, called Nyumbani Village, is a self-sustaining community to assist elders.

Gaisie, E. (2003). Deprived single mothers and the HIV/AIDS scourge. *Ghanaian Chronicle* (Accra), 12 June, 2003.

Women and children form a higher percentage of society. Despite their significant roles in the economic activities at the household level and in the general society, women in Africa seem to have diminished rights and are exploited by their male counterparts.

Germann, S. (1996). *Is community care a vital alternative to institutional care for orphans in Southern Africa?* Swansea: University of Wales.

Germann, S. (2002). *Impact of HIV/AIDS on children in Southern Africa*. Presented at a Workshop on Children, HIV and poverty in Southern Africa, organised by SARP, HSRC, and Save the Children, 9–10 April, 2002.

The paper charts the magnitude of the orphan crisis, focusing on its psychological, social and economic impacts, which together increase the vulnerability of children to poverty and HIV/AIDS. It concludes with some experiences and lessons learnt that have successfully influenced policy, and some recommendations towards improving the quality of life of children affected by AIDS in southern Africa.

Gertler, P., Levine, D., & Martinez, S. (2003). The presence and presents of parents: Do parents matter for more than their money? Unpublished work.

The death of a parent is one of the most severe traumas that a child can suffer. The unexpected loss of a mother or father not only entails emotional and psychological distress for the orphaned child, but parents are no longer present to provide their offspring with love, support, nurturing, values, information and discipline. The loss of a productive household member also diminishes the financial resources available for continued investments in child health and education. This paper investigates the effect of parental death on investments in child human capital using a panel data set from Indonesia. We find that children with deceased fathers are more likely to drop out of school, while children with deceased mothers are less likely to start school and are generally less healthy than non-bereaved children. Controlling for changes in household economic status (consumption) does not substantially reduce the negative effect of parental death on health and educational status. These results suggest that behavioural changes related to the loss of parent's presence mainly explain the reduction in children's human capital rather than loss associated with loss of income from parental death. The results provide strong support for the important role of parental presence in the household for raising healthy and well-educated children.

Gewirtz, A. & Gossart-Walker, S. (2000). Home-based treatment for children and families affected by HIV and AIDS. Dealing with stigma, secrecy, disclosure, and loss. *Child and Adolescent Psychiatric Clinics of North America*, 9, 313–330.

The compelling needs of HIV-affected children and families sometimes appear to represent human struggles under the magnifying glass. The multiple assaults on the healthy psychological development of children through disruptions in caregiving, loss, and abandonment require interventions that are mindful of their mental health needs and longer-term developmental trajectories. An ongoing relationship with a clinical team who can understand and respond to the vicissitudes of the illness and provide calibrated psychotherapeutic and case management services can aid both children and parents in the painful tasks that AIDS presents. Whereas clinically informed case management services can offer respectful and thoughtful concrete help, psychotherapy can offer the opportunity for children to pull together the often fragmented narratives of their family lives and integrate object loss to be free to continue on a normative developmental path. Comprehensive, wraparound home-based services of the type described in this article represent a mostly new tradition in psychiatry, but one that ensures that mental health services are provided to the most vulnerable children and families. For those affected by HIV or AIDS, home-based services can be the key to healthcare and treatment compliance. In addition, when services are well integrated within a community context, such that regular communication with other healthcare providers (AIDS clinics, visiting nurse services, and AIDS care agencies) is ongoing, what is provided constitutes continuity of care in the truest sense.

Giese, S. (2001). *The impact of HIV/AIDS on the health and welfare of children in South Africa and on health and welfare services for children*. Prepared as part of South Africa's contribution to UNICEF's global report on the impact of HIV/AIDS on children. Cape Town: UCT.

Giese, S., Meintjies, H., Croke, R., & Chamberlain, R. (2003). *Health and social services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS*. Cape Town: Children's Institute.

What are some of the implications of an approach that encourages imaginative thinking around the role of service providers? Among other things, such an approach would:

- Demand and facilitate improved co-ordination and collaboration;
- Require a review of performance indicators for service providers, for example, teachers' performance would no longer be measured only on the academic achievements of their learners;
- Introduce new elements into the training of professionals and lay workers;
- Create networks of support for service providers themselves;
- Mainstream children's issues, in line with national and international obligations;
- Address the impact of HIV/AIDS on children within the context of other vulnerabilities of childhood;
- Facilitate early identification of vulnerable children and minimise the risk of any child falling through the service gaps.

Giese, S., Meintjies, H., & Proudlock, P. (2001). *National Children's Forum on HIV/AIDS Workshop Report*, 22–24 Aug. 2001, Cape Town, SA. Children's Institute, UCT.

The National Children's Forum on HIV/AIDS was held in Cape Town between 22 and 24 August 2001. The forum brought together 90 HIV-affected children (7 to 18 years of age) from around SA. The aim of the forum was to provide these children with the opportunity to talk about how HIV/AIDS is impacting on children in SA with the intention that their voices be heard by national decision makers. The forum and subsequent activities will ultimately impact on the drafting, implementation and monitoring of policies and programmes designed to address the needs of vulnerable children. Over the course of the three-day event, the children spoke about the challenges they face on a daily basis, the way HIV/AIDS has changed their lives and about their experiences of services and other support structures. On the last day of the forum, the children met with representatives from national government and parliament to discuss the impact of HIV/AIDS of children and the roles of civil society and government in addressing this impact.

Key themes:

- Many children are being denied access to education because they are unable to pay their school fees. Teachers know too little about children's home circumstances.
- Many healthcare facilities are not child and youth friendly.
- In addition to being HIV-infected or affected, most of the children who attended the forum live in conditions of dire poverty.
- The children's artwork and discussions reflect their outrage at the high levels of sexual abuse in SA.
- The children cited stigma and discrimination against HIV-affected people as key problems.
- HIV/AIDS is typically associated with a long and painful death. Children living with HIV-positive parents or siblings spoke poignantly of witnessing their suffering.
- Children taking on the role of care givers and breadwinners.

Giese, S., & Wilson, T. (2002). *Identifying, monitoring and supporting vulnerable children*.

Presentation at Nelson Mandela Children's Fund Conference, 'A Call for co-ordinated action for children affected by HIV/AIDS'. Midrand, South Africa, 2–5 June 2002.

Gilborn, L. (2001). *Influence of family and community in school attendance and performance of children affected by HIV/AIDS*. Washington, DC: Horizons Program/Population Council. Powerpoint presentation.

Gilborn, L. Z., Nyonyintono, R., Kabumbuli, R., & Jagwe-Wadda, G. (2001). *Making a difference for children affected by AIDS: Baseline findings from operations research in Uganda*. Washington DC: Horizons Program/ Kampala: Dept. Sociology, Makerere University.

The impact of adult illness on children starts when a parent is diagnosed as HIV positive or becomes ill with HIV/AIDS. Property grabbing is widespread, with women and children especially vulnerable. Many guardians are in poor health, and some are even infected with HIV/AIDS. Most older children want their parents to tell them the truth about being HIV-positive. Study participants say that material support is what they need most.

Selected programme and policy recommendations:

Reach children affected by AIDS before they become orphans. Increase community awareness and accountability about the property rights of women and children. Address the critical health needs of adult caregivers, including guardians. Improve capacity for adult-to-child communication, especially about difficult issues such as sex education, and parental illness and parental death. Address material needs in AIDS-affected households.

Gilborn, L. Z., Nyonyintono, R., Kabumbuli, R., & Jagwe-Wadda, G. (2002). *Impact of a succession planning program in Uganda as indicated by parents' actions in planning for their children's future*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

Operations research in Uganda tested the impact of orphan support (OS) and succession planning (SP) on children affected by AIDS (CABA), HIV-positive parents and guardians. SP supports parents in planning for their children's future through: voluntarily disclosing HIV status to children, appointing future guardians, and writing wills and memory books. Each of two rural districts was divided into three arms: a control arm, an arm with OS and an arm with SP. Three surveys were collected at yearly intervals: one before and two after the programmes started. Study participants were HIV-positive parents, CABA (aged 5–18), and future and current guardians (baseline n = 1407). In-depth interviews were conducted with program staff (n=14).

Compared to other parents at observation 3, those exposed to SP were more likely to have disclosed their sero-status to their children ($p<0.05$), arranged for a guardian ($p<0.05$) and appointed an executor for their property ($p<0.05$). They were more confident that their children would be well cared for ($p<0.05$) and their property distributed fairly ($p<0.05$). They were less likely to say there are people to whom they can't disclose their HIV-status ($p<0.05$). Pre/post-intervention comparisons of parents in the SP arm also yield significant changes in the proportion with written wills and other outcomes. Despite initial fears about writing wills and memory books, many parents proceeded to do so and viewed these actions positively. Writing was the greatest challenge for parents.

Conclusions: SP is an effective approach for engaging HIV-positive parents in planning for their children. Initial fears and taboos about making wills can be overcome with support of program staff. SP should be implemented in new settings, but demands a wide range of skills on the part of implementers: legal, writing, counselling and training skills are key.

Goldenberg, D. A. (1996). All children in developing countries will be affected by AIDS, not just orphans. *AIDS Analysis Africa*, 6, 8–9.

The HIV/AIDS pandemic will transform the situation of children in the developing world through direct and indirect increases in child mortality, rising rates of adolescent HIV, widespread orphaning, and the deterioration of societal and community conditions due to adult mortality. Children aged 0–4 years comprise 10–18 per cent of reported AIDS cases in Southern African countries. By precipitating additional deaths, the effect of AIDS upon child mortality will be most marked in relatively low child mortality rate (CMR) countries such as Zimbabwe, Kenya and South Africa, as well as in South Asia. Scant attention has been given to issues surrounding the burden of care for paediatric cases. Among the infants, children, and adolescents who do not succumb to HIV infection and AIDS, many will lose one or both parents due to AIDS. WHO projects that by 1999, 5–10 million children aged 10 years and younger worldwide will have lost either their mother or both parents to AIDS. Adolescents are being infected in increasing numbers, with the WHO estimating that 60 per cent of new infections occur in the 15–24 age group. This article stresses the devastating effect that AIDS has not only upon AIDS orphans, but to all children and society at large.

Gow, J. & Desmond, C. (2002). *Impacts and interventions: The HIV/AIDS epidemic and the children of South Africa*. Pietermaritzburg: University of Natal Press.

Commissioned and funded by UNICEF, this book is a compilation of the most current statistics and analyses of the impacts of the HIV/AIDS epidemic on the children of South Africa.

Over 5 million South Africans are infected with HIV/AIDS. By 2010, it is estimated that, of the 18 million children in South Africa, 3 million will be orphans. These least powerful members of our society will experience parental loss, household upheaval, increased poverty and, for those unfortunate enough to be infected themselves, death as a result of the HIV/AIDS epidemic.

This text provides a comprehensive discussion of current interventions and their effectiveness in addressing the situation. With contributions from leading researchers in the field, it is likely to become an important resource manual for those wishing to gain an understanding of how HIV/AIDS impacts on children and what we're doing about it. Authors, including Rob Dorrington, Sonia Giese, Deborah Ewing, as well as HEARD Research Fellow, Chris Desmond and Research Associates Peter Badcock-Walters, Rose Smart and Jeff Gow, examine and critique the responses of families, communities, civil society and especially governments to the crisis confronting children and offer alternatives which may assist in alleviating these impacts.

Grainger, C., Webb, D., & Elliott, L. (2001). *Children affected by HIV/AIDS: Rights and responses in the developing world (Rep. No. 23)*. London: Save The Children.

The impacts of HIV/AIDS on children; key determinants of need; the direct impacts; the impacts on children's welfare and development; gender and the impacts of HIV on children; a rights-based approach to mitigating the impacts of HIV/AIDS on children; the relief approach; integrating a rights-based approach; programme approaches to caring for children affected by HIV/AIDS; community-based approaches; multi-sectoral and sectoral approaches; integrating prevention, care and impact mitigation activities; the role of government; monitoring and evaluation

Green, K. (2003). *Mobilizing community care for vulnerable children in rural Cambodia*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.aspl>].

By 2005, almost 8 per cent of Cambodian children under age 5 will be social support structures fragile, limiting options for protection of vulnerable members of society. Few grandparents are still alive, and many parents are themselves orphans. Forced labour, neglect and property grabbing are serious problems for orphaned children, particularly girls.

Village child advocates and government staff work in partnership to build the capacity of the government and community in better caring for vulnerable children in rural high prevalence areas. Action research, communal problem identification and solving, and advocacy techniques are employed to bring about a greater level of awareness and response. As a result, children identified as vulnerable by their village do not pay school fees, and are able to participate in vocational training and apprenticeship programs. Children in Distress teams meet with vulnerable children regularly, provide counselling and emotional support, and work closely with home-care teams to help parents plan for their children's future. Children also participate in groups run by local youth where they play games and learn about their health. A community advisory board made up of opinion leaders mobilises human and financial resources from skilled and/or wealthy community members, and advocates for improved local child welfare policies.

Lessons learnt: Community mobilisation is essential for sustained response to the rights and needs of vulnerable children. However, the process is slow and more challenging in less settled communities. Local advocacy efforts were ineffectual at challenging land and property grabbing.

Expand advocacy efforts to national level, with a focus on land and property rights. Work closer with other child protection agencies to reach a greater number of vulnerable children.

Greene, M. F. *What will become of Africa's AIDS orphans?* 12–22–2002. Available online: <http://www.nytimes.com/2002/12/22/magazine/22ADOPTION.html>

Gregson, S., Garnett, G. P., & Anderson, R. M. (1994). Assessing the potential impact of the HIV-1 epidemic on orphanhood and the demographic structure of populations in Sub Sahara Africa. *Population Studies*, 48, 435–458.

Much of the debate on the demographic consequences of the HIV epidemic in sub-Saharan Africa has so far centred around the plausibility of population declines in areas where unprecedentedly high rates of population growth have recently been in evidence. In this article, the authors use a mathematical model, which combines epidemiological and demographic processes, to illustrate how, under a broad range of impacts on population growth, major changes in demographic features, such as the extent of orphanhood within populations, are likely to occur. At the same time, HIV epidemics are liable to cause significant shifts in the age and sex composition of affected populations, which may have important implications for the ways in which they are best able to cope with the increases in orphanhood, as well as those in infant, early childhood and adult mortality.

Grimsrud, B. (2001). *What can be done about child labor? An overview of recent research and its implications for designing programs to reduce child labor.* (Social Protection Discussion Paper No. 0124). Washington, DC: World Bank.

This paper examines the research on child labour and places the phenomenon in a broader development agenda. It explains the demand for and supply of child labour, linking these factors to others such as the supply of education. Then it looks into the private and social costs of and benefits from child labour. Against this background, strategies for reducing child labour are debated.

Guest, E. (2001). *Children of AIDS: Africa's orphan crisis*, 1st edition. London: Pluto Press.

This volume explores the reasons that the world's poorest continent has been so badly affected by AIDS, and examines how families, charities, and governments are responding to the next wave of the HIV AIDS crisis – millions of orphans.

The author poses the question of whether the streets of Africa will be filled with angry, sad and antisocial children, or will homes be found for these children. She examines how the traditional extended family will be stretched to its limits, that orphanages will not be the answer to the problem, and how the wider community will have to become involved in the care of these children.

The author's thoughts are interspersed with true stories of orphans, street children, grandparents, aunts, foster parents and charity and social workers from South Africa, Zambia

and Uganda. The book questions what will happen to the minds of a generation that will grow up alone, poor and stigmatised.

- Gurdin, P. & Anderson, G. R. (1987). Quality care for ill children: AIDS-specialized foster family homes. *Child Welfare*, 66, 291–302.

Children with AIDS and related complexes present a new and serious challenge to the child welfare field's foster care system. At this stage of the world's knowledge of AIDS and treatment capacity for its victims, the children are stigmatised as plague bearers, their viability is unknown, and few, if any, will ever have a home to return to. This article describes a special foster care demonstration on behalf of AIDS infants.

- Gwadz., M. (1998). *New caregivers of adolescents whose parents died of AIDS: Impact and intervention strategies*. Presentation at the Sixth Annual NIMH Conference on The Role of Families in preventing and adapting to HIV/AIDS. Washington, USA, 29–31 July 1998.

- Halkett, R. (1998). *Enhancing the quality of life for children without parents in the South African context*. Conference on 'Raising the orphan generation' organised by CINDI, Pietermaritzburg, 9–12 June, 1998.

There is no quick or easy solution to the enormous problem of meeting the needs and care of children who will be orphaned as a result of the HIV/AIDS epidemic. As it is our children are under attack from widespread poverty and broadly speaking it is difficult to separate the two issues – poverty and orphanhood. Nevertheless, we must look to the future and try our best to find ways to help the increasing number of children who will be without parents – both orphaned and abandoned. The enormous benefit of a conference such as this is that we can share information and ideas and lighten our individual loads a little.

The Child Welfare Movement has indicated a need for information and guidance on the matter of children and HIV/AIDS and National Council has accordingly been collecting data and reviewing literature on the topic for sometime. The intention is to compile and publish two documents; one on care options in the present South African circumstances; the other, guidelines for the placement of children with HIV/AIDS. These have yet to be completed.

The work done thusfar however does allow us to share with you some of the insights gained from the literature as well as some thoughts of our own on what to consider when developing additional care options. The underlying belief of this paper is that the Child Welfare Movement is well placed to make a valuable contribution toward the care of these children.

- Halkett, R. (1999). *HIV/AIDS and the care of children*. Braamfontein: South African National Council for Child and Family Welfare.

The National Programme: HIV/AIDS and The Care of Children, developed by this Council in 1999, had as one of its aims the facilitation of community-based care for children. The piloting of the programme in the Eastern Cape and the subsequent national replication confirmed our position with regard to HIV/AIDS-affected children. It demonstrated the necessity of providing for the various needs of these children within a developmental paradigm and community context by the application of community mobilisation methodology. Community-based care for children can be defined in many ways, but it is our communities, that will, with their support and participation, determine our children's care. Child Welfare as change agent is ideally positioned to facilitate the process of community driven programming and projects to ensure our children's care and protection.

Our second publication 'HIV/AIDS and the care of children: Policy and practice guidelines' was published in 2003. It contains Child Welfare's position and policy on the care of HIV/AIDS-affected children and offers some practice guidelines for programme and project development.

- Hall, N. & Samuriwo, P. (2002). *Children affected by HIV/AIDS: Dissemination workshop report*. Arcadia, South Africa: Save the Children (UK).

This report on a two-day dissemination workshop hosted by Save The Children (UK) discusses the purpose of the workshop, the range of studies presented and the themes that were workshopped. The six sessions covered the following topics:

- Session 1: The role of stigma and discrimination in the increasing vulnerability of children and youth infected and affected by HIV/AIDS.
- Session 2: Research proposal on child sexual abuse (South Africa, Namibia).
- Session 3 Awareness vs behaviour change: Developing the responses of young people to HIV/AIDS in South Africa.
- Session 4: Mechanisms for identifying CINDI ('Children in Distress').
- Session 5. Children , HIV/AIDS and the law.
- Session 6: Desk duty on sexual behaviour and reproductive health of children and youth in Zimbabwe.

Harber, M. (1998). *Developing a community-based AIDS orphans project: A South African case study*. Conference on 'Raising the orphan generation' organised by CINDI, Pietermaritzburg, 9–12 June, 1998.

This research is part of a larger study which looked at three different models of care and support for children affected by HIV/AIDS developed in the Pietermaritzburg area. The research looked at new approaches to the promotion of adoption and fostering for children separated from their families as well as the community-based approach which is presented here. This paper looks at the implications of policy change at a practice level. It traces the experience of the project of one NGO, the Thandanani Association – the AIDS Orphans Project – and explores what it meant for this organisation to change its approach from 'doing welfare' to 'doing community development'. The research was undertaken in 1996/1997, which was the first year of the project's life. The research was qualitative in nature and used a case study approach. The data was collected through a number of different methods, including participant observation, interviewing and use of documentary sources.

Harber, M. (1999). *Models of care for AIDS orphans: Lessons from sub-Saharan Africa*. University of Natal, Durban: Centre for Social & Development Studies.

Harber, M. (1999). Transforming adoption in the 'new' South Africa in response to the HIV/AIDS epidemic. *Adoption and Fostering*, 23, 6–15.

This article presents the results of research on the dilemmas faced by, and achievements of, one child welfare agency as it attempted to adapt the western model of adoption prevalent in South Africa in order to create a more appropriate service for black South African children.

Harrison, K. J., Edstrom, J., & Ly Chan, S. (2003). *Supporting NGOs to develop locally appropriate indicators for work with orphans and vulnerable children*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

Children are affected by AIDS in a variety of ways. It is difficult to establish the numbers of vulnerable children, to keep track of the support provided, and to decide if they are benefiting. KHANA, a partner of the International HIV/AIDS Alliance, brought over 30 Cambodian NGOs together to share experiences and identify strategies for work with children. This included reviewing and adapting indicators suggested by USAID for evaluation of OVC programmes. Locally appropriate indicators, types of intervention and potential quality assurance standards were developed. NGO collaboration: Strong relationships have been developed through the common relationship with KHANA, which leads to greater willingness and ability to share strategies. Developing a shared concept of 'vulnerability': this was greatly facilitated by the NGOs' involvement in a participatory appraisal of children's needs in 2000. Addressing the challenges of using both quantitative and qualitative indicators: the USAID indicators emphasise the importance of measuring numbers of children who have benefited from the interventions. Workshop participants discussed how to decide if a child has benefited or not. Adapting the examples provided by USAID: Innovative approaches were used for adaptation. Participants were split into groups and worked on the indicators, types of intervention and possible quality assurance standards for different aspects of the OVC work. Recommendations were shared at a plenary session. Alliance-building: KHANA worked closely with USAID mission staff on the adaptation exercise.

Technical support for indicator development should include the development of systematic approaches to monitoring and evaluation of OVC work. The challenge is to ensure

consistency and comparability across programmes, and to maintain the focus on the benefit to children.

Harvey, P. (2003). *HIV/AIDS: What are the implications for humanitarian action? A literature review*. Draft 1. Overseas Development Institute.

The impact of HIV/AIDS in sub-Saharan Africa is already devastating and will continue to be so for decades to come, as demonstrated by the fact that 2.4 million Africans are estimated to have died of HIV/AIDS in 2002 alone. This report reviews the growing literature on HIV/AIDS and food security, examines where emergency relief should be situated within the wider response to the HIV/AIDS epidemic and considers how humanitarian aid agencies need to take HIV/AIDS into account in the programming of emergency aid.

Hasewinkel, S. (1999). *Proposed models of services to children made vulnerable by HIV/AIDS*. Cape Town Welfare Society.

HEARD (2003). *A scientific meeting on empirical evidence for the demographic and socio-economic impact of AIDS: Conference programme and abstracts*. Held on 26 March 2003, Durban, South Africa.

Heitzmann, K., Canagarajah, R. S., & Siegel, P. B. (2001). *The source of vulnerability: A rationale and guideline for the assessment of risks and risk responses*. (Prepared for the Social Protection Discussion Paper series). Washington, DC: World Bank.

Social risk management (SRM) is a new means of looking at poverty, risk, and risk management that was recently presented in the World Bank's Social Protection Strategy Paper. The SRM perspective addresses how vulnerable households can be helped to better manage risks and become less susceptible to potentially damaging welfare losses. This paper provides some basic concepts and guidelines for organising ideas and information that are relevant to risk and vulnerability assessments. Several templates are provided in the Annex, along with a list of completed and ongoing World Bank reports that investigate risk and vulnerability.

Henry, K. (2000). Building community-based partnerships to support orphans and vulnerable children. In *Impact on HIV*, Vol. 2, No. 2. Published by Family Health International.

As the growing number of children losing parents to AIDS overwhelms fragile social safety nets, many believe that strengthening community-based efforts is the only hope for building effective, sustainable support systems for orphans and other vulnerable children.

Hepburn, A. (2001). *Primary education in Eastern and Southern Africa: Increasing access for orphans and vulnerable children in AIDS-affected areas*. Masters dissertation submitted to Duke University.

This research and analysis assesses national and community-level initiatives that have the potential to increase primary education access for children who have been orphaned (or made vulnerable) in areas heavily affected by AIDS in the eastern and southern Africa region (ESAR). This assessment analyses various initiatives to learn lessons that can be used to more effectively target resources to increase primary education access for orphans and other vulnerable children in this region.

Holzmann, R. & Jorgenson, S. L. (2000). *Social risk management: A new conceptual framework for social protection and beyond*. (Social Protection Discussion Paper No. 0006). Washington, DC: World Bank.

This paper proposes a new definition and conceptual framework for social protection grounded in social risk management. The concept repositions the traditional areas of social protection (labour market intervention, social insurance and social safety nets) in a framework that includes three strategies to deal with risk (prevention, mitigation and coping), three levels of formality of risk management (informal, market-based, public) and many actors (individuals, households, communities, NGOs, governments at various levels and international organisations) against the background of asymmetric information and different types of risk. This expanded view of social protection emphasises the double role of risk-management instruments protecting basic livelihood as well as promoting risk taking. It focuses specifically on the poor since they are the most vulnerable to risk and typically lack appropriate risk-

management instruments, which constrains them from engaging in riskier but also higher return activities and hence gradually moving out of chronic poverty.

Hope For African Children Initiative (2001). *Hope for African children initiative: About the initiative*. [Available on line: <http://www.hopeforafricanchildren.org/about.htm> [Announcement posted on the World Wide Web. 1–11–2001]

The Hope for African Children Initiative is a community-based, pan-African effort created to address the enormous challenges faced by more than 13 million children who have been orphaned by the AIDS pandemic in Africa and the millions more whose parents are sick or dying of AIDS-related illnesses. Established in the summer of 2000, this unique partnership brings together five organisations that share an international focus – CARE, Plan International, World Conference on Religion and Peace, Save the Children and the Society of Women and AIDS in Africa – with the purpose of increasing the capacity of African communities to provide care, services and assistance to children affected by HIV/AIDS and their families.

Last year the Hope for African Children Initiative received a planning grant from the Bill & Melinda Gates Foundation that enabled partner organisations to identify and build on a variety of existing community-based programmes that offer proven and cost-effective services to children whose lives have been affected by HIV/AIDS. By joining together in this endeavor, the five partner organisations have expanded the scope of their combined efforts on AIDS far beyond what any one of them could ever achieve individually. Each partner in the initiative brings to it unique strength, technical expertise, as well as important constituencies on the ground in Africa.

Horizons (2003). *Succession planning in Uganda: Early outreach for AIDS-affected children and their families – Research Summary*. Washington, DC: Horizons Program

Uganda has been widely recognised for lowering HIV incidence (Asimwe-Okiror et al. 1997; Hogle 2002). However, because so many adults were previously infected and given the long period between HIV infection and death from AIDS, the number of orphaned children is still rising. By the end of 2001, there were 880 000 children under the age of 15 living in Uganda who had lost one or both parents to HIV/AIDS (UNAIDS 2002).

But these orphans represent only the tip of the iceberg, since there are many more vulnerable children whose parents are alive but living with HIV infection. Evidence suggests that the negative impacts of HIV/AIDS affect children long before parents die, beginning when a parent's health starts to decline (Gilborn et al. 2001). Yet few programmes exist to help families before a parent's death, and there is little research on the effectiveness of existing programmes for AIDS-affected children.

Findings from this study suggest that succession planning is a promising approach for increasing the extent to which HIV-positive parents take action to ensure a better future for their children, particularly in terms of appointing guardians and talking to their children about being HIV-positive.

Human Rights Watch (2001). *Kenya: In the shadow of death: HIV/AIDS and Children's Rights in Kenya*. (Rep. No. 4(A), Vol. 13). Human Rights Watch, Children's rights division.

Because HIV/AIDS so often impoverishes and stigmatises the children it affects, and claims the lives of so many in their extended family, these children are at high risk of having to eke out livelihoods on the street or in other potentially dangerous situations. AIDS-affected children face many obstacles to staying in school and thus to fulfilling their right to education. They are further disadvantaged in many cases by the unscrupulous and unlawful appropriation of property they are entitled to inherit from their parents, and in Kenya they are rarely able to take legal action to protect their inheritance rights. These factors together place at risk the realisation by AIDS-affected children of their right to survival and development, which the government has an obligation to ensure 'to the maximum extent possible' under the United Nations Convention on the Rights of the Child. These problems are compounded in Kenya by apparently poor access of children and young adults to appropriate and clear information about HIV/AIDS, which puts children at risk of being unable to protect themselves from HIV transmission. Children have the right to survival; physical, social and

cultural development; health; and education. These rights are guaranteed under the Convention on the Rights of the Child, the International Covenant on Civil and Political Rights, and the African Charters on Human and Peoples' Rights and on the Rights and Welfare of the Child, all of which Kenya has ratified. Kenya is far from alone in needing to strengthen protection of AIDS-affected children. Governments around the world have neglected the consequences of AIDS on children and have failed to provide the necessary protections of their rights to survival and development. This failure is one of the most pervasive and lasting crises of the HIV/AIDS catastrophe, and it must be addressed with the greatest urgency.

- Human Sciences Research Council (2002). *The orphans and vulnerable children project: Baseline survey and multi-sectoral assessment of vulnerable households, key health problems, risk behaviour and poverty*. Cape Town: HSRC.
- Human Sciences Research Council (2002). *Strategy for the care of orphans and vulnerable children in Botswana South African and Zimbabwe*. Document prepared for WK Kellogg Foundation. SAHA and Child Youth and Family Development, Human Sciences Research Council.
- Hundeide, K. (1991). *Helping disadvantaged children. Psycho-social intervention and aid to disadvantaged children in third world countries*, 1st edition. London: Jessica Kingsley Publishers.
- All over the world there are children who have been victims of the silent process of neglect and deprivation of human contact and stimulation, very often combined with malnutrition. Their problem has been largely ignored by most agencies working with children. These children can be found everywhere, in the technically more developed cities of the western world as well as in the slum areas of the third world. This book describes intervention and research related to disadvantaged children in different parts of the world. It is concerned with developing an early psycho-social intervention programme that is applicable to all caregivers and children. It brings the importance of the education of the human potential into the development debate.
- Hunter, S. (1994). *National assessment of families and children affected by AIDS*. Draft report to the Tanzania AIDS Project.
- Hunter, S. (1998). *Essential documents: Zimbabwe orphan support programmes*, cited in 'Community-based orphan assistance in Zimbabwe: Developing and expanding national models by building partnerships with NGOs, CBOs, and the private sector'. Draft report of an assessment of UNICEF Programming in Zimbabwe for Families and Children Affected by HIV/AIDS. 30 September 1998.
- Hunter, S. (1999). *Draft Report of UNICEF's Project to expand programming for families and children affected by HIV/AIDS*. New York: UNICEF.
- Hunter, S. (1999). *Building a future for families and children affected by HIV/AIDS*. Geneva: UNICEF/UNAIDS.

This article is a presentation of the various orphan management systems that are to be undertaken by governments, NGOs, communities and families. Health and social problems of children living in a world with AIDS, international policy response to the need for systems of care for children affected by AIDS, strategy development and systems design on the macro level, orphan estimates and data development are explored. The progress made to date by children, families, communities, governments and partners in finding solutions to these issues and identification of challenges faced by communities threatened by HIV/AIDS is also discussed.

The first section of this document summarises health and social problems of children living in a world with HIV/AIDS, both those arising from the pandemic and those arising from the broader social and economic context in which orphans, families and communities found themselves prior to the pandemic's outbreak. The more problematical of these contextual issues are tackled in the last section of the report, which describes future policy and system design challenges facing governments and partners in heavily affected countries.

The second section describes the international policy response to the need for systems of care for children affected by HIV/AIDS. The third and fourth sections of the chapter speak to

strategy development and systems design on the macro level, and outline the major roles and challenges faced by the two principal levels of orphan 'management'. Other issues of systems design (providing care for HIV-positive children, street children) are also addressed. In the fifth section, the issue of orphan estimates and data development is explored.

The sixth section describes the progress made to date by children, families, communities, governments and partners in finding solutions to these issues. Taking these responses to scale in building systems of orphan management is addressed in the seventh section. Finally, the last section of the chapter identifies additional challenges facing communities threatened by HIV/AIDS.

Hunter S. (2000). *National systems and strategies for the provision of care to HIV/AIDS affected adults and children*. (Presented at the UNAIDS Workshop on the Role of Debt Relief in Financing National HIV/AIDS Programs). Lilongwe, Malawi.

Hunter, S. (2000). *Reshaping societies: HIV/AIDS and social change – A resource book for planning, programs and policy making*. New York: Hudson Run Press.

Hunter, S. (2000). *Orphans and other vulnerable children: A framework for programming*. Synergy Project Draft Report.

Hunter, S. (2002). *Supporting and expanding community-based HIV/AIDS prevention and care responses: A report on save the children (US) Malawi COPE Project*. (Social Protection Discussion Paper No. 0211). Washington, DC: World Bank.

In 1995, Save the Children/US- Malawi introduced a small pilot project called COPE (Community-based Options for Protection and Empowerment) to provide direct services to prevent and mitigate the impact of HIV/AIDS on children, families and communities in district. Over the past six years, the program has evolved and expanded to four districts, covering 9 per cent of the national population. The goal of COPE is to mobilise sustainable community action utilising existing indigenous social infrastructures and a three tier structure – District AIDS Coordinating Committees (DACCs), Community AIDS Committees (CACs) and Village AIDS Committees (VACs). The program is multi-sectoral and involves partnerships with government, business communities, local leaders, other NGOs/CBOs and religious organisations. Programme success and challenges included.

Hunter, S. & Donahue, J. (1997). *HIV/AIDS orphans and NGOs in Zambia: Strategy development for USAID/ Zambia Mission programming for family and community care of children affected by HIV/AIDS (Research Report)*. Washington, DC: USAID

The HIV/AIDS epidemic in Zambia is one of the worst in sub-Saharan Africa. Data from the 1994 national seroprevalence survey estimated overall urban infection levels at 28.2 per cent among women of childbearing age and rural infection rates of 12.9 per cent in the same population. This study looks at the rates of orphaning and points out that the household survey data suggests that the higher NASTLP estimate of 1.8 million orphaned children, or the United States Census Bureau estimate of 1.6 million, better represent the current reality in Zambia.

At the level of social needs and services, the study notes that findings from other countries have demonstrated that children under five who are maternal or double orphans run a higher risk of sickness and are less likely to get immunisations, while paternal orphans of school-going age are at greater risk of lack of education. Double orphans are potentially the most vulnerable, but maternal orphans left with little or no resources following the death of their father also face serious disadvantages. The study reviews orphan living arrangements and indicates that most families expect care for orphans to be provided within the immediate family. The needs of orphans are threefold: 1. the needs of households in poverty-food, shelter, bedding and clothing; 2. the general needs of children under age 15-health, schooling; and 3. the needs of children aged 15 and above for access to work.

Households rely extensively on the labour of children aged 5–11 for cleaning, food preparation, childcare for siblings, gathering food and firewood, carrying water, and farming tasks. Two to three times more girls than boys are required to do household chores, with the

exception of farming activities, gathering and chopping firewood, tending livestock and hunting. Few young children attend to the sick (6 per cent of boys and 8 per cent of girls), although rural children are twice as likely as urban children to help in this area.

If the proportion of households with orphans has increased rapidly since the beginning of the decade, so also has the community response. NGO, CBO and governmental assistance programmes for families and children affected by AIDS are probably more numerous in Zambia than in any neighbouring country. In this area, Zambia is a leader whose experiences challenge other countries to action.

This study also looks at coordination networks, the integration of income-generation with health interventions, and government responses.

Hunter, S. & Fall, D. (1998). *Orphan programming in Zambia: Developing a strategy for very young children in Zambia: Report of an Assessment of UNICEF programming in Zambia for children and children affected by HIV/AIDS*. Report of an Assessment of UNICEF Programming in Zambia for Children and Children Affected by HIV/AIDS. Lusaka: UNICEF.

Following the 1997 World AIDS Day release of the 'Children on the Brink' report, UNICEF decided to assess and intensify its programming efforts for families and children affected by HIV/AIDS. In order to accomplish this goal it set out to document its programming effort to date, develop tools to intensify programmes, and initiate or expand them to scale in 19 of the most heavily affected countries in sub-Saharan Africa. As part of this strategy, a consulting team – which had earlier worked with UNICEF offices in Malawi, Uganda, South Africa, Zimbabwe and Botswana – visited Zambia in July 1998 with a view to 1. documenting the status of programming for families and children affected by HIV/AIDS; (2) assisting in developing a programming assessment for Zambia; 3. investigating the potential for regional network development; 4. assisting UNICEF (Zambia) in assembling the plans and resources needed to expand their current programmes; and 5. participating in a national programme consultation on child abuse, orphans and street children.

Noting that the AIDS epidemic in Zambia is one of the worst in the world, the report draws attention to the 'Children on the Brink' finding that the proportion of children in Zambia who are orphans (missing one or both parents) is the highest of any of the countries that have been studied, being estimated to stand in 2000 at 34.3 per cent or 1.657 million children. Moreover, the proportion of children orphaned by the AIDS epidemic will continue to increase at least through 2010 and will remain unusually high through at least 2030. The report also notes that the vast majority of orphans in Zambia are still being absorbed by the extended family, but saw signs of the strains being placed on this social arrangement by such phenomena as the growing number of street children.

Constraints and weaknesses which hinder the ability of Zambia's institutions to respond to the AIDS epidemic and to the needs of affected families and children are identified at both the contextual and programming levels. The former include the high levels of poverty; the pervasive and chronic child malnutrition (half of all Zambian children are stunted); declines in child health and increases in child mortality; low primary-school attendance rates and inadequate provision for early childhood education; the under-funding and low capacity of the Public Welfare Assistance Scheme and other safety nets; and the relatively high incidence of child abuse. Programming weaknesses refer to limited and uneven NGO coverage; poor coverage in rural areas (notwithstanding their greater vulnerability); lack of information on the extent of provision of health, education and welfare systems for 0–7 year-old children; the need to strengthen capacity in government ministries, to co-ordinate the national response to the problem, and to improve the quality of monitoring systems; and lack of sound information on the nature and extent of the involvement of the commercial private sector.

The report notes that NGO, CBO and government assistance programmes for families and children affected by AIDS are probably more numerous in Zambia than in any neighbouring country. This has given rise to numerous programming strengths: especially good data describing the extreme vulnerability of children and their families; committed communities which manifest high levels of altruistic concern; an ever-increasing number of NGOs and

CBOs with greater ability to respond to the needs of families and children; churches of all denominations which have a strong sense of responsibility and good programmes; a nascent national co-ordinating body (the Children in Need Network – CHIN); commitment to the development of a national strategy; strong government commitment to improving programming for families and children affected by AIDS; an ongoing national policy review to examine and consolidate child law; the establishment of grassroots Public Welfare Assistance Committees, especially in rural areas; the growing community school movement; keen donor interest and support; strong support for income-generating activities; some mapping experience to determine the extent of programme coverage; and a co-operative strategic planning exercise to identify programming opportunities for the coming five years.

The report further considered the need for programme expansion, the development of funding (from both internal and external sources), the existing regional networks, best practices, and lessons learned. Discussion of its findings with UNICEF (Lusaka) Child Protection and Education staff yielded a number of recommendations for immediate action. These were based on the recognition of the extreme vulnerability of children in Zambia, the way this vulnerability is increasing rapidly as a result of high AIDS mortality, and the danger of a sudden further deterioration in child health and well-being. The salient recommendations for UNICEF were to expand co-operation with all partners; to work with other organisations to map the availability of services for affected families and children; to review protection mechanisms, relating to health, education and social well-being, for very young children; to examine the potential of community schools to provide auxiliary programmes in early childhood care or nutrition for children aged 0–7 years; to build monitoring and evaluation approaches for community-based initiatives; to include grief counselling for children and adults in its programme for the training of counsellors; to identify, and where feasible co-ordinate, all programmes currently receiving support for orphans and other vulnerable children; and to explore with partners how the vulnerabilities of children and their rights vary by circumstance and cause of vulnerability.

Finally, the report identified a number of data and research needs, including more updated orphan estimates (with a strong recommendation that future national censuses gather the necessary information); improved estimates of other categories of vulnerable children; the completion of an inventory of service providers and service populations; the elaboration of models of community coping strategies; the development of guidelines to assist communities in accessing resources of other programmes, especially income-generating projects; and the integration of research findings into training for service providers and volunteers. In all cases, community participation in research and data gathering should be encouraged. Responding to this programme of action calls for the expansion of the research capability in Zambia with a capacity to undertake short-term operational research and produce quick and easy-to-understand reports for use by concerned bodies.

Hunter S. & Williamson, J. (1997). *Developing strategies and policies in support of HIV/AIDS infected and affected children*. Arlington, VA: The Pragma Corporation, USAID HIV/AIDS Division.

Hunter S. & Williamson, J. (1998). *Responding to the needs of children orphaned by HIV/AIDS: Discussion paper on HIV/AIDS Care and support*. (Discussion Paper No. 7). Washington, DC: USAID.

Hunter, S. & Williamson, J. (2000). *Children on the brink: Executive summary. Updated estimates and recommendations for intervention*. Washington, DC: USAID.

The scope and complexity of the challenges facing children affected by HIV/AIDS cannot be overstated; they are more likely to drop out of school, contract HIV, or be forced to work in order to survive. USAID is working diligently to improve the safety, health and survival of these children. The first 'Children on the Brink' report – published by USAID in 1997 – elicited a remarkable response and helped to break the silence about HIV/AIDS worldwide. 'Children on the Brink 2000' builds on that legacy. This report should serve as a call to action for developed and developing nations alike.

'Children on the Brink 2000' is an update to a publication released by USAID in 1997 entitled 'Children on the Brink: Strategies to support HIV/AIDS', and included the most

comprehensive global estimates of the effects of HIV/AIDS on the world's children at that time. In the two and a half years since the first 'Children on the Brink' report was published, over 5 million adults have died from HIV/AIDS, leaving at least that many new orphans. 'Children on the Brink 2000' updates the estimates from the 1997 publication and stresses that the fundamental messages presented in the original report are still valid.

Hunter, S. & Williamson, J. (2002). *Children on the brink. Strategies to support children isolated by HIV/AIDS*. Washington, DC:USAID.

In countries across Africa, Asia and Latin America, HIV/AIDS is unravelling years of progress in economic and social development. Life expectancy – which has been steadily on the rise for the last three decades – will drop to 40 years or less in nine sub-Saharan countries by the year 2010. In all 23 countries included in this study, AIDS-related mortality will eliminate the gains made in child survival over the past 20 years. In Zambia and Zimbabwe, infant mortality rates will likely nearly double, and child mortality rates will triple. The economies of the developing nations in this study will all struggle to deal with the immense economic dislocation and costs of illness, death and lost opportunity. And while the bulk of countries in this study are in Africa, this report should also serve as a grave reminder of similar storm clouds gathering now in Asia and Latin America, and of the terrible toll the HIV/AIDS crisis will claim on those continents' children. This report provides a compelling demographic portrait of an immense problem. However, more important than the numbers contained in this study is the human story they tell. Forty million children losing one or both of their parents are 40 million more children likely to be forced into child labour; 40 million children who may never have an opportunity to attend school; and 40 million children more at risk for contracting HIV. This study should serve as a call to action for developed and developing nations alike.

Hunter, S. S. (1990). Orphans as a window on the AIDS epidemic in sub-Saharan Africa: initial results and implications of a study in Uganda. *Social Science and Medicine*, 31, 681–690.

A Save the Children survey of four Ugandan districts (Rakai, Masaka, Luwero, and Hoima) found that there were between 620 000 to 1 200 000 orphans in the country. During 1989 village-level Resistance Committees (RCs) enumerated 40–60 per cent of orphans in each district. In Rakai there were 25 364 cases, or 12.8 per cent of children under 18. In Hoima the number was 9 524, or 4.4 per cent of children under 18. Thus, it is estimated there are between 397 534 to 1 157 367 orphans in Uganda. Rakai had 6 per cent of AIDS cases, 23 per cent of children missed both parents vs. 12 per cent in Hoima, and 65 per cent of parents died since 1986 vs. 44 per cent in Hoima. Mortality was higher among orphans due to intra-uterine transmission to AIDS. Forty-three per cent of guardians were over 50 in Rakai vs. 17 per cent in Hoima; 31 per cent of children were cared for by grandparents in Rakai vs. 18 per cent in Hoima. These differences were caused by the higher incidence of AIDS in Rakai. Other relatives took care of 54 per cent of children in Rakai and 47 per cent in Hoima. A questionnaire assessed community characteristics and resources including water, education and health. Guardians tended to be too old or too young; and there was an acute need for food, blankets, beds and clothing. These disadvantaged orphans left home early and those over 8 had a high rate of delinquency. The traditional fostering system in Uganda has absorbed these children whose parents died or left as a result of AIDS or war. A longitudinal baseline study is needed to analyse the changes of this fostering system calling for the moral resources of action research.

Hyde, J. (1993). Changing concepts of the family: responses to HIV/AIDS and development. *Development*, 2, 22–24.

The idea of 'family' is a cultural concept which varies within and between societies. The 'nuclear' family is a relatively new concept, yet its legitimisation is so strong that, although the majority of families have assumed other configurations, the nuclear family is the norm which many people strive for. Along with others outside of the norm who seek legitimacy, the gay community has overcome tremendous obstacles and has become more economically, culturally, and socially visible. In some countries this has led to immigration and pension

rights for gay people as well as to marriage and partner recognition. As the gay community has begun to develop families of choice, its response to the HIV/AIDS epidemic has been to develop a wide range of community-based organisations such as the Victorian AIDS Council/Gay Men's Health Care Centre in Melbourne, Australia, which provides a significant focus for health and other issues and works with other affected communities to offer a programme of health promotion and home care. The strength of community empowerment and development activities such as this in the South is actually threatened by the North's model of the 'traditional' family. International development agencies based in the North exhibit a considerable degree of homophobia and a poor understanding of HIV/AIDS. Community-based NGOs in the South exhibit a different response and clearly understand issues of empowerment and community development. For example, having an understanding of the importance of families of choice helps people make the proper decisions about the fate of AIDS orphans in Africa (keeping them in their community). The international community-based response to HIV/AIDS has benefited from the ability to work with and learn from diverse groups. In this regard, a fluid and changeable definition of family is essential for the success of efforts made to provide stability.

ICROSS (2003). *ICROSS – Long range strategic plan 2003–2007. (Evidence and rights based approach to creating change).*

Strategic directions:

- Develop and maintain partnerships based on shared goals and collaboration to create measurable change;
- Develop and implement, through long-term partnerships evidence and rights based approaches to reducing poverty and suffering;
- Create a dynamic proactive organisation that responds to the changing needs, problems, decisions and complexities of an uncertain future.

International HIV/AIDS Alliance (2003). *Forgotten families – Older people as carers for orphans and vulnerable children.*

This report by the Alliance and HelpAge International draws on evidence from programme experience in Africa and Asia in order to provide policymakers and other actors tackling the HIV/AIDS epidemic with:

- an overview of the issues identified by older people and orphans and vulnerable children themselves;
- good practice examples from community-based programmes that are improving the lives of older people and orphans and vulnerable children;
- recommendations to help prioritise orphans and their carers within HIV/AIDS and wider development policies, programmes and research.

Ireland, E. & Webb, D. (2002). *No quick fix: A sustained response to HIV/AIDS and children.* UK: Save the Children.

Challenge 1: Protecting the rights of children affected by HIV/AIDS: HIV/AIDS and children's rights. How children's survival and development is affected by the epidemic. Child-focused and rights based programming. Challenge 2: Expanding a sustained global response to HIV/AIDS: A crisis of support for the fund. The scope: the importance of the strengthening of health systems. Addressing the underlying factors contributing to the epidemic. No quick fix: increasing access to drugs through strengthening systems.

IRIN Plus News (2003). *ZAMBIA: Project reaches orphaned and vulnerable children.*

Jackson, H., Powell, G., Purcell, B., Mutsakani, B., & Manyenya, S. (1996). *Orphans on farms: Who cares? An exploratory study into foster care for orphaned children on commercial farms in Zimbabwe.* Harare: Southern Africa AIDS Information Dissemination Service (SAFAIDS) and Commercial Farmers Union (CFU).

The objective of this study was to explore the possibility of developing foster care for orphans on commercial farms in Zimbabwe, recognising that for a significant number of children no other viable option will exist.

The study team made use of individual and focus group interviews, focus group discussions, self-administered questionnaires, records analysis, and case studies. More than 150 branch delegates of the Zimbabwe Commercial Farmers Union completed a questionnaire that probed their assessment of the AIDS situation and their attitudes to supporting foster care on their farms. Household composition data were collected from ten selected farms in Mashonaland. On these same farms, focus group discussions were held with both male and female workers. Interviews were further held with key workers and groups of children. Farm owners were also interviewed both individually and in groups.

Sixty-five per cent of the farmers expressed willingness to support foster care on their farms, if this were necessary. The farm owners' principal concerns were directed to the cost of funding carers, the escalating numbers of orphans, and carers leaving the farms.

An in-depth study of farm workers on the ten selected farms revealed that their concerns focused not only on economic costs but also on cultural considerations. The workers indicated that they would not have problems in fostering if the farm owners adopted some formal responsibility for the children.

A major problem that emerged was that of instability among farm families. The children were almost entirely the woman's responsibility placing a heavy burden on her. It was also very difficult for paternal orphans to gain access to their father's employment-related benefits, and once the mother died, the children were in most cases left completely abandoned.

Interviews with selected groups of children revealed a general consensus that it was better for the children to stay on the farms, rather than to go elsewhere. The children also indicated a degree of personal acceptance for children unrelated by blood or kinship. The principal needs expressed by these children were for food, clothing, shelter, education, and love.

Notwithstanding the problems that families were experiencing, the study found that the extended family network was still functioning, with one-quarter of the households surveyed already caring for an orphan.

The investigation concluded that foster care on commercial farms in Zimbabwe is both necessary and possible. Findings from both the national survey and the in-depth study of farms provided an encouraging expression of support. However, to achieve sustainable fostering arrangements, major changes and developments would be needed in existing statutory monitoring and support for foster care. The study recommended that a national and local decentralised network be developed to disburse funds and to monitor the quality of care. It also identified the need for combined concerns and inputs of commercial farmers, farm workers, the department of social welfare, supportive donors and NGOs. Finally, to minimise administrative costs and to maximise the potential sustainability of long term foster care, the study emphasised the need to make full use of existing structures and personnel already on the farms.

Kalala, T. J. (2003). *OVC's benefit from networking amongst service providers*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. Available online: <http://www.aids2002.com/Home.asp>.

Networking amongst organisations providing services to orphans and vulnerable children has improved planning, use of resources and co-ordination, which have reduced gaps and overlaps in service provision. Forming and building capacities of multi-sectoral OVC committees at community and district levels have facilitated networking. The committees' roles include supporting information sharing, facilitating collaboration, and resource sharing amongst service providers. Information on areas of operation, numbers of OVC served, and type of services have revealed gaps and overlaps in services being provided to OVC. The committees call regular meetings of all stakeholders. The meetings are well received by all who are concerned with the well being of orphans and vulnerable children. *Lessons learnt:* Information sharing is the basis for quality co-operation. In one district four organisations paid school fees for the same 17 children at the same time. By networking they supported 68 additional children with school fees without extra cost. In another district, there was no organisation dealing with street children. A number of fake organisations were exposed and

forced to stop using children for personal gains. To greatly increase the number of OVC benefiting from services being provided and improve the quality of service to OVC stakeholders need to network and share information on a number of aspects of OVC work. For effective information sharing the organisations need to improve the quality of record keeping. It is recommended that continued restating of benefits of networking can enhance organisation commitment. Committed organisations will be able to share resources and undertake joint programmes for the benefit of OVC.

Kalembe, E. (1992). *Policy guidelines for the care of orphans in Malawi and co-ordination of assistance for orphans*. Blantyre: Task Force on Orphans.

Kalembe, E. (1998). *The development of an orphans policy and programming in Malawi. A case-study*. Conference on 'Raising the orphan generation' organised by CINDI, Pietermaritzburg, 9–12 June, 1998.

The problem of orphans is a significant national priority. This paper aims at critically reviewing these efforts to deal with this with a view to elaborating the policies and programming that have developed for the purpose of information sharing since many countries are just beginning to come to terms with the problem. Malawi has over seven years experience of facing the problem, but serious efforts of addressing it have only been in the last 3–4 years. The paper provides a macro-level overview of the problem only, as its emphasis is on the development of policy and how its been applied. A lot is already taking place at the grassroots level and has been documented elsewhere.

With one of the world's highest HIV infection rates, Malawi has taken the problem of orphans as a significant national priority and is making efforts to address the problems systematically. This paper critically reviews these efforts with a view to elaborating the policies and programming that has developed. It provides a macro-level overview of the problem that Malawi is experiencing, the emphasis being on the development of policy and how it has been applied.

The paper gives an outline of the orphans' situation in the country prior to HIV/AIDS. Through an overview of the AIDS situation in the country and its impact on children, this is then contrasted with the HIV/AIDS period. The paper then discusses the response to the problem with emphasis on the developmental approach. This is followed by a discussion of the factors that influenced the formulation of the orphans policy and an outline of the policy itself. A conceptual framework for use in other countries can be developed from this. A brief qualitative overview of the performance of the programme is given.

In conclusion, the paper states that the policy guidelines have proved a useful tool for programme management. They provide necessary guidance on crucial issues in orphan care. It further concluded that as the orphan phenomenon is dynamic, there is an ever-present need to adjust policies to respond to the changes.

Kamali, A., Seeley, J. A., Nunn, A. J., Kengeya-Kayondo, J. F., Ruberantwari, A., & Mulder, D. W. (1996). The orphan problem: experience of a sub-Saharan Africa rural population in the AIDS epidemic. *AIDS Care*, 8, 509–515.

During 1989–90 the Medical Research Programme on AIDS enrolled 4 975 children younger than 15 living in a cluster of 15 villages in rural Masake district, southwest Uganda, into a three-year prospective study. It examined the data to assess the magnitude of the problem of orphans and the extent to which HIV-1 is contributing to their problems. In this area, it is common for children with both parents alive to live with other relatives (e.g., grandparents) to help with domestic work. 518 (10.4 per cent) children had lost one or both parents. These orphans were more likely to have lost a father alone than a mother alone (6.3 per cent vs. 2.8 per cent). 67 (13 per cent) of the 518 orphans (i.e., >1 per cent of all children) had lost both parents. Orphans 0–4 years old and surviving parents of orphans were more likely to be HIV-1 infected than their counterparts (5.6 per cent vs. 0.9 per cent for non-orphans 0–4 years old; $p = 0.01$ and 15.4 per cent vs 6.2 per cent for parents of non-orphans; $p < 0.001$). During the follow-up period, 83 parents of previous non-orphans died, leaving 169 orphans. 42.6 per cent of the newly registered orphans had an HIV-1 positive parent. 98 deaths occurred among

HIV-1 negative children (7 orphans, 91 non-orphans). No significant difference in mortality rates among HIV-1 negative children existed. Yet, in the 0–4 year old age group, orphans had a higher, but insignificantly so, three-year mortality rate than non-orphans (22.1 vs. 15.6/1000 person-years). School attendance in the previous six months was slightly lower among orphans than non-orphans (75.5 per cent vs. 83.6 per cent) but the difference was insignificant ($p = 0.3$). Census data indicate that orphanhood has increased by at least 50 per cent in the last 20 years, probably due to the AIDS epidemic. These findings suggest that the community tends to care well for orphans, but if the HIV/AIDS epidemic continues this coping mechanism may become overly burdened.

Kampala, A., Whitworth, J. A. G., Ruberantwari, A., & Carpenter, L. M. (1997). *Impact of the HIV-1 epidemic on orphan mortality in a rural Ugandan population cohort*. Presented at the 'Sociodemographic impact of AIDS in Africa' Conference, organised by the IUSSP Scientific Committee on AIDS, in collaboration with the University of Natal, Durban, held in Durban, South Africa, 3–6 February 1997.

Kamya, H. (1997). Group work with children from HIV/AIDS affected families. *Journal of AIDS Prevention and Education for Adolescents and Children*, 1, 73–91.

Kanyi, S. K., Adam, A. S., Lubanga, S. M., & Dimba, R. O. (2002). *Communities mobilised in response to children orphaned by AIDS*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

Research studies put the current total number of orphans in Kenya at approximately 1 500 000 and about 2.6 million people are HIV positive and approximately 700 people die of AIDS-related illness every day. Recent statistics also revealed that life expectancy has been reduced to about 30 years. TAPWAK initiated an orphans support programme in mobilising financial and materials support for children orphaned by AIDS. Recently the project has received financial and capacity-building support from the Centre for African Family Studies. The co-ordinators work in collaboration with school headmasters and other community leaders to identify orphans in their communities. The headmaster is requested to write a letter of recommendation for assistance. Where applicable a guardian of the orphan is also requested to write a letter specifying the type of assistance required for the child, stating what the guardian's contribution is. Together with a school fee invoice, a recent photograph of the student is attached to the completed application form. Other relevant documents, including a copy of the parents' death certificates are also submitted. TAPWAK Programme Officers approach churches, business people, ordinary citizens, NGOs, politicians, some local celebrities and international donors and request sponsorship for any number of children they may wish to sponsor. The highlight of the project is that 25 orphans are now in school through the support of this project. *Recommendation*: In the present situation of high number of cases of HIV/AIDS infections and deaths being reported in Kenya, children feel the greatest pain as their parents and guardians succumb to AIDS. This has translated into many children being denied their basic rights. It is therefore very imperative that the community collectively takes the responsibility to offer foster parenting to these children and source for resources to take care of them and enable them lead wholesome

Kaseke, S. & Germann, S. (2002). *Facilitate psychosocial support for children affected by AIDS through Kids Clubs*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

With the scenario that up to 35 per cent of children might be orphans due to AIDS in several southern African countries by 2010, failure to support children to overcome trauma and grief related to HIV/AIDS will have very negative impacts on society and might cause dysfunctional societies, jeopardising years of investment in development. The paper demonstrates an innovative, youth-organised response to facilitate psychosocial support for over 4 500 children affected by AIDS through weekly Kids Clubs. The programme is based in the second largest city of Zimbabwe, Bulawayo. These clubs ensure a continuum of care and are complementary to community-based orphans support programmes. Salvation Army Masiye facilitated and trained youth in Bulawayo to start up and run this program. Through these clubs, ongoing

psychosocial support is ensured. A participative process, involving children, youth and other stakeholders such as city council officials has made this program very successful. This paper is based on personal experiences, working as a programme co-ordinator for Kids Clubs involving 150 youth volunteers and 4 500 children. Psychosocial support for children affected by AIDS is crucial to mitigate the long-term impact of AIDS on societies in southern Africa. With relatively low sophisticated, youth-run programmes there has been a significant increase in the quality of life for children affected by AIDS in urban Bulawayo. Involving youth in facilitating psychosocial support to children is not only an important community service but has shown to be a highly effective youth HIV/AIDS prevention strategy. This programme-based research recommends that all community care programmes for orphans should incorporate psychosocial support. This can be achieved by supporting youth to establish Kids Clubs for children affected by AIDS in every community across Africa.

Kaur, I. & Tzannatos, Z. (2002). *The World Bank and children: A review of activities*. (Social Protection Discussion Paper No. 0220). Washington, DC: World Bank.

This paper reviews World Bank interventions that supported the welfare of children in the last decade. Though the World Bank has always addressed children's development and protection through its focus of broader economic development and social protection, it has recently intensified its efforts to directly address children's issues in the context of a broader international effort to improve the general welfare of children and, more specifically, to reduce child labour. This paper focuses on human development projects with an objective relating to children or that are expected to have an indirect, but non-trivial impact on children. In the last decade (FY1990–2000), the World Bank financed close to 635 human development projects, of which 302 projects fully or partially supported child welfare, development and protection – and the focus of these interventions is discussed in this paper.

Kelly, K., Parker, W., & Oyosi, S. (2002). *HIV/AIDS prevention, children and young people in South Africa: A literature review*. Developed for Save the Children by Centre for AIDS Development, Research and Evaluation (CADRE).

Kelly, K., Parker, W., Fox, S., & Fawcett, C. (2002). *HIV/AIDS prevention, children and young people in South Africa: A bibliography*. Developed for Save the Children by Centre for AIDS Development, Research and Evaluation (CADRE).

Kelly, M. J. (2000). *Planning for education in the context of HIV/AIDS: Draft for Fundamentals of Educational Planning Series*. Paris: International Institute of Educational Planning.

Kelly, M. J. (2003). *The impact of HIV/AIDS on the rights of the child to education*. Paper presented at SADC-EU seminar on the Rights of the Child in a World with HIV and AIDS, 23 October 2000, School of Education, University of Zambia.

Kezaala, R. & Bataringaya, J. (1998). *The practicalities of orphan support in East and Southern Africa: planning and implementation of multi-sectoral social services for children and child carers*. Conference on 'Raising the orphan generation' organised by CINDI, Pietermaritzburg, 9–12 June, 1998.

This paper examines the practicalities of caring for orphans in East and Southern Africa, highlighting the issues, ideas and experiences in responding to the challenges particularly in Tanzania, Uganda, Zambia, Malawi and Zimbabwe with a view to guiding policy direction.

Khan, A., Muia, E., & Leonard, A. (1996). *Designing action-oriented research interventions to increase the ability of community-based HIV/AIDS prevention and care initiatives to sustain and improve their programs*. Presented at the XIth International Conference on AIDS, Vancouver, 7–12 July, 1996.

Khonyoungwa, L. (1998). *Children and families affected by HIV/AIDS. A community-based income generation project with a focus on needy children*. Conference on 'Raising the orphan generation' organised by CINDI, Pietermaritzburg, 9–12 June, 1998.

Kirya, S. K. (1996). *AIDS-related parental death and its effect on orphaned children's self-esteem and sociability at school*. Presented at the XIth International Conference on AIDS, Vancouver, 7–12 July, 1996.

Kitonsa, E. N. K., Antivelink, L., Kajura, C. A., Kaleebu, P., & Opolot, J. A. (2000). *The needs and coping mechanisms of children orphaned by AIDS in semi-urban South Uganda: Implications for policy makers*. Presented at XIIIth International Conference on AIDS, Durban, South Africa, 9–14 July 2000.

Kmita, G., Baranska, M., & Niemiec, T. (2002). Psychosocial intervention in the process of empowering families with children living with HIV/AIDS – a descriptive study. *AIDS Care*, 14, 279–284.

Knodel, J. & Van Landingham, M. (2000). Children and older persons: AIDS' unseen victims [editorial]. *American Journal of Public Health*, 90, 1024–1025.

This article focuses on the impact of the HIV/AIDS epidemic on non-infected family members who are affected emotionally, economically, socially, and physically by the illness and death of a person with AIDS. In terms of the impact of parental AIDS on the children, it has been noted in the study of Schuster et al. that 28 per cent of persons with AIDS in the US have children younger than 18 years of age. Although the study does not provide evidence about the nature of the impact of parental AIDS on these children, it is assumed that most of them are or will be affected by their parent's illness in profound and lasting ways. For parents of AIDS-infected adult children, its effects are manifested in the caring for AIDS orphans, financial demands, physical and health impacts, economic and social opportunity costs, and emotional impacts. The research conducted in Thailand revealed an extensive parental involvement in living and care-taking arrangements of adult children with AIDS, especially in a developing country. This article suggests that more attention should be given in assessing the ways and extent to which the AIDS epidemic affects the older population in a developing world, as well as the public health implications for older persons who are affected.

Knodel, J. & Im-em, W. (2002). *The economic consequences for parents losing an adult child to AIDS: Evidence from Thailand: PSC Research Report*. (Rep. No. 02-504). Michigan: Institute for Social Research.

We examine the economic consequences for older-age parents of losing an adult child to AIDS in Thailand based on quantitative and qualitative data derived from a key informant study, a direct interview survey with parents, and open-ended interviews. This multi-method approach generates complementary data sets allowing a comprehensive investigation of relevant issues. Our main findings are as follows.

1. AIDS parents were frequently and substantially involved in paying for their children's care and treatment costs, but government health insurance and, to a less extent, welfare services helped alleviate these expenses.
2. Parental caregiving often involved disruption of economic activity, although the generally short duration of caregiving lessened the extent of opportunity costs.
3. AIDS parents frequently paid for their children's funeral costs, with funeral society memberships and customary contributions from those attending substantially reducing these costs to parents.
4. Although a minority of all parents were involved in supporting AIDS orphans, orphaned grandchildren often ended up with their grandparents.
5. Most deceased children had contributed financially to the parental household before becoming ill, but with a minority acting as main providers. Poorer parents, however, were far more likely than better-off parents to lose a main provider and to experience severe financial hardship because of this loss.
6. Although poorer AIDS parents spent much less than their better-off counterparts on expenses related to the illness and death of their children, they were burdened to a greater extent by these expenses. One important implication of these findings is that programmes are needed that recognise and address the plight of older persons who lose a child to AIDS. These programmes must take into account the considerable range of vulnerability that exists and target those who are most susceptible to resulting economic hardship.

Koko, E. (2002). *Children, HIV and poverty. Botswana country paper*. Presented at a Workshop on Children, HIV and poverty in Southern Africa, organised by SARP, HSRC, and Save the Children, 9–10 April, 2002.

- Konde-Lule, J. K., Ssengonzi, R., Wawer, M. J., Serwadda, D., McNamara, R., Edmondson, J., & Kelly, R. (1995). *The HIV epidemic and orphanhood*. Presented at IXth International Conference on AIDS and STD in Africa, Kampala, Uganda.
- Koyakou, B., Kouame, A., Gonhy, C., & Tanoh, T. (1998). *Community care and program support for AIDS orphans in Abidjan*. The XIIIth International AIDS Conference, Geneva, Switzerland, June 28–July 3, 1998. (abstract number 34300)
- Krfit, T. & Phiri, S. (1998). *Developing a strategy to strengthen community capacity to assist HIV/AIDS-affected children and families: The COPE program of Save the Children Federation in Malawi*. Conference on 'Raising the orphan generation' organised by CINDI, Pietermaritzburg, 9–12 June, 1998.
- Mobilise sustainable, effective community action to mitigate the impacts of HIV/AIDS on children and families. In pursuit of this, COPE:
- Catalysed the formation of community-care coalitions that united government officers, religious leaders, business persons, and other concerned community leaders and members in efforts to respond to the needs of children and families affected by HIV/AIDS;
 - Strengthened the capacity of these coalitions to: Mobilise internal resources, access external resources, organise village care committees and build their capacity to undertake initiatives intended to assist AIDS-affected children and families.
- This case study paper describes the COPE project carried out by SCF in Malawi. The purpose of this project was to develop an intervention strategy that can be utilised by external change agents to mobilise sustainable, effective community action to mitigate the impact of HIV/AIDS on children and families.
- In pursuit of this purpose, COPE catalysed the formation of community-care coalitions that united government officers, religious leaders, businesspersons, and other concerned community leaders and members in efforts to respond to the needs of children and families. It also strengthened the capacity of these coalitions to mobilise internal resources, access external resources, and organise village care committees and build their capacity to undertake initiatives intended to assist AIDS-affected children and families.
- Lachman, P., Poblete, X., Ebigo, P. O., Nyandiyi-Bundy, S., Bundy, R. P., Killian, B., & Doek, J. (2002). Challenges facing child protection. *Child Abuse & Neglect*, 26, 587–617.
- The challenges facing children in the twenty-first century are immense and will need to be faced if we are to achieve the goal of child protection for all. Three specific constraints on child protection are examined in this article, namely poverty, HIV/AIDS infection, and war. The authors use their experience in Africa to raise issues of resilience and adaptation, dangers to child protection programmes, and possible solutions. Poverty can be both financial and psychological, and this affects the effect of prevention programmes. In many African and Asian countries the AIDS pandemic has changed the social structure of society with AIDS orphans and children infected and affected by HIV/AIDS becoming more common. The impact has devastating effects on the way we view child protection and in particular child sexual abuse. The consequences of post-traumatic stress resulting from war need to be addressed, and the development of programmes that place children in the centre of relief programmes to foster a culture of child protection is essential.
- Finally, the article notes that the picture is not overly pessimistic and the examines the achievements in the field of children's rights which underpin all programmes aimed at protecting children and the future need to consolidate successes achieved.
- Lawyers for Human Rights (2001). *Children affected and infected by HIV/AIDS*. Pietermaritzburg: Lawyers for Human Rights.
- Lee, T. (1999). *Evaluating community-based orphan care in Zimbabwe. Paper presented at the Fourth Interantional Conference on Home and Community Care for PWHAs*. Paris, 5–8 December 1999.
Available online: http://www.hdnet.org/Paris1999_reports/60.htm
- Lee, T., Foster, G., Makufa, C., & Hinton, S. (2002). Families, orphans and children under stress in Zimbabwe. *Evaluation and Program Planning*, 25, 459–470.

This paper evaluates a programme called FOCUS (Families, Orphans, and Children under Stress) in Zimbabwe. The programme was initiated in 1993 and works with seven community groups, providing support to around 6 500 children in 2 000 households. The programme succeeds through committed community volunteers, who made over 93 000 visits to households in 1999. Communities are mobilised by building on existing practices, using natural entry points, and careful selection of local volunteers and supervisors. There is good community ownership, extremely low volunteer turnover, and reporting systems verify that aims and objectives are met. The programme maintains good ethics, addresses a range of children's rights, and is sustainable through a mixture of donor funds, FACT (sponsoring organisation) support and community support. Issues of concern include better recognition of psychosocial needs, prevention and protection from sexual abuse, reducing stigma and discrimination, increasing child-centred approaches and participation, and reducing gender imbalance among volunteers.

Levine, A. (2001). *Orphans and other vulnerable children: What role for social protection?* Presented at a World Bank/World Vision Conference, held on June 6–7, 2001, Washington DC: World Bank/ World Vision.

Levine, C. (1993). A death in the family: Orphans of the HIV epidemic. In C. Levine & B. O. Dane (Eds). *Aids and the new orphans: Coping with death*. Westport: Auburn House.

Levine, C. (1996). Children in mourning: Impact of the HIV/AIDS epidemic on mothers with AIDS and their families. In L. Sherr, C. Hankins, & L. Bennett (Eds.), *AIDS as a gender issue: psychosocial perspectives*. London: Taylor and Francis.

By the year 2000, an estimated 72 000–125 000 US children and teenagers will have lost their mothers to AIDS. Children orphaned by AIDS are at increased risk of economic deprivation, emotional and developmental problems, and high-risk behaviours. Mothers with HIV report severe anxiety regarding their health, their children's future, and the financial burdens of illness. In addition to the specific stress posed by an HIV-infected parent, these families are often dealing with poverty, family disruption, and child behaviour problems. Environments that foster open communication of feelings such as guilt, anger, loss, and sadness have been shown to enhance the adjustment of children to parental death from causes such as cancer. However, the stigma and secrecy that surround AIDS often impede such open expression of emotions. To address children's anxieties about who will care for them after a parent's death, HIV-infected parents should be helped to make feasible, legally acceptable guardianship arrangements. New laws should be enacted to allow parents to appoint standby guardians, permitting them to care for their children as long as their health permits. AIDS programmes that serve women and children should build alliances with child welfare organisations to ensure that the special needs of young people affected by AIDS are recognised. Child welfare policies should emphasise the provision of monetary benefits and support services, a preference for maintaining children in the extended family, and permanency planning.

Levine, C. & Foster, G. (2000). *The White Oak Report: Building international support for children affected by AIDS*. New York: The Orphan Project.

Loening-Voysey, H. (2002). HIV/AIDS in South Africa: Caring for vulnerable children. *African Journal of Aids Research*, 1, 103–110.

South Africa currently has the fastest growing HIV/AIDS pandemic in the world. Efforts to manage the plight of children affected by HIV/AIDS has however been thwarted by two ubiquitous factors – poverty and inefficient state services. Caregivers, who are generally not public advocates for children's rights, disguise the state's negligence to respect, fulfil and protect children's rights. This paper suggests that the caring for HIV/AIDS-affected children in South Africa needs to go beyond looking for willing and available members in the community to take on this responsibility. A developmental approach to addressing disparity, forming policies and implementing programmes could help in curtailing the effects of the pandemic.

Loening-Voysey, H. & Wilson, T. (2001). *Approaches to caring for children orphaned by AIDS and other vulnerable children. Essential elements for a quality service*. Report prepared for UNICEF by the Institute for Urban Primary Health Care (IUPHC).

- Lorey, M. & Sussman, L. (2001). *Handbook for programs to assist children affected by HIV/AIDS*. (Draft for review, April 2001 ed.). Supported by USAID and the Synergy Project of TvT Associates.
- Lund, F. (2000). *Welfare provisions for children in South Africa*. Presented at a Fogarty Maternal and Child Health Workshop, held at the Rob Roy Hotel and the Valley Trust, Durban South Africa, 14–18 August, 2000.
- Lundberg, M., Over, M., & Mujinja, P. (2001). *Sources of financial assistance for households suffering an adult death*. (Working Paper No. 2508). Infrastructure and Environment Development Research Group of the World Bank. Washington DC: World Bank.
- Lusk, Huggman, & O’Gara (2000). *Assessment and improvement of care for AIDS-affected children under 5*. Washington, DC: Agency for Educational Development.
- Aids-affected children include orphans and children whose parents are ill or too busy caring for ill family members. Very little is known specifically about the 0–4 AIDS-affected age group, since most orphan assessments treat the 0–15 (or 0–18) year age span only as a whole. Because of their nutritional, health and psycho-social needs, children under age 5 represent a group that demands special attention.
- This paper presents: 1. current knowledge about the caring situation of AIDS-affected children under 5 years of age; 2. pre-existing tools relevant for assessing young child care; and 3. new assessment tools targeted to assessing the care of AIDS-affected children under 5.
- Lynas, M. (2001). *No excuses. Facing up to sub-Saharan Africa’s AIDS orphans crisis*. London: Christian Aid.
- AIDS is not just an health issue. AIDS is fuelled by poverty. It is no coincidence that the countries most ravaged by the HIV/AIDS pandemic currently changing the face of Africa are also the poorest. This is a consequence of a situation where about half of the world’s population – nearly 3 billion people – live in poverty. Africa today faces a deepening humanitarian and economic crisis as the rate of increase of people contracting HIV/AIDS reaches staggering proportions. A total of 25.3 million African people are now living with the condition. Millions of young adults have already died. AIDS thrives in sub-Saharan Africa because health provision is minimal in the poor countries where the disease is most prevalent. When services are available, people cannot afford them. AIDS thrives also because less than 20 per cent of children in the poorest countries in Africa get a decent education: just half can read and write. Without good schooling, Africa’s children are unlikely to have the information and skills necessary to reduce their own risk of contracting HIV. AIDS cannot be looked at in isolation from the factors that have allowed it to flourish. A vaccine will not solve the problem in countries where health care services are almost non-existent, neither will cost-price access to anti retroviral drugs. There is a real danger that current debate about access to drugs will obscure a bigger problem.
- Mabetoa, M. (2002). *Discussion document on home/community-based care and support*. Conference on Children, HIV and Poverty in Southern Africa, organised by SARP, HSRC, and Save the Children, 9–10 April, 2002.
- Mabetoa, M. (2002). *National integrated plan for children infected and affected by HIV/AIDS*. Presented at a Workshop on Children, HIV and Poverty in Southern Africa, organised by SARP, HSRC, and Save the Children, 9–10 April, 2002.
- Mabude, Z., Zodidi Ndudane, N., Fipaza, N., Mfenyana, N., Ndukwana, Z., & Mabandla, S. (2001). Identification of children in distress (CINDI) at Lusikisiki and Umzimkulu Districts of Region E – In the Eastern Cape Province. Unpublished work.
- MacLeod, H. (2001). Residential care. In A. Levine (Ed.), *Orphans and other vulnerable children: What role for social protection?* Proceedings of a World Bank/World Vision conference, June 6–7, 2001 Washington, DC (Social Protection Discussion Paper No. 0126).
- This report records the proceedings of the conference ‘Orphans and Other Vulnerable Children: What Role for Social Protection?’ which took place in Washington, DC in June 2001. Co-sponsored by the World Bank and World Vision, the two-day conference sought to

promote awareness of the extent of this crisis, to provide practitioners with a forum to share best practices and other insights, and to probe the role of social protection in implementing a balanced response.

- Madörin, K. & Killian, B. A. (2003). A structured group therapy programme to assist vulnerable children affected by HIV/AIDS, poverty and violence. Unpublished work.
- Magalla, A., Houlihan, H., Charwe, D., Kipagasi, K., Bhatt, P., & Reeler, A. (2002). *Urban-rural differences in programs on orphans and vulnerable children in AIDS affected areas in Tanzania*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

Differences between rural and urban environments may influence programme design on orphans and vulnerable children as OVC needs differ in these two settings.

Axios is implementing a comprehensive program on OVC funded by Step Forward, Abbott Laboratories Fund, in the rural Rungwe District and the urban Mbeya Municipality (MM) in Tanzania. The four programme components are: basic needs, education, health care and voluntary counselling and testing (VCT), implemented in close collaboration with district authorities and local actors. MM programme has just completed a needs assessment while the Rungwe programme is well underway. Assessments in the two areas showed similarities and differences.

Similarities:

1. A need for direct support to the most needy OVC;
2. A desire for income generating activities because of general poverty;
3. Schools are crowded with lack of equipment and sanitation facilities;
4. School health surveillance to improve the health status of children;
5. Increase VCT outlets and raise awareness.

Differences:

1. Issues of inheritance of OVC came up in urban setting only;
2. Several needy orphanages in urban area, one in rural area;
3. Food for OVC more of an issue in urban area with OVC resorting to stealing food;
4. Burden of care perceived as heavier in urban area with fewer caretakers;
5. More requests for home-based care in urban setting as more people had done VCT.

The above illustrate the different needs of urban and rural areas that are geographically close but socio-economically different. Differences are related to social cohesion being less strong in urban areas or people being more informed (i.e. inheritance). It is important to take them into account by doing needs assessments in each district before expanding programmes. Programme design should disaggregate rural and urban settings when considering needs and intervention designs for OVC. Policies, strategies and resources need to be focused on these differences.

- Majola, N. (2002). Co-ordinated orphan response. *International AIDS Conference*, 14 (abstract number MoPeF4095).

Young and dependent children are increasingly facing risk of neglect, infection and also prejudice because of the AIDS epidemic. By 2005, South Africa will be accounting for at least 2.5 million orphans, and this number will be doubled by 2010. It is estimated that 9 to 12 per cent of these orphans will live in Kwa-Zulu Natal. Providing institutional care is unaffordable and at the same time to rely on communities to carry the burden without external assistance is unfeasible and will lead to the total violation of children's rights. The presentation is looking at responding in a collaborative manner to the needs of young children affected by HIV/AIDS and other vulnerable children by:

- Forging partnership between various community-based service providers and the community members;
- Early identification of vulnerable children in order to allow for timeous pre-statutory intervention;
- Identify and recruit potential foster parents and strengthen that relationship between foster parent, child and biological parent while still alive.

The approach has sensitised members of the community about the needs of children affected by the epidemic and their families and they have learnt to respond in a supportive manner to the challenges posed by the epidemic. With good information and support the communities are prepared to foster non-related children. The project has seen a tremendous response of people coming forward to foster non-related children. Recommendation: In response to HIV/AIDS it is necessary for service providers to work in partnership with each other including the community.

Makame, V., Ani, C., & Grantham-McGregor, S. (2002). Psychological well-being of orphans in Dar El Salaam, Tanzania. *Acta Paediatrica*, 91, 459–465.

Forty-one orphans whose fathers and/or mothers had died from AIDS and who were living in the poor suburbs of Dar El Salaam, Tanzania, were compared with 41 matched non-orphans from the same neighbourhoods. The subjects were given an arithmetic test and a semi-structured questionnaire concerning any internalising problems, their attendance at school and their experiences of punishment, reward and hunger. The scale of internalising problems comprised 21 items adapted from the Rand Mental Health and Beck Depression Inventories concerning mood, pessimism, somatic symptoms, sense of failure, anxiety, positive affect and emotional ties. Most orphans lived with aunts and uncles. Compared with non-orphans, they were significantly less likely to be in school but those who did attend school had similar arithmetic scores. Significantly more orphans went to bed hungry. Orphans had markedly increased internalising problems compared with non-orphans ($p < 0.0001$) and 34 per cent reported they had contemplated suicide in the past year. Multiple regression analysis indicated that the independent predictors of internalising problem scores were sex (females higher than males), going to bed hungry, no reward for good behaviour, not currently attending school, as well as being an orphan.

Marcus, T. (1999). *Wo! zaphela izingane – It is destroying the children – Living and dying with AIDS*. Johannesburg: CINDI.

This is a qualitative study of death and dying in the context of AIDS. As such, it is a study both of the social processes and responses that surround death as well as where AIDS-related deaths fit in. As we know little about either of these aspects in contemporary SA this exploratory work aims to bring out people's perceptions and experiences – especially as they are being played out in poor communities in and around greater Pietermaritzburg. This study shows death to be a complex process that has a forceful, mostly negative impact, which extends far beyond the dying individual and the event of death itself. The economic and social pressures in the family begin long before an individual's demise. Loss of income and health status is accompanied by a costly pursuit of treatment, if not cure, as people struggle to understand and find a satisfactory explanation of the condition they find themselves or those they care for in. With death itself the lives of surviving individuals and their families are reshaped, often in a fundamental way. Families compact, expand or disintegrate altogether. Basic needs – food, shelter, clothing, education etc. – become even harder to meet as they are jeopardised through inadequate preparation for death, too few resources within surviving families and the limited responsiveness of 'community', broadly defined. Through all this, the aged and children are made particularly vulnerable and responsible, being the least resourced and the most burdened. This study highlights the extreme hardship and suffering that (young) adult death bring for those who survive. It suggests that there is a real need and a window of opportunity for major social intervention to support those living with AIDS, including those who are HIV positive. And that this intervention needs to be driven by practical, multi-sectoral social interventions in a range of areas.

Martin, T. (1998). AIDS hospices and orphanages. *Annals of Tropical Paediatrics*, 18 Suppl., 21–25.

At the beginning of the twenty-first century, more than 5 million children worldwide will have lost their mothers to AIDS. Already, 1.4 million children are believed to have died since the beginning of the pandemic and more than 1.2 million children are currently infected with HIV/AIDS. Paediatric hospice care is a philosophy of care which offers healing where cure is not possible, creatively affirms the unique value of each young life no matter how short, honours family ties where they still exist, and is culturally transcendent. During the 1990s, WHO has identified as a priority the delivery of palliative care services throughout the

developing world. The author considers the magnitude of the problem, the social impact of HIV infection upon children, the psychological impact on the child with AIDS, models of care, death in hospital, the AIDS family hospice model, orphans, an AIDS foster parent programme in Scotland, Africa, a Nairobi hospice project for abandoned HIV-positive children, the challenge for paediatric AIDS hospice projects in Africa, and the vision of care for the future.

Masresha Hailu, Y. M. H. (2002). *The importance of organizing support group for care givers of persons living with AIDS (PLWA) and orphaned children*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

The role of community-based 'support groups' for caregivers of PLWA (home care) and HIV/AIDS orphaned children is found to be an effective and sustainable method that can ensure community ownership in reducing the impact of the disease. *Description:* The Medical Missionaries of Mary Counseling & Social Services Center, that has rendered support to PLWA and their families for the last 11 years in Addis Ababa, conducted a case study of caregiver groups. The objective of the study was to assess their needs and the effect of mobilising and organising voluntary support groups for caregivers of PLWA & AIDS orphans. Data collected from 40 caregivers and a series of discussions held on major problems of caregivers and the orphaned children helped to identify the type of support they needed. It was noted that HIV/AIDS stigma is not limited to PLWA but also to their caregivers and children. Usually the caregivers are elderly persons without sufficient knowledge about HIV/AIDS. It was also understood that such deep-rooted stigma could not be easily reduced through generic and stereotyped awareness creation campaigns. It is rather through community-based and trained support groups that the issue of HIV/AIDS could be discussed openly. Based on the findings of the study the Center formed a number of support groups that enhanced better care for PLWA and their children. The support groups educate the caregivers on the ways of the transmission of HIV/AIDS and how to take care of themselves. *Lesson learned:* Families, caregivers and the community in the focus area accepted and cared for PLWA and orphaned children so reducing stigma. *Recommendation:* NGOs working in care and support for PLWA and orphaned children are applying the support group initiative to have more effective and sustainable results.

Mataka, E. (2001). Supporting orphans and vulnerable children in Zambia. *Sexual Health Exchange*, 1, 2–5.

Matshalaga, N. R. & Powell, G. (2002). Mass orphanhood in the era of HIV/AIDS. *British Medical Journal*, 324, 185–186.

Mayrose, M. R. (2002). *Setting up educational support programme for AIDS orphans*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

An increasing number of children orphaned by AIDS deaths in Churachandpur, Manipur, in north east India has necessitated developing and implementing educational support for 125 AIDS orphans. Shalom is a community-based health organisation (NGO) which has focused on five broad areas of services: (a) Community education and advocacy; (b) Healthcare and support services; (c) Injecting drug users services (IDU); (d) Vocational rehabilitation of women; and (e) AIDS orphan support programme. Shalom staff have identified 200 AIDS orphans over the last five years and have provided educational support to 125 of them during the last two years. These 125 orphans, aged 5 to 14 years, are reading in 38 different schools, in classes from nursery to class X. The scholarship covers admission and tuition fee, text book, exercise books and school uniforms. *Lessons learned:* Providing educational support for AIDS orphans goes a long way in reducing the socio-economic impact of HIV/AIDS on affected families. *Recommendation:* Limiting the socio-economic impact of HIV/AIDS on families and the community should always be given a priority in areas where the epidemic has stayed.

McDermott, P. (2001). *Children and adolescents affected by HIV/AIDS*. USAID.

McKay, P. (2002). *Community-based care for children*. Presented at a Workshop on Children, HIV and Poverty in Southern Africa, organised by SARPN, HSRC, and Save the Children, 9–10 April, 2002.

What is the potential role of government welfare departments in ensuring that HIV-affected children can best have their basic needs met at community level? What are the challenges faced by communities in responding to the needs of HIV-affected children? It is internationally accepted that children are best cared for in and by their families and in their communities. Should the children be orphaned then the extended family provides the best caregivers. Should the extended family not be available for any reason then the community could provide a better alternative than an institution.

McKelvy, L. (1993). The well children in AIDS families project: A hospital-based program. In C. Levine (Ed.), *A death in the family: Orphans of the HIV epidemic*. New York: United Hospital Fund of New York.

McKerrow, N. (1996). *Implementation strategies for the development of models of care for orphaned children*. Zambia: UNICEF.

This document is a follow-up on the earlier study, 'Responses to Orphaned Children in the Southern and Copperbelt Provinces of Zambia'. It re-emphasises the importance, when considering the needs of vulnerable children and orphans, of the four-tier response developed in the earlier study, namely:

1. It is the family who must identify vulnerable children and orphans and provide the basic daily needs of the children, as well as emotional support;
2. The community must support both the children and their caretakers, as well as act as a forum for lobbying authorities to assist in providing an effective response to their needs;
3. The churches, NGOs and CBOs should co-ordinate all responses whilst also providing material help and other support services; and
4. The state must develop local infrastructure, empower state personnel, create an enabling environment at all levels, modify state services, and facilitate funding for grassroots responses. At each level, the response should be recognised and developed by elaborating on the responsibilities and needs of the available role players.

The study was an attempt to identify any innovative or indigenous models of care for orphaned children and to gain insights into the requirements needed to improve existing models of care. During the study two communities in each of the Copperbelt and Southern provinces participated in a three-stage process, consisting of a brief situation analysis, two household surveys, and a community workshop.

The household surveys revealed that 51 per cent of children had lost one or both parents (10.7 per cent were maternal orphans and 22.6 per cent double orphans), that 71.5 per cent of all households are home to orphaned children, that only 80 per cent of the households are able to feed their members without outside assistance, and that only 58 per cent can afford to educate their children.

Participants in the study identified six principles that should guide strategies for the development of models of care for orphaned children:

1. Siblings should remain together;
2. Children should as far as possible remain in their homes or communities of origin;
3. Caretakers should be supported through skills-training in income-generation activities and child-care skills;
4. Communities should provide support systems for both children and their caretakers;
5. Responses should facilitate the provision of both direct and indirect aid packages; and
6. State resources should be made user-friendly and should aim at creating an enabling environment in which communities are able to care for their own members.

To facilitate an appropriate holistic response to the needs of vulnerable children in Zambia, the document stresses the importance of clear identification of the aims, objectives and role players involved. Because of the government's limited capacity in Zambia, the principal strategy should be to make more effective use of existing state resources, and of non-governmental role players, such as NGOs, CBOs and churches. The overall strategic aim should be to strengthen the community's capacity to provide its vulnerable children with acceptable, adequate, appropriate and affordable levels of care. In order to do so it will be necessary for Zambia to attend to the development of a policy for vulnerable children,

creating national awareness of children's rights, develop advocacy and lobbying for a for the implementation of the national policy, build capacity at national, district and local levels, create horizontal and vertical inter-sectoral network systems, develop regional and local intervention programmes, identify appropriate local structures for the implementation of interventions, and identify, recruit and train appropriate persons for the delivery of programmes to communities and their members.

In its conclusion, the document outlines the major reasons why a community-based response to the plight of vulnerable and orphaned children is the most appropriate primary response: firstly, the majority of these children are already living with their extended family in their communities; secondly, a child's needs are most effectively met in its own community at a standard comparable to that experienced by other children in the community and without a risk of stigmatisation or alienation; thirdly, the number of vulnerable and orphaned children is increasing rapidly to a level that is set to overwhelm existing resources; and fourthly, community-based care is a very cost-effective coping mechanism with potential coverage of a large number of communities. Institutional care may be needed on a temporary basis to offer children a temporary home until a more permanent solution can be found. But as a long-term solution, this intervention should always be seen as being the last resort for vulnerable children.

For successful implementation of community-based initiatives, the goodwill and enthusiasm of community members should be complemented by a multi-disciplinary support structure. This structure should seek to develop local capacity, skills and structures, and should access appropriate outside resources to complement these. The document concludes with a practical framework for a stepwise approach to the implementation of local initiatives to assist vulnerable children. The process basically involves nine steps: community engagement; identification of a facilitating agency; definition of an area of operation; identification of an implementing party; a situation analysis; preliminary planning; detailed planning and establishment of the programme; development of ongoing support; and monitoring and evaluation.

McKerrow, N. (1997). *Responses to orphaned children: A review of the current situation in the Copper Belt and Southern Provinces of Zambia* (Research Brief No. 3). UNICEF: Lusaka.

The objectives of this study were to identify any innovative or indigenous models of care for orphaned children, and to gain insights into the requirements needed to improve existing models of care.

Household interviews were used in the two survey regions (the Copperbelt and Southern Provinces). However, due to the differing nature of these communities different sampling techniques were used. Three questionnaires were prepared in English and then modified for use by local interviewers. The first was a household questionnaire, the second an orphans' questionnaire, and the third a caretakers' questionnaire. In order to identify the models of care being used, one-day workshops were held in each of the selected four communities within the two regions, with the proceedings being recorded by one of the participating community members.

The investigation found that the status of children in the participating communities was poor and that the ability of households to meet the basic needs of their members was very limited. Fifty-four per cent of the children in the survey regions were orphans who had lost one or both of their parents, while 71.5 per cent of the households were homes to orphans. The most frequent caretaker was the surviving parent, his/her siblings, or the orphan's grandparents. Although this showed the current cohesiveness of the Zambian extended family in the care of orphans, this network was facing a lot of stress. This was brought out by the finding that 60 per cent of the caretakers were providing orphan care rather reluctantly, largely because there was no one else prepared to do so.

Unlike their urban counterparts, rural households were better able to feed their members. However, fewer rural children were able to attend school, whereas more were able to in the urban areas.

The community workshops failed to identify any new innovative models for the care of orphaned children. They did however create an increased local awareness of the problems facing both them and their children.

A four-tier response to the problem of orphans was developed and discussed. The workshop participants insisted that this be recognised and developed with the assistance of local communities. The role-players in the four-tier response are: 1. The family, which must identify children at risk and orphans and provide the basic day-to-day needs of the children as well as emotional support; 2. The community, which must support both the orphans and the caretakers as well as act as a forum for lobbying authorities to assist in providing an effective response to their needs; 3. The churches, NGOs and CBOs, who should co-ordinate all responses whilst also providing material support and support services; and 4. The state, which must develop local infrastructure, empower state personnel, create an enabling environment at all levels, modify state services, and facilitate funding of grassroots responses.

McKerrow, N. H. & Verbeek, A. E. (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*. Edendale Hospital, KwaZulu-Natal.

McKerrow, N. H., Smart, R. A., & Snyman, S. A. (1996). *AIDS, orphans and affordable care*. Pretoria: Human Sciences Research Council.

McLeod, D. & Tovo, M. (2001). *Social services delivery through community-based projects*. (Social Protection Discussion Paper No. 0118). Washington, DC: World Bank.

The World Bank is financing an increasing number of community-based social services projects. The objective of this paper is to review and categorise the extent, scope and mechanisms of these projects in the current Bank portfolio, and to identify good practices and potential pitfalls. The authors identify 99 projects that finance at least \$1.6 billion in social services. While most of the projects surveyed deliver 'traditional' services such as nutrition, maternal and child care, and literacy, the scope of many projects has expanded to include newer services such as counselling, home-based care for the elderly and disabled, and early childhood development.

Menting, A. (2000). The village and the children. *Harvard AIDS Review*, Spring-Summer, 15–18.

In 1997 USAID published 'Children on the brink: Strategies to support children isolated by HIV/AIDS', a report that gave estimates of the number of orphans the AIDS epidemic has produced. A total of 23 countries were examined, subsequently determining that the number of orphaned children could reach 40 million by the end of 2010. In addition, the report estimated that in the 19 African nations the orphan crisis would affect one in every five children below 15 years of age, and one in every three children in some nations, by the year 2000. Responding to the needs of the millions of African children who have been orphaned by HIV/AIDS, Millicent Nomisa Mnyayi and several women from the Melville Community Development Group founded centres that focused on caring for the orphans. These include the Othandweni Children's Home in Kwa-Zulu Natal, the Vulamehlu Health Resource Centre, the Enduduzweni Information and Drop-in Centre, and the Siphesihle Centre. These community-based programmes aim to build the skills in the orphaned children so they may be able to do things for themselves while remaining a part of the village. Although much controversy surrounds these programmes, these community-based responses should be fostered through building an enabling environment.

Miller, R. & Murray, D. (1999). The impact of HIV illness on parents and children, with particular reference to African families. *Journal of Family Therapy*, 21, 284–302.

Misore, J. A. (2003). *Community-based orphan care*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.aspx>].

Due to deaths mainly occasioned by HIV/AIDS, extended family support system was found and known to be the most common in care and support of orphans. Organisations working within the project area were unable to cope with large number of orphans. At the same time

extended families, although willing to take care of orphans, were unable to provide basic needs to orphans due to poor social economic status. This paper will highlight the partnership based intervention model in community-based orphan care. It focuses on promotion of access to essential elements of dignified livelihood that is, guaranteed food security, functional education, income, access to health, security, social capital and shelter through capacity building of caretakers and orphans. The main entry point to the community (affected households) is through schools, where partnerships with relevant stakeholders are developed with parents, teachers association committees.

Orphan care is more of community concern sustainability and equity of orphan care can only be enhanced through capacity building of caretakers and orphans at household level. The community schools has been ineffective entry point to the affected households.

The practice and importance of partnership based intervention model on community based orphan care should be established and applied. This model merits further study.

Misore, J. A. (2003). *Orphan support system in rural peri-urban*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

Background: To investigate the practice of caretakers and orphans towards orphanhood, as well as the various forms of support systems, and copy mechanism for dealing with orphanhood in the study area. *Method:* A descriptive exploratory study using qualitative and quantitative data was conducted in the year 2001. Eight focus group discussion were held, 30 orphans and their caretakers were interviewed in depth and later on 119 caretakers filled out a structured questionnaire. Furthermore orphans were asked to narrate the experiences in their lives since the death of their parents.

Results: Prevalence rate of orphanhood was 119 out of 324 households or (37 per cent). Eighty-seven per cent of caretakers were females, 48 per cent of caretakers who attained school-going age were not able to go to school, and the majority of those who went to school (68 per cent) dropped out between class five to seven including those whose education was sponsored. The copy mechanisms adopted by 38 per cent of orphans were mainly involving income-generating activities. In two cases boys aged 16 and 17 entered into leviratic union and a girl aged 13 years was already involved in early sexual relationships. Four aged between 15 and 17 years were household heads.

Conclusion: From the findings of the study, coping mechanisms adopted by orphans involving income-generating activities were mainly to assist caretakers in feeding the family. In most cases the caretakers encouraged the orphans to do so. This led to high school dropout rate, inability to attend school for those who had acquired school going age and high risk behaviour amongst the orphans.

Mkhabela, S. (2002). *A call for co-ordinated action for children affected by HIV/AIDS*. Presented at South Africa National Conference on Children Affected by HIV/AIDS, 2–5 June 2002.

Mkhize, Z. (1998). *Paper presented by the Minister of Health for KwaZulu-Natal, Dr Zweli Mkhize, to the CINDI Conference held in Pietermaritzburg from 9 to 12 June 1998*. Conference on 'Raising the orphan generation' organised by CINDI, Pietermaritzburg, 9–12 June, 1998

Monasch, R. (2003). *The orphans crisis: Evidence on the impacts on children & response*. Global Partners Forum for OVC

Morch, J. (2002). *Presentation by Jesper Morch, Representative, UNICEF South Africa*. Presented at South Africa National Conference on Children Affected by HIV/AIDS, 2–5 June 2002.

Morgan, S. (2000). Response for all AIDS affected children, not AIDS orphans alone. *AIDS Analysis Africa*, 10, 3.

This article focuses on the response for all AIDS-affected children in SA. In a study by the National HIV/AIDS Care and Support Task Team in South Africa and the Save the Children Fund by the UK, a variety of categories were identified when defining children living with HIV/AIDS. Among the most threatened groups identified were those children from infected households where children carry the burden of caring for their dying parents. In response, the

government must incorporate planning for the future of children who will be orphaned as well as provide support for those children who act as caregivers while their parents are still alive. Another group are those from uninfected households who are affected by reduced access to core services and decline in economic capacity. Moreover, the escalating phenomenon is worsened by the prevailing sexual abuse cases in the country. The situation is further aggravated by the lack of policy framework that acts as a barrier to an effective and co-ordinated action. This article advocated the mainstreaming of HIV/AIDS and children's issues into all key programme and development areas across all sectors. Likewise, moving the children from the peripheries of the planning process and acknowledging their pivotal role, practitioners will immeasurably strengthen the capacity of SA in its fight against AIDS.

- Motsepe, J., Esu Williams, E., Chambeshi-Moyo, M., & Chomba, M. (2002). *Building the capacity of young people to care for PLHA and orphans and vulnerable children (OVC)*. New York: USAID/Population Council/Horizons.

Young people are increasingly caring for PLHA and OVC. To make these experiences productive and positive, young people need to be properly trained and supported. The Horizons Program and CARE/Zambia are conducting an intervention study to build the capacity of young people to care for and support PLHA and OVC. The study involves about 1 000 youth, belonging to 30 school-based and community clubs. Prior to intervention activities, the attitudes of young people toward PLHA and orphans and treatment of orphans in the community were determined from a PLA study and in-depth interviews. A training curriculum was developed and pre-tested, covering topics such as: stigma and HIV disclosure, gender, children's rights, HIV/AIDS related conditions, VCT, referral, community and home-based care, youth and community involvement in care and support and monitoring. Follow-on field activities were conducted and club patrons were trained to facilitate activities of youth caregivers. Ten kits containing basic materials such as apron, soap, salt, disinfectant, gloves, cotton wool, bandages, notebooks, pens and monitoring forms were provided to each club and instructions on use provided. The support of adult home-based caregivers, clinic staff, village chiefs and leaders was solicited.

Lessons learnt: Workshop-based and hands-on field training activities are important ways to build the capacity of youth caregivers. Gender-related care and support capacity needs of youth caregivers should be identified and addressed. Advocacy to enhance the participation of OVC in club activities is important. Periodic retraining and feedback are essential to strengthen skills and to address emerging issues. Effective ways to monitor and sustain youth care and support activities, and the use of consumable materials should be established.

- Mudekunya, L. (2002). *Children's rights and access to care and support*. Presented at a Workshop on Children, HIV and Poverty in Southern Africa, organised by SARPN, HSRC, and Save the Children, 9–10 April, 2002.

This paper discusses the interaction of HIV/AIDS and poverty and its impact on children, and considers the ways of ensuring children's rights in vulnerable communities. Suggests community foundations a means to raises resources at the local level as well as to develop participatory decision-making processes. It further explores existing resources, as well as schools and faith-based organisations as resources. The Goelama Programme of the Nelson Mandela Children's fund is used as an example of an organisation that has had some success in these endeavours.

- Mugabe, M., Stirling, M., & Whiteside, A. (2002). *Future imperfect: protecting children on the brink*. Presented at the Africa Leadership Consultation: Urgent Action for Children on the brink, Johannesburg, 9–10 September 2002 .

- Mukiza-Gapere, J. & Ntozi, J. P. (1995). Impact of AIDS on the family and mortality in Uganda. *Health Transition Review*, 5, 199–200.

- Muller, O. & Abbas, N. (1990). The impact of AIDS mortality on children's education in Kampala, Uganda. *AIDS Care*, 2, 77–80.

- Muller, O., Sen, G., & Nsubuga, A. (1999). HIV/AIDS, orphans, and access to school education in a community of Kampala. *AIDS*, 13, 146–147.

Mutangadura, G., Mukurazita, G., & Jackson, H. (2000). A review of household and community responses to the HIV/AIDS epidemic in the rural area of Sub-Saharan Africa. Geneva: UNAIDS.

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

If programmes are to be effective it is also important to target households that are most in need. However, targeting AIDS-affected households only is unethical, since it may leave out households that are equally in need for other reasons. It is, therefore, important that programmes target a wider group of households based on both poverty and AIDS indicators. This can be achieved best by working through communities identifying the most needy themselves. Without investment in human development, there is no long-term progress in national development, stability and the skills base to overcome development obstacles. Government alone cannot achieve the basic well-being of the entire national population. This calls for meaningful partnership between the communities, governments, donor agencies, international NGOs, local NGOs, private sector and others in order to address the problems of HIV/AIDS successfully. But governments should be prepared to play a more active leadership role and review their commitment to rural development. They need to undertake this with a clear analysis of the impact of AIDS on development, and of the impact of development on the AIDS epidemic itself.

Mutangadura, G. & Jackson, H. (1998). HIV/AIDS and the young: Three studies in Southern Africa. *SafAIDS News*, 6, 2–8.

Muwonge, J. (2003). *World Vision's experience working with HIV/AIDS orphans in Uganda 1990-1995*. (Social Protection Discussion Paper No. 0210). Washington, DC: World Bank.

Uganda, projected to have 3.5 millions orphans by 2010, was the site of World Vision's first major programme of assistance to orphans of HIV/AIDS and war. This paper examines how the program, which was implemented in the rural districts of Masaka, Rakai and Gulu from 1990 to 1995, addressed the critical challenge of ensuring sustainable orphan welfare in a family and community setting. The paper considers how impact was achieved through activities that focussed on direct support to vulnerable children (access to education and vocational training skills), while at the same time as strengthening the capacity of families and communities to cope (increasing food production of foster families, strengthening basic social services in the area, and mobilising the community for orphan care). Community participation and collaboration with government and other NGOs were important elements in all components.

Mwape, G., Sheth, G., & Boswell, D. (2003). *Training community members to provide psychosocial support to orphans and vulnerable children and guardians*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

Zambia is one of the countries most severely affected by HIV/AIDS with an estimated national sero-prevalence rate of 20 per cent. One million children are believed to be orphans. As part of a study conducted on psychosocial issues faced by orphans, psychosocial support persons (PSSP) were trained to provide emotional support during and after data collection to OVC and their caregivers. Two psychologists and one social worker designed and implemented a two-week training program to train PSSP. Participants were recruited and selected by community programme staff based on their active involvement in their communities, previous counselling training and experience with children. Participants were trained in child development, sexuality, loss and grief, child abuse, communication skills, helping skills, HIV/AIDS, needs of

OVC and guardians. Twenty-five PSSP demonstrated ability to address the needs of OVC and their caregivers to provide support to community members. During data collection this cadre provided support to over 3 000 beneficiaries. The team of PSSP have continued implementing activities in their communities which include advocacy and sensitisation, training teachers and other community leaders, and direct psychosocial support to OVC and their care givers.

Conclusions: Training a small number of carefully selected community cadres to respond to psychosocial issues faced by OVC has a rippling effect on community projects. Community support persons are a reflection of their communities. They include orphans, caregivers, and people living with HIV/AIDS. Their psychological needs warrant address within experiential training program in order to foster self-awareness and coping capacity, so they are empowered to serve as role models and effective helpers within their communities. Psychosocial interventions can and are best met by community members.

Nakayiwa, N. A. A. (2003). *Creating an innovative care model for children living with HIV/AIDS in Uganda*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

The number of orphans due to HIV/AIDS is on the increase worldwide, Uganda is not exceptional. Orphans are subject to multifaceted problems that range from physical, psychosocial to economic problems. These include social stigma, rejection, severe malnutrition, to mention a few. *Description:* Mildmay is a specialist tertiary referral centre for people living with persistent HIV/AIDS-related symptoms, children and adolescents (0–18) Inclusive. At the Mildmay Centre exists a child centre (Noah's Ark) that caters for the children and adolescents alike. Noah's Ark programmes involve receiving, registering and providing daycare services to the children and respite to the carers. These services include picking children up from home, providing meals, administering drugs, planning therapeutic play and education activities plus child counselling and occasionally making referrals to other departments, and children are dropped home in early afternoon. A monthly training for the children's carers is held at the Mildmay centre. The interdisciplinary team holds weekly meetings to discuss the challenge faces. Recommendations made include hospital visits, home visits and school visits by the Noah's Ark staff and other members of the interdisciplinary team. *Lessons learnt:* Through information, education of and effective communication with the children affected by HIV/AIDS and the carers of these children, there has been reasonable social acceptance and improvement in the care of children affected by HIV/AIDS. The general welfare of the children has improved tremendously. It will be through such innovative models of care that issues around problems of children affected by HIV/AIDS will be appropriately addressed.

Nampanya-Serpell, N. (1998). *Children orphaned by HIV/AIDS in Zambia: Risk factors of premature parental death and policy implications*. Family AIDS Caring Trust, Zimbabwe, and The Orphan Project, New York, Jacksonville, Florida.

National Programme of Action for Children in South Africa in the Presidency (2000). *National report on follow-up to the World Summit for children*. National Programme of Action for Children in South Africa: The Presidency.

National Programme of Action for Children in South Africa in the Presidency (2001). *Implementation of the Convention on the Rights of the Child*. National Programme of Action for Children's South Africa.

South Africa's supplement to the Initial Country Report of January 2000 is a follow-up to the initial country report of November 1997. The questions (issues) here were posed by the UN Committee on the Rights of the Child as update and further clarification to the 1997 Initial Country Report. The reporting was as follows: – The Initial Country Report of November 1997 was submitted to the UN committee on Child Rights. The NGOs then submitted their First Supplementary Report in May 1999. NGOs then made their presentation to the committee in Geneva. The committee then posed questions to the government. This publication is a response to the questions raised by the committee to government.

National Programme of Action for Children in South Africa in the Presidency (2001). *National Programme of Action 2000 & beyond*. National Programme of Action for Children in South Africa. The Presidency.

- Ndlovu, D. & Ngwenya, S. (2001) *Establishment of options for orphans: The Bushbuckridge Professional Foster Care Project*. Paper presented to AIDS in Context Conference. Johannesburg, 4–7 April 2001.
- Nduati, R. W., Muita, J. W., Olenja, J., Muiva, E., Muthani, N., & Manguyu, F. (1993). *A survey of orphaned children in Kibera urban slum, Nairobi*. Presented at the IXth International Conference on AIDS held in Berlin, Germany, in June 1993.
- news24.com 'Extended family' in crisis (2002). [Announcement posted on 12-11-2002] www.news24.com/News24/South_Africa/Aids_
- Ngcobo, S. L. N. (2002). *Role of educators in identification of children affected by HIV/AIDS*. Presented at South Africa National Conference on Children Affected by HIV/AIDS, 2–5 June 2002.
- Ngwenya, S. & Ndlovu, D. (2001). *Establishment of options for orphans*. The Bushbuckridge Professional Foster Care Project.
- Nsetebu, E., Walley, J., Mataka, E., & Simon, C. (2001). Scaling-up HIV/AIDS and TB home-based care: Lessons from Zambia. *Health Policy and Planning*, 16, 240–247.
- Abstract:* Home-based care coverage in Africa is currently very low and likely to reduce drastically in the near future. This paper investigates the low coverage of home-based care programmes in Africa and uses two home-based care projects in Zambia as case studies. The very limited involvement of governments in the provision of home-based care services appears to be one of the main reasons behind the low coverage of home-based care in Africa. Governments therefore should provide some form of basic home-based care services and/or strengthen support to other institutions providing home-based care. In order to facilitate governments' involvement in home-based care activities, an analysis of tasks performed by community nurses and volunteers is used to identify tasks that government, missionary or NGO-employed nurses may be able to provide without, or with very limited, donor assistance. However, further research and development is needed to develop affordable, feasible and sustainable home care programmes that can be implemented by staff working in government, NGO and missionary health facilities. In addition, innovative strategies are required to establish effective partnerships between the NGO, missionary and government health services.
- Ntozi, J. P. (1997). Effect of AIDS on children: The problem of orphans in Uganda. *Health Transition Review*, 7, 23–40.
- The problem of orphans is serious in sub-Saharan Africa and has been increasing with the deaths of both parents from AIDS. A study of six districts of Uganda conducted in 1992 investigated the problem. Almost all the orphans are cared for by their extended family members who made the decisions to do so. It is recommended that more assistance be given to the family to enhance its capacity to cope with increased orphans expected in the future.
- Ntozi, J. P., Ahimbisbwe, F. E., Odwee, J. O., Ayiga, N., & Okurut, F. N. (1999). Orphan care: The role of the extended family in Northern Uganda. In J.C. Caldwell, I.O. Orubuloye & J.P.M. Ntozi (Eds). *The continuing African HIV/AIDS epidemic*. Canberra: Health Transition Centre Books.
- This paper examines the traditional role of the extended family in orphan care in northern Uganda. The extended family provides much support in looking after orphans, but has been overburdened by the AIDS epidemic with the result that some care is being provided by the older orphans, who are too young for the responsibility. The main problems of orphans are lack of money, inadequate parental care and some mistreatment by the caregivers.
- Ntozi, J. P. & Mukiza-Gapere, J. (1995). Care for AIDS orphans in Uganda: findings from focus group discussion. *Health Transition Review*, 5 Suppl., 245–252.
- The care of AIDS orphans in several regions of Uganda has recently been studied. The study also investigated how the various societies in Uganda have coped with the orphan problem since the onset of the AIDS epidemic. Changes in past and present coping mechanisms are discussed, with recommendations made for the future. Data were collected during 1992 from

241 men and 218 women in focus groups in Uganda's Hoima, Kabale, Mbarara, Masaka, Iganga and Mbale districts. The participating men and women were aged 19–92 years and 14–92 years, respectively. Orphan care by a surviving parent, care by relatives, and other assistance to orphans are discussed. Orphan care in Uganda has changed since the onset of the AIDS epidemic. The changes are due mainly to the large number of orphans which have overwhelmed the extended family structure. Nonetheless, relatives still care for orphans despite their own problems, albeit at great financial hardship to the caregivers. It is recommended that governmental and non-governmental organisations increase their levels of assistance to households caring for orphans. The authors further note the higher mortality of orphans, how many people who care for orphans are either too old or too young to fulfil the responsibility which they have assumed, and stigmatisation.

- Nyambedha, E. O., Wandibba, S., & Aagaard-Hansen, J. (2001). Policy implications of the inadequate support systems for orphans in Western Kenya. *Health Policy*, 58, 83–96.

This paper describes the support systems available for orphans in a rural Luo community in Nyang'oma sub-location in Bondo District of Western Kenya. Qualitative data were collected through in-depth interviews with orphaned children and their caretakers as well as key informants, and through focus group discussions with orphaned children, widows and community elders. Quantitative data were obtained by questionnaires administered to 100 caretakers of orphaned children. The most serious problem was inability of the orphan households to afford school fees, although lack of food, medical care and clothing were also prominent. The traditional, kinship-based support systems made a major contribution to catering for the orphans though the resources were far from enough. Various community-based groups in the area did not contribute significantly. The problem is getting desperate due to a combination of an exponentially increasing prevalence of orphans, poor socio-economic conditions and decline of the traditional support systems. For health planners and policy makers there are two major concerns. In the short term, a big and rapidly growing group of children are without adequate access to health services, while in the long term, the negative consequences for (in particular the girl) orphans' schooling pose a serious threat to the health of their future children. Based on the study findings, two recommendations are made: That the responsible parties address the issue of education for orphans rapidly and sufficiently and with due consideration of their food security and medical care; and that potential community resources such as kinship networks and community groups are mobilised in order to achieve the goal.

- Nyamukapa, C. A., Foster, G., & Gregson, S. (2002). Orphans' household circumstances and access in a maturing HIV epidemic in Eastern Zimbabwe. *Journal of Social Development*, 18, 2.

- Nyumbani. (2003). *Nyumbani: Providing an orphanage, hospice service, and community care for HIV+ infants and children in Africa*. [Available online: <http://www.developmentgateway.org/hiv>].

Notes: Nyumbani was founded in Nairobi, Kenya in 1992 by Father Angelo D'Agostino, SJ, MD. The orphanage was inspired by the rising number of HIV-infected children born and too often abandoned in Africa.

- Oak Foundation (2000). *Oak Foundation Report: AIDS orphan program in Zimbabwe*. Zimbabwe: Oak Foundation.

- Over, M. & Ainsworth, M. (1997). Coping with the impact of AIDS. In World Bank (Ed.), *Confronting AIDS: Public priorities in a global epidemic*. Oxford: Oxford University Press.

Abstract. The AIDS epidemic is straining the limited resources available to many developing country governments. How can governments provide support to those affected by AIDS without neglecting others in need or abandoning important development goals? The first part of the chapter shows that there are affordable, effective, and humane ways for governments in low-income countries to help ease the suffering of individuals infected with HIV. However, both governments and individuals in the poorest countries should be wary of funding expensive treatments with uncertain benefits. The second part of the chapter suggests how governments can cope with the increased demand for and scarce supply of healthcare

brought on by the AIDS epidemic in ways that are effective and compassionate, as well as fair and affordable. The third part proposes a strategy for developing countries to address the needs of poor families hit by the AIDS epidemic in the context of other poverty programmes. The chapter concludes with a summary of the policy recommendations for governments attempting to cope with the impact of HIV/AIDS on healthcare and poverty.

Parry, S. (2000). *Community care of orphans in Zimbabwe. The farm orphans support trust (FOST)*. <<http://www.togan.co.za.cindi/papers/paper5.htm>> [Announcement posted on the World Wide Web] <http://www.togan.co.za.cindi/papers/paper5.htm>.

Zimbabwe is a country where for many years the presence of HIV/AIDS as a threat in the country was not only not openly acknowledged, but was actually strongly denied. The concept of orphans was not an alarming spectre because of the belief that: 1. The extended family is always there and that there is no such thing as a real orphan in Africa; and 2. If there ever did exist a problem, the government would resolve it with orphanages. Now that AIDS is openly acknowledged, the country lacks the resources to deal with what appears to be a runaway situation.

The FOST programme can thus be summarised as having four aspects:

1. The structural: this is a skeletal organisation with a largely facilitatory role in awareness creation, networking, and in developing community care for orphans, and children in need, on commercial farms;
2. The farm worker community who will continue to care for their children and will, in innovative ways, contribute to their corporate upbringing;
3. The farmers who can provide many of the necessary resources essential to the well-being of children;
4. The agricultural industry and the society at large who have a corporate responsibility to assist in meeting the cost of raising the orphan generation. It is everyone's responsibility.

The problems of orphans and children in need are there and will escalate. The children deserve a chance, if only an equal chance to that of their non-affected peers. Not only do they deserve a chance but we must do all we can to ensure that the crisis which occasioned their orphanhood is not repeated in the next generation.

There is no doubt that both in human development and financial terms, the cost of care now will be less than the price society will ultimately pay for the neglect of these children to the streets, the bush or their life in institutions.

Pedro, P. P. T. (2002). *Promising experiences in mobilising the community toward the care taking of HIV/AIDS orphans and vulnerable children (OVC). The case of Komtoega village in Burkina Faso*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

The number of HIV/AIDS orphans and vulnerable children is growing rapidly. As at the year 2000, the following figures were registered in Komtoega: over 2 631 OVC registered, 60.22 per cent of them are under the age of 15 and have lost one or both parents. Those left with only one parent alive have 40 per cent chance of going to school; while those who lost both parents have only 10 per cent chance of being schooled. Thus, the phenomenon of street and homeless children is increasing drastically and needs to be addressed urgently. The issue of HIV/AIDS-affected children should be treated together with prevention programmes and HIV/AIDS caretaking organisations' activities. Considering the fact that each community member decides himself about his sexual habit, his attitudes toward people living with HIV and the type of care he wants to provide to HIV/AIDS OVC, it is imperative to introduce an approach that will enable every member to be a facilitator and share responsibilities relating to HIV/AIDS. This could be done by the following methods:

- Mobilising and training village-based committees that facilitate the mobilisation in favour of HIV infected people and OVC;
- Strengthening village-based committees in order to develop and enforce community response in favour of HIV infected people and OVC;
- Involving community members in taking decisions regarding the care of OVC and HIV infected people. Community members get more interested and concerned about the

welfare of OVC and HIV-infected people. Each member is willing to lend a helping hand at all cost and thus easily accepts the integration of OVC and HIV infected people in his family and environment. The community itself has the best answers to its problems and preoccupation regarding HIV/AIDS and people living with it. Every community, no matter how poor, illiterate and enclosed it is, has its own potentialities for its development.

Petty, C. (2002). *Child poverty and HIV/AIDS*. Presented at a Workshop on Children, HIV and poverty in Southern Africa, organised by SARP, HSRC, and Save the Children, 9–10 April, 2002.

A key aim to many agencies working with HIV-affected children – including SC UK – is to promote community-based care for those whose parents are sick or have died. The widespread impoverishment of many of the worst hit communities makes this task problematic. Unless additional resources are directed to these communities, the policy of ‘community-based care’ loses credibility and can become a byword for neglect, abandonment of the weakest and, from a rights perspective, abrogation of responsibility on the part of national and international duty bearers. However, getting the right inputs to the right people, where resources are scarce, infrastructure is weak, and livelihood systems themselves are affected by the pandemic, is problematic. In this presentation, we will describe practical research tools that should assist in this task, by enabling government and other agencies to more effectively:

- Assess the capacities of households with different characteristics to support additional children;
- Identify different ‘typologies’ of households in a given locality, and the inputs that could most effectively strengthen their economic status;
- Illustrate and explain the way in which HIV/AIDS will affect production, cash income and expenditure patterns of affected households, and the policy and programme interventions needed to mitigate these effects.

The methodologies that are used are the household economy approach and the ‘intra household model’.

Phiri, S. N. (2002). *Responding to the needs of children and adolescents affected by AIDS in sub-Saharan Africa: Issues and challenges: Perspectives from communities*. Available online: www.synergyaids.com/documents/3510_Phiri_Presentation.ppt.

Phiri, S. N., Foster, G., & Nzima, M. (2001). *Expanding and strengthening community action: A study of ways to scale up community mobilization – Interventions to mitigate the effect of HIV/AIDS on children and families*. Washington, DC: DCOF/USAID.

The Displaced Children and Orphans Fund (DCOF) requested a three-person team to conduct this study. The members of the team were Stanley Ngalazu Phiri, former Director of the Community-Based Options for Protection and Empowerment (COPE) program of Save the Children Federation (US) in Malawi; Dr. Geoff Foster, outgoing Director of Family AIDS Caring Trust (FACT) in Zimbabwe; and Masauso Nzima, former Deputy Director of Project Concern International’s Orphans and Vulnerable Children (OVC) program in Zambia.

HIV/AIDS has had a debilitating effect on many nations, communities, and families. Some parts of the world have been particularly hard hit, with sub-Saharan Africa bearing the brunt of the epidemic. Of the approximately 50 million HIV infections in the world, more than 72 per cent are in sub-Saharan Africa. In addition, 84 per cent of AIDS deaths are from Africa; of the 13.2 million children who have had mothers or both parents die because of AIDS, 95 per cent are in Africa. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), the numbers of orphans will continue to rise, reaching 40 million by 2010 (UNAIDS 2000). Even if rates of new infections levelled off, mortality rates would not plateau until around 2020 because of the unusually long HIV incubation period. Hence, the proportion of orphans will remain unusually high for several decades, at least until 2030. UNICEF estimates that Botswana, Malawi, Zambia, and Zimbabwe will have the highest proportions of orphans through this period (Levine & Foster 2000). Even though Africa has been hardest hit by the pandemic, the problem is not unique to that continent. There will be

large-scale effects in Asian countries such as India, Cambodia, Myanmar, and Vietnam. The former Soviet Union countries have experienced a six-fold increase in the number of HIV infections since 1995. In the United States, HIV rates and orphaning are on the increase among poor urban and rural populations (UNAIDS 2000).

Clearly, the major – and indeed most immediate – challenge is scaling up the responses to match the magnitude and duration of the HIV/AIDS pandemic. Families and communities, absorbing and providing for orphans as best as they can, are the first line of response to the pandemic. However, the unprecedented scale of the problem has weakened the ability of families and communities to respond as they have in the past. Extended families must be strengthened to absorb the growing numbers of orphans in view of increasing dependency ratios as a result of increasing deaths among adults. Community mobilisation and capacity building are practical responses to the effects of HIV/AIDS on families and communities. Little is known, however, about how well communities are actually coping, what efforts appear to be successful, and what circumstances may affect those efforts. Even less has been documented about how effective community mobilisation approaches may be scaled up to benefit more children and families.

Phiri, S. N. & Webb, D. (2002). The impact of HIV/AIDS on orphans and programme and policy responses. In G. A. Cornia (Ed.), *AIDS, public policy and child well-being*. New York: UNICEF.

As policy-makers assess the growing weight of the orphan and children affected by AIDS burden, there are key policy challenges apparent. These challenges relate to: 1. Reaching consensus on policy related definitions of orphans and vulnerable children; 2. The emergence and realisation of rights-based approaches to programming for orphans and vulnerable children; 3. The explication and scaling up of 'good' practices in supporting orphans and vulnerable children; 4. Effective flow of 'resources to the base'; and, finally 5. Mobilising political will. These challenges overlap and interrelate, but constitute the key constraints on widespread and effective responses. The synergy needed between community-rooted responses and international and national political will is slowly emerging but is still fundamentally absent. Policy priorities relate to resources primarily, and the balance between community mobilised resources and external financing and intervention. This balance will vary from place to place and current operational research can provide an understanding of economic realities to be combined with the emerging ethical and principle based ethos of programmers. Addressing the psychosocial welfare elements of orphans and children in affected communities is now a matter of urgency. The cycle of infection will be exacerbated by young people growing up in contexts where mental ill health is rife, combined with feelings of isolation, despair and social disenfranchisement. The responses required are in themselves not complex, but are needed at such an unprecedented scale that we are only starting to comprehend the implications. While constraints remain in the form of chronic and deepening poverty, capacity limitations and political indifference at all levels, the challenges have never been greater.

Poulter, C. (1997). *The impact of HIV/AIDS on families in Lusaka*. Lusaka: Family Health Trust/UNICEF.

Poulter, C. A. (1997). *Psychological and physical needs profile of families living with HIV/AIDS in Lusaka, Zambia*. Research Brief No. 2. Lusaka: UNICEF.

Prang, C. (2002). *Care and support for orphans and vulnerable children based on strengthening family and community support structures in Cambodia*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

The growing demand for care and support of orphans and vulnerable children in Cambodia is creating the need for new ways to improve coping mechanisms among families and communities. Greater knowledge of HIV/AIDS in communities can reduce discrimination against PLWHA but this alone does not help poor families in supporting orphan children. *Description:* Increasing coping mechanisms for families and communities promotes sustainability and effectiveness of care and support programmes. Providing knowledge and

skills to care for the orphan children combined with supporting recipient families by integrating other development programs such as micro-credit, agriculture, vocational training, psychosocial support and access to affordable medical care can help meet families needs in caring for orphan children. *Lessons learned:* Some poor families volunteer to adopt children orphaned by AIDS, and some refuse. Collaboration with local authorities is one method of increasing community support for foster care. Community members are now aware and concerned of the problems of orphaned and vulnerable children, but due to poverty, they do not have the ability to solve their problems and support their needs. The creation of village-based volunteers can help address these issues, encourage families to foster orphans and provide the knowledge and skills needed to meet their basic needs. *Recommendations:* Strengthening the capacity of families, communities and CBOs to care for and provide follow-up support for orphan children by collaborating with local religious leaders, organisations providing vocational training opportunities, social workers, and authorities, continues to decrease discrimination against children affected by AIDS and other chronic illnesses, and reinforce the importance of children remaining in families and not in institutions

Quinlan, T. & Desmond, C. (2003). Costs of care and support. In HEARD (Ed.), *Literature review: The economic impact of HIV/AIDS on South Africa*. Durban: HEARD, University of Natal.

Rau, B. (2002). *Intersecting risks: HIV/AIDS and child labour* (Working Paper 8). Geneva: International Labour Office.

The prevalence of child labour and the risk of children becoming infected with the human immunodeficiency virus (HIV) are both influenced by the socio-economic factors that shape children's lives. An individual child does not choose to work in hazardous conditions. Similarly, an increased risk of HIV infection does not simply result from individual behaviour and choices. Rather, the acquired immunodeficiency syndrome (AIDS) pandemic is driven by the powerful inequalities that exist between social groups. Although HIV/AIDS cuts across socio-economic groups, its transmission follows the paths created by those inequalities, particularly those that intensified during the last three decades of the twentieth century. From the outside, some of the inequalities that foster the spread of HIV/AIDS may appear mundane: no ready access to diagnosis and treatment of a sexually transmitted disease, living away from a family for many months at a time, or working at a job that pays too little to buy adequate food. These have been some of the situations so conducive to the rapid spread of HIV/AIDS. Significant changes in the global economy over the past 50 years have sharpened some of the inequalities that HIV has readily exploited. The AIDS pandemic is partly fuelled by children in the workforce, working in prostitution or as low-cost labourers who might be sexually exploited. And, as the pandemic has spread among adults, millions of children have been affected: they have been orphaned and their opportunities for a complete education seriously compromised. Many of these children have had to enter the workforce to survive.

Rehle, T., Saidel, T., Saidel, S., & Magnani, R. (2003). *Evaluating programs for HIV/AIDS prevention and care in developing countries: A handbook for program managers and decision makers*. Arlington: Family Health International.

The focus of this handbook is on evaluating programmes related to the sexual transmission of HIV. It was developed for a target audience of programme managers and decision makers of service delivery programmes as opposed to researchers who are evaluating the efficacy of interventions through experimental or quasi-experimental research methods.

Section I lays the foundation for HIV/AIDS programme evaluation by describing the current consensus on generic concepts, approaches, and frameworks (Chapter 1) and by outlining the practical development of an integrated evaluation and monitoring plan for projects (Chapter 2).

Section II describes the operational approaches for evaluating the core programme strategies necessary to effectively reduce the sexual transmission of HIV (Chapters 3, 4, 5, 6), illustrating the unique and often very disparate methodologies needed to evaluate different programme components. The section concludes with long overdue guiding principles on how to evaluate HIV/AIDS care programmes (Chapter 7). This may help to increase the commitment to

funding care-related activities by providing donors and decision makers with the necessary feedback to determine whether the invested resources have yielded the expected results.

Section III focuses on measuring behaviour change as the key outcome of standard prevention efforts. State-of-the-art methodologies and survey instruments for collecting behavioural data (Chapters 8, 9, 10) and assessing their validity and reliability (Chapter 11) are covered here, complemented by a chapter on tools for collecting qualitative information (Chapter 12). The section concludes with effective strategies for disseminating survey data to key audiences (Chapter 13).

Finally, Section IV tackles evaluation issues related to assessing program impact, emphasising the need to analyse behavioural and sero-epidemiological data in tandem (Chapter 14). It also describes a newly developed tool for estimating the impact of different prevention strategies on HIV transmission (Chapter 15), and provides practical guidelines for cost and cost-effectiveness analysis (Chapter 16, 17).

The individual chapters in this handbook attempt to follow the logic of a programme evaluation cycle, and though they are written as 'stand-alone pieces', they are clearly interconnected. Cross-references to other chapters are found throughout the book to assist readers in understanding how the individual components of evaluation fit into the larger whole.

- Reid, E. (2003). *Children in families affected by the HIV epidemic: A strategic approach*. <http://www.undp.org/hiv/issuesli.htm> [Announcement posted on the World Wide Web].
- Richter, L. M. & Swart-Kruger, J. (1995). AIDS risk among street children and youth: Implications for intervention. *South African Journal of Psychology*, 25, 31–38.
- With the co-operation of staff and volunteers from non-governmental programmes in nine South African cities, focus group discussions were held with 141 street children and youth, 79 of whom were enrolled in shelter programmes while 62 were still living independently on the streets. The group discussions focused on knowledge about transmission and prevention, attitudes towards AIDS and people with AIDS, and sexual and other behaviours related to AIDS risk. Both quantitative and qualitative information on the topics covered was extracted from the transcriptions of the discussion. The results indicated that, on a superficial level, South African street youth possessed relatively good knowledge about transmission and prevention. However, a more critical analysis showed that knowledge is obscured by moral imputations. In addition, street youth disclosed extremely negative attitudes to condoms and to people with AIDS. Accounts of sexual behaviour confirmed that street children and youth engaged in a number of high-risk behaviours. The results are discussed in terms of their implications for intervention and, in particular, the inadequacies of the Health Belief Model and related theories, as the sole theoretical foundation for the design of intervention programmes.
- Richter, L. M. (2000). *Impact of social and environmental conditions on child care and development*. Proceedings of a Fogarty Maternal and Child Health Workshop, held at the Rob Roy Hotel and the Valley Trust, Durban South Africa, 14–18 August, 2000.
- Richter, L. M. (2001). Slipping through the safety net. *Children First*, 5, 30–33.
- Richter, L. M. (2001). *The impact of HIV/AIDS on South Africa children*. Cape Town: Human Sciences Research Council.
- Richter, L. M. & Shisana, O. (2001). *Children affected by HIV/AIDS*. Unpublished work.
- Rosen, J. E. (2002). *Responding to the education needs of children and adolescents affected by AIDS in sub-Saharan Africa*. Report on Town Hall Meeting, October 23, 2001. Washington DC: Synergyaids.
- Russell, M. & Schneider, H. (2000). Models of community-based HIV/AIDS care and support. In Health Systems Trust (Ed.), *South African Health Review*.

Over the past few years, the previously largely silent epidemic of HIV in South Africa has shifted to a visible epidemic of AIDS. The impact of this on health services, families and communities are emerging at a rapid pace. In an attempt to deal with this impact, it is

common practice for health care facilities to ration services to people with HIV, with much of the burden of caring for the ill falling onto households and communities. In South Africa, 'home-based care' has become a national policy priority. This chapter presents the findings of a review of various NGO, community and religious-based projects which are involved in helping people infected and affected by AIDS.

The chapter looks at programmes which provide funding, technical assistance and support to communities, those which are involved in advocacy and community mobilisation, drop-in centres and support groups, home visiting and comprehensive home-based care as well as the care of orphans. The challenges to these programmes are listed and discussed, as are the factors that promote their success.

- Rutayuga, J. B. (1992). Assistance to AIDS orphans within the family / kinship system and local institutions: a program for East Africa. *AIDS Education and Prevention*, Fall, Suppl., 57–68.

IDS will cause the deaths of 1.5–2.9 million women of reproductive age in Africa during the 1990s which in turn will result in 3.1–5.5 million orphans especially infants (6–11 per cent of the <15-year old population). The large numbers of orphans overwhelms and weakens the family/kinship network which often abandons them. The orphans and their families are sometimes victims of discrimination due to misunderstandings about AIDS. Most orphans in East Africa live in rural areas. Many relatives who become responsible for the well being of these orphans tend to be old, in bad health, and/or socio-economically disadvantaged. Thus they cannot give adequate care to these orphans who, under these conditions, are often neglected, abused, and dislocated. The extended family/kinship system therefore needs outside assistance. Financial assistance and social services can help ensure stability for these children within the family/kinship system which is preferable to institutions. The host families and the orphans must have access to basic medical services including immunisation, antimalarials, and screening for HIV and sexually transmitted diseases (STDs). Public health messages about STDs, HIV/AIDS, nutrition, and health promotion are also needed. Religion can contribute to public health education and provide a moral and ethical base for the families and orphans with which they can develop their sense of self-worth. Assistance programmes should encourage families to develop and boost food resources on the land left by deceased parents. Such programs should also provide food subsidies and advocate breastfeeding by a lactating relative, if needed, to ensure adequate nutrition. The programmes need to see to the inclusion of orphans into the educational system, and they need to advocate and facilitate agricultural, economic, and community development. Funding must come from non-profit organisations, donor nations, and multilateral organisations.

- Ryder, R. W., Kamenga, M., Nkusu, M., Batter, V., & Heyward, W. L. (1994). AIDS orphans in Kinshasa, Zaire: Incidence and socioeconomic consequences. *AIDS*, 8, 673–679.

A longitudinal case-control study was conducted over the period 1986–90 to assess the incidence, morbidity, mortality, and socio-economic consequences of becoming an AIDS orphan in Kinshasa, Zaire. One group of control children was comprised of age-matched children with HIV-1-seropositive mothers who were alive at the time of death of the AIDS orphan case mother. Participants were recruited from the obstetric ward and follow-up clinic at two large municipal hospitals in Kinshasa, Zaire and included 466 HIV-1 seropositive women, their children and their fathers, and 606 HIV-1-seronegative women, and their children and their fathers. The AIDS orphan incidence rate was 8.2 per 100 HIV-1 seropositive women-years of follow-up. Vertical rates of HIV-1 transmission were 41 per cent and 26 per cent respectively, in AIDS orphan cases and in control children with HIV-1-seropositive mothers. Among children without vertically acquired HIV-1 infection, morbidity rates and indices of social and economic well-being were similar for both AIDS orphans and control children. Five of 26 AIDS orphan cases and three of 52 control children died during follow-up. The authors conclude that children with HIV-1 seropositive mothers had a considerable risk of becoming AIDS orphans, but the presence of a concerned extended family appeared to minimise any adverse health and socio-economic effects experienced by orphan children.

Salvation Army (2002). *First regional think tank on psychosocial support for children affected by HIV/AIDS*. Harare, Zimbabwe: Salvation Army.

At the UNICEF/USAID/DIFID-organised conference on Orphans and Vulnerable Children in Lusaka, November 2000, it was recognised that there was an urgent need to accelerate responses in the field of psychosocial support and life-skills education for children affected by AIDS in Africa. A working group on psychosocial OVC issues identified the need for a smaller specialised conference on these issues.

Thirty-five implementers and policy-makers worked to share experience, build consensus and plan for a regional scaling of psychosocial support for children affected by AIDS (PSS-CABA). Five key themes were explored:

1. Formulation of working definition on psychosocial support, how to operationalise the concept of 'walking the road', and identify key operational research areas;
2. Partnership criteria/exchange learning/accountability and transparency;
3. Objectives/target groups/ strategies for regional scaled up response;
4. Monitoring, evaluation and indicators for psychosocial support programme impact assessments;
5. 'School without walls' – Regional training concept for mentors and field staff in psychosocial support for children affected by AIDS.

The participants also produced a statement or declaration for the upcoming UN special session on children regarding psychosocial support for children.

Saoke, P. & Mutemi, R. (1995). *Needs assessment of children orphaned by HIV/AIDS. Final report*. Nairobi, Kenya: APMS.

This study aimed to ascertain the immediate needs of AIDS orphans, the underlying socio-economic issues, as well as the existing care structures in Kenya. The study was conducted in Kisumu and Busia in the Western region, Kitui in the Eastern Province, and Mombasa in the Coast Province. The data were collected by conducting an interview among 304 orphan children and 98 caretakers, single focus group discussions in each study site, 20 case histories, and repertoire grid. Results revealed that the rural areas and the orphans were severely affected by the combined effects of both inflation and unstable climatic conditions. Such have affected agricultural output in the last few years. Most of the orphans lacked the basic necessities for survival – food, shelter and clothing. In some parts of the study areas, fostering families were found incapable of coping with their own health demands. In other sites, chloroquine-resistant malaria, dysentery, meningitis and typhoid present serious health problems for the rural poor who have taken the burden of caring for the bulk AIDS orphans. Furthermore, most of the caretakers spent 90 per cent of their time generating food, which was hardly enough for their families. The social impact of orphans who are deprived, hungry, unemployed, poorly socialised and uneducated is likely to radically change the rule of law and order. These orphans are extremely vulnerable to exploitation by others.

Saoke, P., Mutemi, R., & Blair, C. (1996). Another song begins: Children orphaned by AIDS. In USAID AIDSCAP/Family Health International (Ed.), *AIDS in Kenya: Socioeconomic Impact and Policy implications*. Washington, DC: USAID.

SARPN/HSRC/Save the Children (2002). *Children, HIV and Poverty in Southern Africa. Workshop papers*. Pretoria: HSRC.

Saunders, N. & Brisbane, C. (2001). *Speak out: On vulnerable children, HIV/AIDS, and housing*. Presented at workshop held on 14 March 2001 at the AF Wood Centre, Pietermaritzburg.

In January 2000, a number of NGOs active in the city of Pietermaritzburg were invited by the Kwa-Zulu Natal Department of Housing to a workshop, to seek their assistance in implementing housing programmes for people living with HIV/AIDS (PWAs) and AIDS orphans. The majority of NGOs involved in service provision rejected the initiative, which focuses primarily on providing institutional and residential care. The view of those service providers, and the provincial Department of Welfare, was that the housing policy is contrary

to trends in welfare policy and practice, where institutional care and statutory support for such institutions is being phased out in favour of family- and community-centred support strategies.

Participants/mothers made the following recommendations as an attempt to address the realities of HIV/AIDS with regard to vulnerable/distressed children: Provision of shelter/housing is a necessity; provision of good infrastructure is necessary; mothers should be given grants that will enable them to provide for basic needs such as food and clothes; provision of free education is necessary; provision of mobile clinics; effective mechanism to monitor the use of public finance (ensure effective use); disseminate information and promote education campaigns; counselling for both children and mothers; social workers should pay regular visits; monitor the living conditions that children are exposed to on a daily basis.

Save the Children (1996). *Promoting psychosocial well-being among children affected by armed conflict and displacement: Principles and approaches from the international Save the Children Alliance*. London: Save the Children Alliance.

Save the Children (2001). *Child friendly version of the revised draft outcome document 'A world fit for children'*. London: Save the Children Alliance.

The document is called 'A world fit for children'. It is also known as the 'Outcome Document'. It outlines the promises that world leaders and governments will be making to address children's rights for the next ten years. What you are about to read is a childfriendly form of the original document. We believe that it is vital that children and young people have the possibility of expressing their views on this key document. This childfriendly version is meant to help this happen. It might seem like there are a lot of pages but we felt it was important for you to know what was in the original document. We have also included the original so that you have everything you could possibly need. The childfriendly version follows the same format and paragraph numbering as the original document. If you still need more information the UNICEF web site is full of information @ www.unicef.org. Attached with this document is a list of words and their meanings. It is there to help you out with some of the more difficult words that can be found throughout the document.

Save the Children (2001). *The role of stigma and discrimination in increasing the vulnerability of children and youth infected with and affected by HIV/AIDS*. Pretoria: Save the Children.

Save the Children (2001). *'A world fit for children'. The views of children and young people*. London: Save The Children.

Save the Children, UK (2003). *Care for children infected and those affected by HIV/AIDS: A handbook for community health workers, Uganda*.

This is a practical handbook for community-based health workers, and others, who are responsible for the care and support of children living with or affected by HIV/AIDS. The handbook provides guidelines that aim to increase these children's access to proper care and support within the communities in which they live.

A training manual to accompany the handbook will soon be available on the website as well.

Schneider D.H. & Dorrington, R. E. (2003). *Estimates of the number of HIV/AIDS orphans in various Southern African countries*. Available online:

http://www.aids2002.com/Program/ViewAbstract.asp?id=/T-CMS_Content/Abstract/200206290751023152.xml.

Estimating the number of children likely to be orphaned by HIV/AIDS is not a simple task, yet in many sub-Saharan countries coping with the rapidly rising number of orphans is fast becoming a most urgent problem. *Method:* This paper presents the results of applying an adaptation of a model for estimating the number of HIV/AIDS maternal, paternal and dual orphans developed by Johnson (Johnson & Dorrington 2001) to projections of the demographic impact of the epidemic in a number of sub-Saharan countries produced using the ASSA2000 Urban-Rural and Lite models (Dorrington & Schneider 2002). The results are compared with results from DHSs in countries where these are available and estimates derived of the implied bias in the DHS results as well as of the extent of absent fathers. These

results show that the DHSs consistently underestimate the extent of orphanhood, and that there are absent (but not dead) fathers in all countries, but particularly in South Africa. Orphanhood is likely to be most extensive in Southern Africa and South Africa in particular. *Conclusions:* The model for approximating the number of orphans from projections using models developed by the Actuarial Society of South Africa appear to be reasonable and suggest that the DHSs tend to underestimate the extent of orphanhood and that paternal orphanhood is likely to be particularly pronounced in South Africa, both owing to the relatively high levels of male mortality as well as a relatively high level of absent fathers.

Semali, I. & Ainsworth, M. (1995). *The impact of adult deaths on the nutritional status and growth of young children*. Presented at IXth International Conference on AIDS and STD in Africa, Kampala, Uganda.

Sengendo, J. & Nambi, J. (1997). The psychological effect of orphanhood: A study of orphans in Rakai district. *Health Transition Review*, 7, 105–124.

This paper examines the psychological effect of orphanhood in a case study of 193 children in Rakai district of Uganda. Studies on orphaned children have not examined the psychological impact. Adopting parents and schools have not provided the emotional support these children often need. Most adopting parents lack information on the problem and are therefore unable to offer emotional support; and school teachers do not know how to identify psychological and social problems and consequently fail to offer individual and group attention.

The concept of the locus of control is used to show the relationship between the environment and individuals' assessment of their ability to deal with it and to adjust behaviour. Most orphans risk powerful cumulative and often negative effects as a result of parents' death, thus becoming vulnerable and predisposed to physical and psychological risks. The children were capable of distinguishing between their quality of life when their parents were alive and well, when they became sick, and when they eventually died. Most children lost hope when it became clear that their parents were sick, they also felt sad and helpless. When they were adopted, many of them felt angry and depressed. Children living with widowed fathers and those living on their own were significantly more depressed. These children were also more externally oriented than those who lived with their widowed mothers.

Teachers need to be retrained in diagnosing psychosocial problems and given skills to deal with them. Short courses should be organised for guardians and community development workers in problem identification and counselling.

Serpell, N. & Williamson, J. (1999). *Review of the COPE 11 and OVC programs*.

http://www.usaid.gov/pop_health/dcofvvf/dcwvprogs.html [Announcement posted on the World Wide Web].

Shung-King, M., Abrahams, E., Giese, S., Guthrie, T., Hendricks, M., Hussey, G., Irlam, J., Jacobs, M., & Proudlock, P. (2000). Child health. In Health Systems Trust (Ed.), *South African Health Review 2000*.

Children have been prioritised in the process of South Africa's transformation. In the health sector, a number of policies and programmes have been formulated in the past five years. Implementation of these policies and programmes has not been uniformly successful. This chapter examines the progress made within the health sector and whether children's health needs have been adequately addressed. Health status indicators for children reflect a mixture of successes and concerns. The majority of areas in the country still have child mortality rates that are much higher than in other countries with comparable levels of income. Immunisation coverage has not improved much in the last five years. Yet, there has been a considerable drop in childhood infectious diseases such as measles, polio and neonatal tetanus. The countrywide Integrated Management of Childhood Illnesses has the potential to improve child health significantly. Two problems that have emerged as serious threats to child health and well-being are highlighted. These are the rapidly rising rate of HIV-infections, and the scourge of trauma and violence against children. The current organisation and delivery of child health services are not adequately equipped to deal with these emerging problems. The chapter

concludes that some important strides have been made in terms of responding to the health needs of children, but many challenges and gaps still remain.

- Siwela, J. & Germann, S. (1996). *Mobilising community coping mechanisms to cope with rising numbers of orphans – An integrated approach*. Presented at the XIth International Conference on AIDS, Vancouver, 7–12 July, 1996. (abstract number TH.D. 4873).
- Skweyiya, Z. S. T. (2002). *Speech by Minister Z S T Skweyiya* at the opening of the Conference on Co-ordinated Action for Children affected by HIV/AIDS, 2 June, 2002.
- Skyways: Insights for executives on the move (2001, January 11). *The children are our future*. Skyways (Insights for executives on the move).
- Sloth-Nielsen, J. (2003). *Provisioning for child-headed households*. Community Law Centre, University of the Western Cape.

Projections indicate that the number of AIDS orphans in South Africa will double to 800 000 by the year 2005. Indications are that the majority of children orphaned by AIDS at present are not being accommodated through formal placements in alternative care structures. The African kinship care system that would once have absorbed children without parents into communal life can no longer be relied upon to fulfil that function. Current figures suggest that foster parents are looking after 35 per cent of orphaned children and only 0.1 per cent are being adopted. A significant percentage of children orphaned by AIDS will find themselves in households headed by children.

Recent community-based research into approaches to caring for children orphaned by HIV/AIDS details seven typical models currently in use for these vulnerable children. These include:

1. Independent orphaned households in which children have no formal assistance in looking after one another;
2. Orphaned households where informal care is offered by community members to children in their area (also called indigenous care);
3. Government- or NGO-run programmes that seek to identify and support children, for example, through income-generation and awareness-raising programmes;
4. Home-based care offered both to critically ill adults, and their dependent children;
5. Non-statutory residential care, operating from private homes without them being registered as places of care or children's homes; and
6. Recognised formal placements of orphans with other families.

A right to family life:

Although international treaties affecting children do not adequately deal with the position of states facing large-scale orphanhood, these treaties clearly endorse a policy that orphaned children should not be institutionalised, but should, where at all possible, grow up in some form of family environment. In the *Grootboom judgment* the Constitutional Court held that the socio-economic rights of children to basic nutrition, shelter, basic health care services and social services (s 28[1][c]) should be understood in the context of the child's right to family care or parental care, or appropriate alternative care (s 28[1][b]). Parents and other family caregivers thus have the primary duty to provide children with the socio-economic necessities set out in s 28. But when children are orphaned or abandoned and thus find themselves without families, the responsibility for fulfilling their socio-economic rights rests squarely on the state.

Ensuring the survival and development of children:

The State consequently has two distinct constitutional duties:

1. It has a duty to ensure that children in child-headed households are linked with some form of parental, familial or institutional care.
2. It has a duty to provide the resources necessary for the survival and development of the children.

The latter duty in s 28(1)(c) of the Constitution is not subject to the qualification of available resources. This means that ultimately the state has a constitutional duty, as the surrogate

'parent' of such children, to ensure that their basic needs are met. Given the especially vulnerable position of children in child-headed households, it can be argued that the state has a primary obligation to provide immediate and direct assistance to such children to ensure their continued survival and development. The state could fulfil these obligations through the payment of grants, the direct provision of food and clothing, providing relief from payment of school fees and the like.

The government has begun to take steps to fulfil its constitutional obligations with regards to child-headed households with the adoption of a National Integrated Plan for Children and Youth Infected and Affected with HIV/AIDS (NIP). This plan endorses a community and home-based care model, which has reportedly been most successful in other African countries. These models are based on a children's rights approach and accepts that children orphaned by AIDS face special challenges. Such children face threats to their survival, threats to their security, and have special needs such as the need for self-actualisation, palliative care and bereavement counselling. These needs, it is said, are often best met in supportive community settings. Community and home-based care models mostly use volunteers as the backbone of a care-giving strategy. However, given the fact that the state bears the primary responsibility for the welfare of orphaned children, such home-based care must include some form of material assistance to ensure the survival and development of orphaned children. The NIP does not only provide for community and home-based care, but also for voluntary counselling and testing for HIV, life-skills and community-outreach programmes. Currently, the preponderance of the annual NIP budget has been allocated to the life-skills and education component of the programme, and is thus spent on HIV-prevention programmes in schools. Only a relatively small proportion of the overall budget is dedicated to the community and home-based care programme, although this proportion increases over time. Even then, the budget allows for an amount of R120 million to be spent on community and home-based care programmes in the 2004–2005 fiscal year, which given the huge demand, seems like a very small amount indeed.

Although the state's chosen policy response towards children living in child-headed households can be regarded as a reasonable one, the programme falls short of the criteria spelt out in the Grootboom case because of the low priority given to the care of AIDS orphans within the fiscal allocations. In addition, the programme does not make adequate provision for emergency relief for those in desperate need. Seen together with the difficulties that are presently experienced at grassroots level in accessing material support and social security, there are substantial barriers to the implementation of the socio-economic rights of children living in child-headed households.

Although this is a difficult and complex issue, the failure on the part of the state to allocate adequate resources to address the very serious needs of one of the most vulnerable groups in society cannot be judged as reasonable.

Smart, R. (2000). *Children living with HIV/AIDS in South Africa – A rapid appraisal*. Pretoria: Save The Children.

Whilst looking at all children living with AIDS, the document's principal focus is on affected children. It shares the salient lessons learnt from the experiences of selected models of care and support that are already in the frontline of the national response against the pandemic. 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. It emphasises the need for a multi-sectorial approach to HIV/AIDS, calling upon the private and public sectors, NGOs, families and communities to work together to develop responses that mitigate the worst of the pandemic's impact on children. The recommendations will additionally provide core input for the National Strategic Framework for Children and HIV/AIDS. This is a process led by national Government, which will address the immediate and urgent needs of children at the present time and also develop a longer-term strategy that will prepare SA adequately for future challenges. The need to develop such a response is, of course, paramount. SA already has suffered one 'lost generation'. It can ill afford to lose another.

Smart, R. A. (2003). *Policies for orphans and vulnerable children: a framework for moving ahead Policy*. Pretoria: USAID/Save the Children.

This document presents a summary of the global OVC situation and identifies policy-level gaps in national responses to the growing crisis. Importantly, the report proposes a country-level OVC 'policy package' and offers recommendations to guide future policy dialogue and action. Adopting laws that protect the rights of all children, encouraging multi-sectoral collaboration, placing a special emphasis on educational opportunities, and establishing systems to identify the most vulnerable children are all crucial aspects of a comprehensive OVC policy response.

Smart, R. A. (2003). *Children affected by HIV/AIDS in South Africa: A rapid appraisal of priorities, policies and practices*. Pretoria: USAID/Save the Children.

Smith, C. L. (1996). *Planning for the future. Care of children whose parents have AIDS*. Colchester, UK: Development Services Consultancy in HIV/AIDS & Childcare.

Some, P. A. & Van Renterghem, H. L. M. (2003). *Community responses for orphans and vulnerable children (OVC) in Burkina Faso*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.asp>].

Community responses for OVC based on community mobilisation and awareness raising in the community appear to provide a sustainable strategy to reduce the impact of HIV/AIDS on families and communities. This abstract describes the mechanisms put in place in 55 villages in Burkina Faso for mobilising community care and support activities for OVC. In order to plan and implement community responses for OVC, the village communities, after conducting a participatory analysis of the situation and the responses, identified priority actions to take and the organisational set up to put in place to implement the responses. At village level, a committee for the well-being of children was set up. This committee brings together all the resource people of the community: notables, customary, religious and opinion leaders, teachers, health care workers, social workers, etc. Community volunteers are identified and trained to ensure regular follow up of OVC and the families caring for them. In collaboration with teachers, an emphasis is placed on ensuring that OVC are able to attend school. Confidence-building and awareness-raising activities are developed at school and in the village for out-of-school children. Meetings are organised on to work with the volunteers on the psychosocial aspects of care. At the same time socio-economic initiatives are set up to strengthen the capacity of the families that care for OVC.

Lessons learnt:

In view of the importance and the complexity of care and support for orphans and vulnerable children and considering the preliminary results of the current experiences, it appears that community mobilisation and involvement offers a comprehensive answer to increasing needs for care and support for OVC in Burkina Faso.

Recommendation:

Community responses developed by communities must be supported, promoted and should be models for the implementation of a national response to the plight of OVC.

Ssekkadde, R. S. B. (2003). *HIV/AIDS and orphans in Uganda: A church community response from the Diocese of Namirembe, Province of the Church of Uganda*. Namirembe, Uganda. Accessed from the HIV/AIDS, Malaria, and Tuberculosis Resource Project (HARP). <http://www.ccih.org/harp>

Details the Diocesan response to the AIDS crisis in Uganda and the results of effective church-community partnerships to improving health and changing behaviour of children, youth, and adults. Focuses on the challenge of taking care of orphans in the wake of the epidemic.

Stein, J. (1997). The impact of HIV/AIDS on the household. *AIDS Bulletin*, 6, 20–23.

The severe economic and psychosocial consequences of HIV have overwhelmed the capacity of both individual households and communities to absorb the impact of the epidemic. Moreover, in countries such as SA, many HIV-positive individuals are homeless or without effective family structures. This article reviews the impact of HIV on households during the

initial stages of infection, AIDS disease, and bereavement. The psychosocial stress and heightened depression and anxiety that accompany the initial disclosure of HIV often diminish households' ordinary coping skills, with adverse effects on the school and work performance of family members and the quality of family relationships. Multiple AIDS-related illnesses reduce the capacity of wage-earners to work and incur additional expenditures for medicines and health care. The quality of care provided to children may be adversely affected; in many families, children become caregivers to a parent. As a result of the social stigma surrounding AIDS, AIDS-related deaths may not be socially acknowledged, impeding resolution of the burials. As a result of patrilineal inheritance laws, women widowed by AIDS become dependent on their husband's family for support. The tradition of orphan care through the extended family network has broken down in countries such as Uganda and Zimbabwe, where orphan rates close to 25 per cent are reported in some areas. There is an urgent need for societal interventions to cushion the impact of HIV/AIDS on the household and community.

Steinberg, M., Kinghorn, A., Söderlund, N., Schierhout, G., & Conway, S. (2000). HIV/AIDS – Facts, figures and the future. In Health Systems Trust (Ed.), *South African Health Review 2000*. Durban: Health Systems Trust and the Henry J Kaiser Family Foundation.

Using data obtained from annual surveys of pregnant women attending public sector antenatal clinics, this chapter attempts to estimate the current and future size and impact of the HIV/AIDS epidemic by means of projection models. The chapter looks at the possible impact of HIV/AIDS on the economy of the country as well as the economies of the households, the capacity of traditional coping mechanisms to deal with ill and dying people and orphans, future healthcare costs in both the public and the private sectors, and the possible impacts of various interventions on the growth of the epidemic.

Steinberg, M., Johnson, S., Schierhout, G., Ndegwa, D., Hall, K., Russell, B., & Morgan, J. (2002). *Hitting home: How households cope with the impact of the HIV/AIDS epidemic – A survey of households affected by HIV/AIDS in South Africa*. (Rep. No. 6059). Washington, DC: The Henry Kaiser Family Foundation.

This report summarises the results of a survey of 771 AIDS-affected households in different parts of South Africa. The households were randomly selected from the client lists of NGOs providing support to AIDS-affected households in the regions where the survey was conducted. The survey and this report are an attempt to document the impact of HIV/AIDS on South African households. Although it is not representative of all AIDS households in South Africa, the report provides a snapshot of the devastating impact of HIV/AIDS on already poor families. As bleak as the findings of this survey are, the households in this survey are likely better off than most since all households in the survey had contact with NGOs providing support to HIV-affected households. No sector of the population is unaffected by the HIV epidemic, but it is the poorest South Africans who are most vulnerable to HIV/AIDS and for whom the consequences are inevitably most severe. The average age of the AIDS-sick person in the households surveyed was 35 years – in most cases these were breadwinners and the parents of young children. This report illustrates that in already poor households HIV/AIDS is the tipping point from poverty into destitution.

This report documents the impoverishing impact of HIV/AIDS on households and the inordinate burden of caring for AIDS-sick family members. It also documents access to and satisfaction with public services, as well as access to government financial support for AIDS-affected households.

Strode, A. & Barrett Grant, K. (2001). *The role of stigma and discrimination in increasing the vulnerability of children and youth infected with and affected by HIV/AIDS*. Pretoria: Save the Children.

This paper aims to identify:

1. The nature and extent of discrimination against children and youth infected with and affected by HIV/AIDS;

2. The responses to stigma and discrimination, including legal and programmatic responses in SA and other African countries, to counteract stigma and discrimination;
3. The lessons we have learned about stigma and discrimination;
4. The gaps in our understanding of stigma and discrimination;
5. Recommendations for priority interventions.

This research has used three different methodologies to obtain information around stigma and discrimination against children and youth infected with and affected by HIV/AIDS:

1. A desk review of relevant literature, law, and programmatic responses regarding HIV/AIDS and discrimination and stigma;
2. A series of interviews with selected key role players working in the field of children, HIV/AIDS and/or human rights;
3. A series of participatory workshops.

Strode, A. & Barrett Grant, K. (2001). *The rights of children and youth infected and affected by HIV/AIDS: Trainers' Handbook*. Pretoria: Save The Children (UK).

In 2001, a survey conducted by Save the Children (UK) amongst key stakeholders working with children and youth infected and affected by HIV/AIDS, highlighted the lack of information and training on children's rights as a key concern. The survey prioritised four areas where increased information and awareness was urgently required:

1. Human rights, discrimination and HIV/AIDS;
2. The health rights of children and youth;
3. The education right of children and youth; and
4. The welfare rights of children and youth.

In response Save the Children (UK) commissioned the development of four training modules dealing with these prioritised areas.

The four training modules aim to:

1. Raise awareness of the rights of children and youth, particularly as they relate to HIV/AIDS;
2. Develop an understanding of the ways in which children's and youth's rights are abused in the context of HIV/AIDS;
3. Enhance the capacity of children and youth, their caregivers and service providers to recognise and realise these rights and to respond to the HIV/AIDS epidemic in a rights-based manner.

The trainers' handbook is designed for trainers who conduct training for service providers working with children and youth infected and affected by HIV/AIDS. The handbook is intended for use by trainers from all sectors, such as health, welfare and education, and from both government and NGOs.

Strode, A. & Barrett Grant, K. (2002). *Children, HIV/AIDS and the law*. Pretoria: Save the Children.

Subbarao, K., Mattimore, A., & Plangemann, K. (2001). *Social protection of Africa's orphans and other vulnerable children. Issues and good practice program options*. Washington, DC: World Bank.

The number of orphans and OVC has reached proportions that now threaten the traditional coping mechanisms, increasing the need for public intervention. These interventions need to address the risks specific to orphans in a given environment, and must strengthen the existing community coping strategies, instead of replacing them.

There is no single 'best practice' option applicable to all countries. Programme choice is dependent on country circumstances, and the nature and scope of the problem.

Fostering as a care strategy is more attuned to the African socio-cultural milieu than many other options, but requires NGO oversight to minimise child abuse, in extended families stretched to capacity.

To promote and encourage fostering, it is necessary to ensure that direct and indirect subsidies are available for foster families. Indirect subsidies such as education vouchers and food supplements are more likely to benefit the orphan than direct cash subsidies which are easily utilised by other family members, thus depriving the orphan. Subsidies that are strongly

grounded in the community are more cost-effective, but are also likely to need oversight by religious groups and NGO's.

Income-generation schemes for fostering families are unlikely to be effective unless supported by training and marketing. Institutional innovations such as 'children's villages' are recommended where orphans are numerous and community coping has reached its limits. These are believed to be cheaper and more culturally appropriate. Orphanages are deemed to be expensive and are only recommended as a last resort. However, alternative types of group care are to be considered, e.g. children's homes in the centre of a village, and that are overseen by the community.

The need for a co-ordinated response to counteract the piecemeal nature of ongoing efforts to address the problem is emphasised in the light of the enormity of the African orphan crisis.

Subbarao, K. (2003). *Systemic shocks and social protection: Role and effectiveness of public works programs*. (Social Protection Discussion Paper No. 0302). Washington, DC: World Bank.

Public welfare programmes have been important counter-cyclical programme interventions in both developed and developing countries. In the developing world generally and in Africa and Asia particularly, public works programmes have been significant policy instruments for mitigating the negative effects of climatic and systemic risks on poor farmers and unskilled and semi-skilled workers. The paper first discusses the rationale behind welfare programmes in the context of social risk management and goes on to give an overview of welfare programmes in Africa and Asia with respect to such design features as wage rates and labour intensity and to how they were selected and implemented. Using available estimates and evaluations, the evidence on whether these programmes have achieved their goals and are cost effective is presented. Finally, the paper concludes with summary lessons from experience.

Subbarao, K. & Coury, D. (2003). *A template on orphans in sub-Saharan countries*. (Social Protection). Washington, DC: World Bank.

Swartz, L., Mbalo, M., & Ngenzi, I. (2002). *Final rapid appraisal report on HCBC projects. Executive summary*. Report prepared for the Departments of Social Development and Health. Presented at the South African National Conference on Children Affected by HIV/AIDS, 2–5 June 2002.

From the executive summary

The Departments of Health and Social Development identified a need to audit all home community-based care (HCBC) projects countrywide. At a workshop held at Kopanong in June 2001, various HCBC activities, amongst others, the rapid appraisal tool for the project, were discussed.

After receiving comments the tools were refined and workshopped with some provinces. After the fifth provincial training workshop, the tool was finalised and distributed to the various provinces for data collecting. The Chief Directorate: Population and Development held workshops in all nine provinces with the Department of Welfare, Health and Provincial Population Units official regarding the administration of the tool and capturing the data. A final workshop was held on 5 October 2001 at the Department of Social Development where all existing problems were addressed.

The role of the different parties in the process was also spelled out. The main parties involved in this rapid appraisal were the Department of Social Development, and the Department of Health, and their provincial counterparts.

Terres des Hommes, Humuliza Project, Salvation Army Africa Regional Team, Pact, & International HIV/AIDS Alliance. (2002). *Regional psychosocial support initiative for children affected by AIDS*. Harare, Zimbabwe: Terre des Hommes/ Salvation Army/ International HIV/AIDS Alliance.

The REPPSI program initiatives are to: 1. enhance existing psychosocial support programmes and service delivery to CABA; 2. scale up psychosocial support activities for CABA by adapting current pilot programmes and/or supporting new community models with additional partner organisations; and 3. strengthen the enabling environment for organisations assisting with CABA through advocacy at regional, national and local levels.

The proposed regional initiative will integrate three types of partner organisations with diverse levels and areas of expertise in psychosocial programming. Primary programme components will include operational research to document best practices and lessons learned, training to build capacity among nascent psychosocial service providers, sub-grants to promote programme scale-up and replication, and advocacy to strengthen the enabling environment for psychosocial assistance programs. The program will strengthen the SADC Human and Social Development cluster by supporting an OVC Program Officer with special focus on psychosocial services in the office of the HIV/AIDS Programme Manager.

Proposed implementation will capitalise on the strengths and experience of the four collaborating agencies as well as the capacity of orphans and vulnerable children themselves to exercise community leadership in responding to their own needs. Two chiefs of party, from Terre Des Hommes and Salvation Army, will assume primary responsibility for programme leadership and management. These two lead agencies will also oversee programme finances, administration and donor reporting. Pact, Inc., a US NGO with more than 30 years of capacity-building experience, will implement institutional strengthening activities. The International HIV/AIDS alliance will contribute its experience in documentation, tools development, transferring of lessons learned, advocacy and policy development.

The Life Skills Development Foundation (2002). *Child-friendly community schools approach for promoting health, psychosocial development, and resilience in children and youth affected by AIDS*. Chiang Mai, Thailand: The Life Skills Development Foundation.

The following report is a compilation of all implemented activities and results derived from the Child Friendly Schools project for AIDS-affected children in three provinces of northern Thailand. The report outlines the methodology utilised and highlights the best practices and lessons learnt during the planning and implementation period of the project. The report illustrates the crucial importance of incorporating communities into the planning and implementation process of any intended development project. This report will be an invaluable tool for organisations planning to replicate this or similar projects in the future. The Thai Life Skills Development Foundation formally wishes to acknowledge the strong support it received from UNAIDS, UNICEF, ONPEP, core educational supervisors, teachers, and all other persons who contributed to implement this important project that helps to improve the life situation of many innocent children.

The Synergy Project (2003). *USAID efforts to address the needs of children affected by HIV/AIDS: An overview of US Agency for International Development programs and approaches* (Rep. No. HRN-C-00-99-0005-00). Washington, DC: The Synergy Project:

This document responds to a Congressional request for USAID to report on actions taken to expand access to food and education specifically for children affected by HIV/AIDS. While improving access to food and education is an important goal of many USAID initiatives targeting orphans and vulnerable children, this access must be part of a holistic approach to address the needs of this population, including support for and strengthening of entire communities to better care for these most vulnerable children. USAID uses several sources of funding to support comprehensive programmes that provide care and protection to children affected by HIV/AIDS. These include child survival funds, HIV/AIDS funds for orphans and vulnerable children, Title II Food for Peace funds, and basic education funds.

The Thandanani Association (2001). *Thandanani Association Annual Report – 2001*. Pietermaritzburg: Thanandani Association.

Thomas, M. (2002). *Focusing on the education needs of children affected by AIDS*. Available online: www.synergyaids.com/documents/3512_Thomas_Presentation.ppt

Tollman, S. (2000). *Delivering primary health care (PHC) and implementing health programmes within district health systems in Southern Africa*. Proceedings of a Fogarty Maternal and Child Health Workshop, held at the Rob Roy Hotel and the Valley Trust, Durban South Africa, 14–18 August, 2000.

Tomkins, A., Conroy, R., Achenbach, T., Nyambati, W., Elmore-Meegan, M., Reid, G., Reynolds, B., & Agala, B. (2003). *Identifying vulnerable children: Interim results of the adapted Achenbach child behavioural scale*. Powerpoint presentation.

Townsend, L. (2001). *Decisions to care for HIV/AIDS orphans*. Masters Dissertation, Department of Psychology, University of Cape Town.

There is substantial evidence to indicate that SA is facing the prospect of a large number of children, now and in the future, who will be orphaned as a result of the HIV/AIDS pandemic. In all likelihood, these children would have experienced psychological trauma through the illness and death of people close to them, and the social isolation that accompanies HIV infection and AIDS-related illness and death. The ideal would be for as many of these children as possible to experience some type of family life in which to grow and mature into responsible adults. The aim of the present study was to explore a range of factors that might influence prospective carers' decisions to care for children orphaned by HIV/AIDS. These include features of prospective carers; features of the orphaned child; and forms of assistance that may be required. By means of a postal survey, the present study explored existing adoptive and foster parents' (N=175) willingness to care for an HIV/AIDS orphan. Results show that close to 69 per cent of respondents indicated a willingness to care for an HIV/AIDS orphan. Although some differences were noted depending of the HIV status of the child and whether the respondent was an adoptive or foster parent, on the whole they also indicated a preferred willingness to care for an HIV-negative female child, up to the age of 6 years old, of the same culture and from the same family as themselves, and without surviving relatives or siblings. Free medical care and schooling for the child were the suggested forms of assistance required. The Theory of Planned behaviour (Ajzen 1991), explored in the present study, did predict intentions to care for either an HIV-negative or HIV-positive orphan. However, certain components of the models did not have good predictive ability calling into question the usefulness of the model as a means to explain and predict intention to care for an HIV/AIDS orphan. Implications of the study provide recommendations for persons involved with children orphaned by HIV/AIDS.

Turner, A. G. (2003). *Guidelines for sampling orphans including those in group quarters and homeless to estimate the size and characteristics of orphan populations*. New York: UNICEF.

Twesigye, P. & Kyakulaga, J. (1996). *Economic empowerment of people living with AIDS, widows and orphans: successes and constraints*. Presented at the XIth International Conference on AIDS, Vancouver, 7–12 July, 1996. (abstract number Th. D. 5066).

UNAIDS (1999). *U.N.: AIDS orphans portend catastrophic future in Africa*. cnn.com [Announcement posted on the World Wide Web] from the World Wide Web: cnn.com/1999/HEALTH/AIDS/12/06/aids.Africa.

Report: A United Nations report shattered notions that the AIDS epidemic is subsiding worldwide and raised an even more alarming spectre: the effect of the disease on children and implications for the future in parts of the world.

The report contains dire predictions, particularly for Africa, where experts say the impact, present and future, of millions of children orphaned by AIDS and abandoned is tearing at the very fabric of the entire continent.

According to the new report by UNICEF and UNAIDS, Africa has been overwhelmed by AIDS orphans – more than 10 million. The epidemic has yet to peak, and the numbers are expected to grow massively. In Zambia alone, more than 360 000 children – one in ten of the total population – have lost either their mother or both parents to AIDS.

With resources already stretched to the breaking point, many of these Third World countries – with the focus in eastern and southern Africa – have been forced to leave millions of these youngsters to fend for themselves. Poor, malnourished, uneducated and unwanted, they represent a social plague yet to come.

UNAIDS (1999). *National Policy on HIV/AIDS for the Republic of Zimbabwe*. Washington, DC: USAID.

UNAIDS (1999). *Orphan programming in Mozambique: Combining opportunities for development with prevention and care*. (Report of an assessment of programming in Mozambique for families and children affected by HIV/AIDS). Geneva: UNAIDS.

The purpose of this national assessment of children and families affected by HIV/AIDS is threefold: to review Mozambique's overall programming and policy for orphans and other children made vulnerable by the AIDS epidemic; to identify opportunities for development of community-based responses in a multi-sectoral planning context; and to work with UNICEF staff and others to mainstream programming across sectors.

UNAIDS (2000). *Report on the global HIV/AIDS epidemic*. Geneva: UNAIDS.

This comprehensive report includes analysis on all aspects of the HIV/AIDS epidemic, from the spread of HIV and treatments to the availability of resources, and provides country-by-country figures on the extent of the epidemic.

Launched before the XIV International AIDS Conference, held in Barcelona in July 2002, it is sometimes referred to as the 'Barcelona' report.

UNAIDS (2002). *Principles to guide programming for orphans and other children affected by HIV/AIDS*. UNICEF/UNAIDS.

The need for guiding principles to protect and fulfil the rights of children and adolescents affected by HIV/AIDS was highlighted at the XII International AIDS Conference in South Africa in July 2000. Since that time, formal and informal consultations among and between governments, NGOs, international agencies, the private sector, community organisations, and young people have been held to develop consensus on principles to guide programmes for children and adolescents affected by HIV/AIDS. These principles now serve as a common point of reference at all levels (local, district, national, and global) to encourage actions that are child-centred, and family and community focused:

1. Strengthen the protection and care of orphans and other vulnerable children within their extended families and communities;
2. Strengthen the economic coping capacities of families and communities;
3. Enhance the capacity of families and communities to respond to the psychosocial needs of orphans, vulnerable children, and their caregivers;
4. Link HIV/AIDS prevention activities, care and support for people living with HIV/AIDS and efforts to support orphans and other vulnerable children;
5. Focus on the most vulnerable children and communities, not only those orphaned by AIDS;
6. Give particular attention to the roles of boys and girls, men, women and address gender discrimination;
7. Ensure the full involvement of young people as part of the solution;
8. Strengthen schools and ensure access to education;
9. Reduce stigma and discrimination;
10. Accelerate learning and information exchange;
11. Strengthen partners and partnerships at all levels and build coalitions among key stakeholders;
12. Ensure that external support strengthens and does not undermine community initiative and motivation.

UNAIDS (2002). *A review of household and community responses to the HIV/AIDS epidemic in the rural areas of sub-Saharan Africa*. Geneva: UNAIDS.

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

UNAIDS, UNICEF, & USAID (2002). *Children on the brink 2002: A joint report on orphan estimates and program strategies*. UNAIDS/UNICEF/USAID.

The paper details a number of impacts of the HIV/AIDS pandemic on children. It estimates that there are around 3 million children (under 15 years old) living with HIV worldwide.

Impacts on children that are discussed include:

1. Children who are orphaned or have lost one parent; estimated at 13 million and expected to rise to 25 million by 2010;
2. Large numbers of children are living in households with sick adults;
3. The pandemic is increasing poverty in communities, with children often the first to be affected by consequent deprivation;
4. Children are often expected to care for sick parents and consequently drop out of school;
5. As adults within a household become unable to work, children are required to take on farm and other work;
6. Stigma, abuse and discrimination may occur where children are affected by HIV/AIDS.

The report contains statistics on children orphaned by HIV/AIDS from 88 countries, analysis of the trends found in those statistics, and strategies and principles for helping the children. There is a section of selected electronic resources on the subject and recommendations for programming in this area.

The report recommends that:

1. Communities with high proportions of orphans be immediately and specifically targeted;
2. Other vulnerable children must also be helped;
3. Agencies, governments and communities must collaborate in order to tackle the crisis.

UNAIDS (2003). *Guide to the strategic planning process for a national response to HIV/AIDS: Resource mobilization, situation analysis, response*. Geneva: UNAIDS.

UNAIDS/World Health Organization (2000). *AIDS epidemic update: December 2000*. Geneva: UNAIDS/WHO.

UNICEF (1990). *World declaration on the survival, protection and development of children*. New York: UNICEF.

The World Summit for Children was held at the United Nations, New York, on 30 September 1990 and was attended by 71 Presidents and Prime Ministers – the largest gathering of heads of state and government in history. And the outcome was an extraordinary new commitment – a decision to try to end child deaths and child malnutrition on today's scale by the year 2000 and to provide basic protection for the normal physical and mental development of all the world's children.

UNICEF (1997). *Sustainability of the community-based orphan/children in especially difficult circumstances Care Program in Masvingo and Mwenezi through community income generating projects*. Harare: IDS.

UNICEF (1999). *Children orphaned by AIDS. Front-line responses from Eastern and Southern Africa*. New York: UNICEF.

UNICEF (1999) *UNICEF's Project to expand programming for families and children affected by HIV/AIDS*.

This report summarises the results of a two-year project by UNICEF headquarters to develop responses for families and children affected by HIV/AIDS with particular emphasis on children orphaned by AIDS and other causes. While UNICEF has been developing basic programming approaches in this area since 1987, the growing number of children placed at risk by loss of care givers due to the HIV/AIDS pandemic has created the possibilities of a crisis of very large proportions in many Sub-Saharan African countries in the coming decade.

In January 1998, UNICEF, in collaboration with UNAIDS, decided to examine programming by UNICEF and its partners (governments, NGOs, UNAIDS co-sponsors) for children and families affected by HIV/AIDS in the most affected countries. Where possible, it was intended to initiate planning processes to expand programming to scale, and document best practices so that countries with little or no experience could initiate programmes. The project's overall intention was to develop a global programming strategy by examining existing solutions on the ground. The strategy includes children who have suffered temporary or permanent loss of family and/or primary caregivers whether orphaned by AIDS or other causes, reflecting on UNICEF's 1996 policy on children in need of special protection measures.

- UNICEF (1999). *The Progress of Nations, 1999*. New York: UNICEF.
- UNICEF (1999). *Orphan programming in Tanzania: Building on experience to expand to scale*. (Report on an assessment of programming in Tanzania for families and children affected by HIV/AIDS). New York: United Nations Children's Fund.
- UNICEF & USAID (2000). *Eastern & Southern Africa Regional Workshop Report*. New York: UNICEF/USAID.
- Between 5–8 November 2000, some 80 delegates from 14 countries in eastern and southern Africa gathered in Lusaka to discuss the crisis facing children in the region, largely as a result of the HIV/AIDS pandemic. The workshop was initiated jointly by UNICEF and USAID. Countries were asked to send a delegation of four members, including representatives of government and civil society. This was the second regional gathering to discuss orphans and vulnerable children, the first being the conference on 'Raising the orphan generation' in Pietermaritzburg, South Africa, in June 1998.
- UNICEF, USAID, & UNAIDS (2000). *Global framework for addressing the plight of children and adolescents affected by AIDS*. Draft discussion paper. New York: UNICEF/USAID/UNAIDS.
- UNICEF (2002). *Coordinating community orphan care in Uganda*. Presented at South Africa National Conference on Children Affected by HIV/AIDS, 2–5 June 2002.
- UNICEF (2002). *Child workers in the shadow of AIDS. Listening to the children*. Nairobi, Kenya: UNICEF.
- UNICEF (2002). *Plan of action for implementing the world declaration on the survival, protection and development of children in the 1990s*. New York: United Nations Special Session on Children.
- UNICEF (2003). *UNICEF Statement for Stockholm Conference on Residential Care – 14 May 2003*.
- We know a great deal now about what institutional care does to children. Deprived of a family environment, children receive less stimulation, individual attention and love. Their lives are often lived in a parallel world that does not prepare them for life and for healthy social interaction. Their voices are not heard. In the worst scenarios, children lose contact with their families, suffer physical and psychological abuse, are denied access to appropriate medical care, education and other services, and may become the victims of sexual exploitation or trafficking. In short, we know that institutional care, unless used only when there is absolutely no other alternative and carefully regulated, violates the very principles of the CRC as well as many of its articles.
- We are also coming to realise what institutional care does to societies. It perpetuates discrimination, by providing tacit approval for the idea that certain groups of children, whether orphaned, abandoned, living with disabilities, from families affected by AIDS or by poverty, should live apart from society. It absorbs resources – institutions are always an expensive proposition. Allocated differently, these resources could provide the services needed to help families keep their children with them, and thus build communities. It creates an underclass; young people and adults who lack the experience and skills to function effectively in the wider world, and become a charge on their communities. In short, in addition to being an obstacle to the individual child's healthy development, the use of institutional care also impedes the healthy development of communities and society as a whole.
- UNICEF (2003). *Africa's orphaned generations*. New York: UNICEF.
- The HIV/AIDS epidemic in sub-Saharan Africa has already orphaned a generation of children – and now seems set to orphan generations more. Today over 11 million children under the age of 15 living in sub-Saharan Africa have been robbed of one or both parents by HIV/AIDS. Seven years from now, the number is expected to have grown to 20 million. At that point, anywhere from 15 per cent to over 25 per cent of the children in a dozen sub-Saharan African countries will be orphans – the vast majority of them will have been orphaned by HIV/AIDS. 'Africa's orphaned generations' reports on the life circumstances of today's orphans with new data and fresh analyses. It presents the possibility of change – for those already orphaned and for the generation to come – if certain things are done now.

Tragically, the number of orphans in sub-Saharan Africa will continue to rise in the years ahead, due to the high proportion of sub-Saharan African adults already living with HIV/AIDS and the continuing difficulties in expanding access to life-prolonging antiretroviral treatment. But, it is not inevitable that these children should be left to suffer twice, denied their rights because they are orphaned. 'Africa's orphaned generations' presents a strategy for ensuring that all of Africa's orphaned children have a safe, healthy and well-educated childhood, establishing the foundation for a productive adult life and for their countries' overall development. It encourages hope in the face of an epic disaster.

UNICEF & UNAIDS (2002). *Report on the Africa Leadership Consultation: Urgent action for children on the brink*. New York: UNICEF.

UNICEF & UNAIDS (1998). *Programming consultation on care and protection of orphans* (Executive Summary). Kampala, Uganda.

In a programme consultation jointly organised by UNICEF and UNAIDS, 73 stakeholders representing CBOs, NGOs, church groups, UNAIDS co-sponsor agencies and bilateral donors in 12 countries in the Eastern and Southern Africa region met for three days to identify key programming issues and lessons learned in addressing problems arising from the unprecedented number of children orphaned as a result of the AIDS pandemic.

The consultation identified critical needs and discussed the role of governments, civil society and international partners in accelerating the fulfilment of the rights of orphans, their families and communities. An agreement was reached on the issues for guiding principles and it was proposed that an international country technical support network of key stakeholders be established to facilitate technical assistance to community-based activities in affected countries. Participants also identified areas for further programme development.

UNICEF, USAID & Family Health International (2002). *Meeting on African children without family care*. Windhoek: UNICEF/USAID/Family Health International.

Report of meeting on African children without family care held on 30 November 2002. Presentations made by representatives from seven countries (Ethiopia, Zimbabwe, Rwanda, Uganda, Namibia, South Africa, and Malawi) are outlined. The document also reports on discussions regarding the role of older people in caring for OVC, and an in-depth look at Save the Children Fund's position paper on residential care. The latter discusses what SCF have learned about institutional care of children, and residential care in Eastern block countries, European countries and some African states. It also looks at residential care in the light of the principles of the International Convention on the Rights of the Child, and then highlights SCF's position on residential care and the key areas of action required.

Urassa, M., Boerma, J. T., Ng'weshemi, J. Z. L., Isingo, R., Schapink, D., & Kumugola, Y. (1997). Orphanhood, child fostering and the the AIDS epidemic in rural Tanzania. *Health Transition Review*, 7, 141–153.

USAID (2000). *AIDS orphans: Towards an action plan for going to scale*. Interagency Meeting on Children Affected by HIV/AIDS. Washington, DC: USAID.

This interagency meeting tackled the problem of collaboration with three distinct objectives in mind: to describe the current global situation, to define common goals and to prescribe next steps. Those working in the field must present a common agenda to leaders and policymakers in the world, beginning at the XIIIth International AIDS Conference (Durban, July 9–14, 2000) and continuing through a mediation and liaison framework to be developed over the coming few months.

The common agenda should centre on four key areas: child welfare, community development, organisational policy and planning and informed, targeted leadership. Panel members will promote this agenda through the advocacy and mediation, and it is hoped that by the time of the follow-up meeting in May 2000 all members will have a clear idea of how a functioning framework for interagency collaboration can be developed, sustained and directed effectively towards the needs of orphans and children affected by HIV/AIDS.

Organisations attending include DCOF/USAID, World Bank, UNICEF, UNDP, Harvard Centre for Population & Development Studies, Children's Research and Education Institute.

- USAID (2001). *USAID project profiles: Children affected by HIV/AIDS*. Washington, DC: USAID.
- USAID (2001). *Background paper on children affected by AIDS in Zimbabwe*. Washington, DC: USAID.
- USAID (2001). *Guidance on the definition and use of the child survival and disease programs fund*. Washington, DC: USAID.
- USAID (2002). *The situation of orphans in Haiti: A summary assessment*. Proceedings of a World Bank/World Vision conference, June 6–7, 2003, Washington DC (Rep. No. HRN-A-00-97-0017-00).
- USAID (2002). *Children on the brink. Strategies to support children isolated by HIV/AIDS*. Washington, DC: USAID.

This report tells a powerful and deeply disturbing story of crisis proportions. More than 40 million children in 23 developing nations will likely have lost one of both of their parents by 2010. Most of these deaths will be the result of the HIV/AIDS pandemic and complicating illnesses. The human and social costs of these numbers are staggering. In countries across Africa, Asia and Latin America, HIV/AIDS is unravelling years of progress in economic and social development. Life expectancy – which has been steadily on the rise for the last three decades – will drop to 40 years or less in nine sub-Saharan countries by 2010. In all 23 countries included in this study, AIDS-related mortality will eliminate the gains made in child survival over the past 20 years. In Zambia and Zimbabwe, infant mortality rates will likely nearly double, and child mortality rates will triple. The economies of the developing nations in this study will all struggle to deal with the immense economic dislocation and costs of illness, death and lost opportunity. And while the bulk of countries in this study are in Africa, this report should also serve as a grave reminder of similar storm clouds gathering now in Asia and Latin America, and the terrible toll the HIV/AIDS crisis will claim on those regions' children. This report provides a compelling demographic portrait of an immense problem. However, more important than the numbers contained in this study is the human story they tell. Forty million children losing one or both of their parents are 40 million children more likely to be forced into child labour; and 40 million children who may never have an opportunity to attend school; and 40 million children more at risk of contracting HIV. This study should serve as a call to action for developed and developing nations like alike.

- USAID (2003). *Displaced Children and Orphans Fund: Honoring a commitment to vulnerable children*. Washington, DC: USAID.
- USAID (2003). *Displaced Children and Orphans Fund: Portfolio synopsis*. Washington, DC: USAID.
- USAID (2003). *USAID-supported activities for orphans and other vulnerable children*. May 2001 Draft. Washington, DC: USAID.
- USAID (2003). *USAID Project Profiles: Children Affected by HIV/AIDS – Third Edition*. Washington, DC: USAID.
- USAID-PVO Steering Committee on Multisectoral Approaches to HIV/AIDS. (2003). *Multisectoral responses to HIV/AIDS: A compendium of promising practices from Africa*. Washington, DC: USAID.

Abstract: This compendium was developed by USAID, Bureau for Africa, Office of Sustainable Development as a means for PVOs and NGOs to share multi-sectoral HIV/AIDS promising practices and innovations. Because innovative and multi-sectoral responses are necessary to fight an epidemic as complex and destructive as HIV/AIDS, PVOs and NGOs must share experiences and lessons learned so that promising practices become best practices. By documenting the experiences of 13 organisations, this compendium aims to assist organisations with programme development and implementation and facilitate ongoing

discussion and collaboration to develop effective and innovative multi-sectoral responses to the HIV/AIDS epidemic in Africa.

- USAID & The Synergy Project. (2001). *Handbook for programs to mobilise community care for children affected by HIV/AIDS*. Revised draft for review, Dec 2001. Washington, DC: USAID/The Synergy Project.
- USAID/UNICEF/SIDA Study Fund Project (1999). *Orphans and vulnerable children: A situation analysis*. Lusaka: NHPP.
- Varga, C. (2001). Identifying (Policy) gaps and needs for orphans and children made vulnerable by HIV/AIDS. Unpublished work.
- Verhoef, H. S. (2002). DRAFT: Seeing beyond the crisis: What international relief organizations are learning from community-based childrearing practices. Prepared for R. Lerner, F. Jacobs, & D. Wertlieb (Eds.), *Promoting positive child, adolescent and family development: A handbook of program and policy innovations*. Thousand Oaks, CA: Sage.
- Volpi, E. (2002). *Street children: Promising practices and approaches*. Washington DC: World Bank Institute.
- In many regions of the world, the phenomenon of street children is unabated, while it is emerging in others where it was unknown so far. Behind child disconnection lie highly vulnerable families and communities, many struggling to come to terms with economic liberalisation and growing inequality. Disconnection can also be traced to a lack of communication in the family and the weakening of social capital. Street children are an alarm signalling the dire need for social development and poverty reduction policies to improve the situation in the community at large, and to prevent more young people from becoming marginalised. While preventive interventions are essential, those children already facing the hardships of street life need immediate opportunities for human development via special protection programmes. This report distils the main lessons learned from a number of programmes that have attempted to meet the special needs of street children worldwide. Its purpose is to help potential donors understand activities in this area and identify promising practices.
- W. K. Kellogg Foundation & Human Sciences Research Council. (2003). *Helping people help themselves: Orphans and vulnerable children program*. Pretoria: W.K. Kellogg Foundation/HSRC.
- Walker, L. (2002). *Children, HIV and conflict: Children on commercial farms in Zimbabwe*. Presented at a Workshop on Children, HIV and Poverty in Southern Africa, organised by SARP, HSRC, and Save the Children, 9–10 April, 2002.

The Farm Orphan Support Trust of Zimbabwe (FOST) is a state registered PVO implementing a programme which solicits and facilitates support for children in especially difficult circumstances, particularly orphans, on commercial farms in Zimbabwe. The FOST vision is 'all orphans' rights realised' and our overall aim is to proactively increase the capacity of communities to respond to the orphan crisis and ensure that systems are in place to protect and care for the most vulnerable children in commercial farming communities. Our programme is based on the belief that orphaned children have the best opportunity to develop to their full potential within a family situation without sibling separation, in an environment that is familiar to them and where they have the opportunity to learn their culture first hand. The past two years have been a period of change and challenge for commercial farm communities in Zimbabwe. The land reform programme has led to a changing environment and has meant that FOST has had to reassess the needs of orphans and develop strategies to address the challenges. The designation and occupation, both legal and illegal, of many commercial farms had a marked effect on the stability of farm worker communities meaning that children in these communities have lived in a climate of uncertainty and insecurity for a prolonged period. Children in many farm communities have also had to contend with violence and intimidation and this has had a marked effect on their lives, exacerbating their vulnerability.

Walker, L. (2003). *We will bury ourselves: A study of child-headed households on commercial farm in Zimbabwe*. Harare, Zimbabwe: Farm Orphan Support Trust of Zimbabwe.

Farm Orphan Support Trust of Zimbabwe (FOST) undertook this study into child-headed households on commercial farms in April/May 2002 with the aim of identifying their problems and needs and planning potential interventions. The unique nature of farm worker communities makes them particularly vulnerable to the effects of HIV/AIDS. In particular, the lack of traditional safety nets within these communities increases the vulnerability of children, especially orphaned children.

The methodology employed for the study was action-research oriented and involved interviewing 17 child-headed households in Mashonaland Central and Manicaland provinces. Half of a day was spent with each household and a further half day was spent talking to members of the farm community. In total 47 children and 27 community members were interviewed.

The findings of the study reveal that child-headed households on commercial farms face a number of problems including:

- Food insecurity;
- Problem of access to education and skills training;
- The struggle to meet material needs;
- The absence of psychosocial support;
- Poor life skills and knowledge;
- Abuse and exploitation;
- No extended family network;
- Poor housing conditions and lack of tenure security;
- Poor access to healthcare.

These are common problems to most orphaned and vulnerable children but it was found that child-headed households are especially vulnerable because of the lack of the usual community 'safety nets'.

The report makes a number of recommendations regarding interventions. It suggests that psychosocial support (PSS) interventions should be integrated with the meeting of material needs. All stakeholder groups in farm communities need to be involved in the delivery of PSS, especially the youth and the children themselves. Ways to meet material needs are suggested including external funding and utilisation of existing systems such as BEAM. Advocacy and awareness raising are needed to ensure that child-headed households are cared for, protected and included in national development agendas.

It is concluded that future interventions to respond to the needs of child-headed households will need to balance material and psychosocial aspects in order to avoid undermining existing coping mechanisms. Supporting community-based responses will involve long-term capacity building and training and require thorough support and follow up.

Webb, D. (1995). Who will take care of the AIDS orphans? *Aids Analysis Africa*, 5, 12–13.

There will be 500 000 AIDS orphans in SA by the year 2000. They will need proper care in order to avoid poverty, marginalisation, and ultimately resorting to crime, prostitution, and drug abuse. More than 500 respondents in five communities in SA and Namibia were surveyed in 1992–93 about what they think should happen to AIDS orphans. 52.5 per cent feel that relatives or other community members should take care of the orphans. Support for government care averages 45.3 per cent but varies widely across the sites, ranging from 5 per cent in the Oshana region to 80.2 per cent in Natal. The pattern is reversed for those favouring community care, with a low of 16.5 per cent in Natal and a high of 97 per cent in Oshana Region. More than 75 per cent of people in Soweto, the only urban sample, feel that the government is responsible in some way, mostly through orphanages. Teenagers and elderly people, most likely to be dependent themselves, were the least likely to be sympathetic to orphans, while the poorest and most affluent households were the most sympathetic. Individuals of parental age were most likely to prefer orphan care within the community, either by a family unit or at an inter-household level, and the middle-income

group regards the government as the primary caregivers. There is no doubt that the government of SA will find it very difficult to cope if communities refuse to care for AIDS orphans. Reciprocity must be identified within social networks and strengthened institutionally, with education programmes launched to emphasise that providing for orphans is primarily the responsibility of relatives and that institutional response can only supplement rather than replace community support systems.

Webb, D. (1996). Zambia's AIDS orphans will change the structure of society. *Aids Analysis Africa*, 6, 10–11.

In Zambia, 10–15 per cent of the rural population and 25–30 per cent of the urban population is infected with HIV. An estimated 500 new people daily are infected in the country. HIV infection in Zambia is therefore widely disseminated and spreading rapidly. Infection rates are expected to peak in urban areas in 1998 at 28 per cent and in rural areas in 2004 at 22 per cent. AIDS mortality rates continue to increase. As the toll of AIDS mortality mounts, the number of orphans will increase. Indeed, the number of orphans will continue to increase well into the next decade, stabilising approximately six years after national HIV prevalence rates peak. The number and concentration of orphans are highest in urban and peri-urban areas. A 1993 national survey determined that 42 per cent of urban households cared for an orphan, compared to 33 per cent in rural areas. In 1995, the national AIDS program estimated that there are 200 000–250 000 orphans and that the total should increase to 550 000–600 000 by the year 2000. 53.9 per cent and 18 per cent of orphans in Zambia are paternal and maternal orphans, respectively. The number of children who have lost both parents will continue to increase. The author discusses the differing living standards of orphans and coping.

Webb, D. (1996). Children in especially difficult circumstances (CEDC) in Zambia: A situation analysis. *SafAIDS News*, 4, 2–6.

Webb, D., Foster, G., Kanya, H., & Nampanya-Serpell, N. (1998). Children affected by HIV/AIDS: Priority areas for future research. Unpublished manuscript.

Whiteside, A. (2000). The real challenges: The orphan generation and employment creation. *Aids Analysis Africa*, 10(4), 14–15.

A baby born to a HIV-positive mother has close to a 100 per cent chance of being orphaned before reaching the age of 10. In SA nearly 1 million children under the age of 15 are projected to lose their mothers by 2005 due to AIDS. These orphans are less likely to receive adequate parenting, education, and nutrition; others will seek to survive on the streets and thus will be more likely to face sexual abuse and exploitation. The long-term impact of HIV/AIDS on both the children and society will be severe. The orphans that AIDS is creating pose serious social, economic, political, and developmental challenges for SA. There are two options left for the government: 1. Dramatically increasing welfare grants and staffing of welfare departments in order to care for the orphans; 2. Finding new imaginative measures of meeting the challenge. In addition, provision of employment for its population is another challenge the region is facing. Having the required resources and infrastructure, a potential intervention for SA would be training and employing a new cadre of workers to care for AIDS orphans. This type of response would also help build a civil society.

Whiteside, A. & Erskine, S. (2002). *The impact of HIV/AIDS on Southern Africa's children: Poverty of planning and planning of poverty*. Report for Save the Children. University of Natal: HEARD.

WHO & UNICEF (1994). *Action for children affected by AIDS. Programme profiles and lessons learned*. (Rep. No. WHO/GPA/TCO/HCS/94.7). New York: WHO/UNICEF.

The HIV/AIDS pandemic has given rise to a host of problems for children. Fortunately, a growing number of programmes around the world are responding to their special needs. Because both these needs and the responses are in many ways unprecedented, it is crucial that the lessons learned in responding to children affected by HIV/AIDS should be documented and shared with those who will be facing similar needs in the years ahead. By presenting this survey of programmes that have addressed themselves to AIDS-affected children, we hope to contribute to the experience-sharing process, and help stimulate and

guide action to mitigate the impact of the pandemic on children. This document is meant above all for those who carry responsibility for responding to the many challenges posed by HIV/AIDS, including policy makers at all levels, programme planners, and those working directly with affected individuals and families. For many others with an interest in children, the information presented should raise awareness of the pandemic's profound consequences for this most vulnerable population group.

Wilkins, C.M. (2003). *Re-establishing family structures affected by HIV/AIDS: Is there hope? Zimbabwe case study*. (Capstone Advisor: Kanthie Athukorala).

This paper studies how family structures are affected by HIV/AIDS in rural and urban Zimbabwe, and the devastation HIV/AIDS is having on family structures, especially as children and elderly people are left taking care of each other when the adult generation, aged 15–49 years old, disappears. Greater numbers of extended families absorb orphans into the household, creating economic, social and psychosocial hardships for the family unit. Reluctance to place orphans in institutions continues because of isolating them from their social network, traditions and cultures.

The author describes the importance of keeping families intact, as mutually supportive units, and therefore creating resilience among them to the impacts of the epidemic is essential. It explores the role of cultural traditions in the changing environment because of HIV/AIDS, with particular reference to preparing and writing wills to secure inheritance.

Strategies are required to eliminate the ambiguity surrounding HIV transmission due to unsafe medical procedures, increase the availability of antiretroviral therapy at affordable costs, continued HIV/AIDS awareness and education to bring about behaviour change, and measures to address and reduce the stigma currently attached to HIV in Zimbabwe.

The paper provides recommendations for donors, governments, international, national and faith-based organisations to address re-stabilising family structures in Zimbabwe.

Williamson, J. (1995). *Children and families affected by HIV/AIDS: Guidelines for action*. New York: UNICEF.

This document calls for strategic, participatory planning and action involving the government, international organisations, NGOs, donors and grassroots groups from communities affected by HIV/AIDS. Through suitable policies and programmes, the capacity of families and communities to meet the needs of the affected families and their children would be strengthened. Society's obligation to protect and care for vulnerable children is stressed and the essential action described.

The basic themes that run through the guidelines are the need to build the capacity of families and communities to cope and provide for children's needs; the importance of assessing all situations from the perspective of the rights of the child; the dominance of children's developmental needs as a fundamental reality that must be recognised by those who take action on their behalf; and the central role that women must play in activities to benefit children and families affected by HIV/AIDS.

The document begins from the principle that action to benefit children and families affected by HIV/AIDS must be based on a clear understanding of the problems they experience. Programme developers and policy makers need also to understand the adjustments HIV/AIDS-affected households and families are making, because strengthening selected coping mechanisms can be an effective way to help. They also need to recognise that some coping strategies have negative effects that may be prevented or mitigated. Policies and programmes will have significance to the vast majority of those affected by HIV/AIDS only to the extent that they strengthen family and community coping capacity. The most vulnerable children are those who are on their own, those with little or no family and community support.

Governments and other bodies must give these priority attention for protection and care. Priority for action should also go to the geographic areas where families are under the greatest pressure – where problems and the growing number of orphans are overwhelming existing coping capacities and services.

Because of the importance of the context in which problems occur and assistance is given, the paper describes how to plan and carry out a situation analysis concerning children and families affected by HIV/AIDS. It describes ways of identifying problems, factors that contribute to or mitigate these problems, and coping mechanisms which can be adopted by those affected.

Because of the importance of helping children and families affected by HIV/AIDS cope more easily, the document presents ways for developing a conducive environment. These include: increasing awareness, understanding and a sense of responsibility among policy makers, leaders and the public; reducing stigma and discrimination against those with HIV/AIDS and their families; ensuring that laws and government action protect the rights and support the coping capacities of individuals, families and communities (above all, those of women and children); increasing the impact and effectiveness of community-level programmes; and monitoring the AIDS epidemic and its effects.

The paper also looks at general programming issues directed to options for direct work with children and families. Hence it identifies activities for identifying and monitoring the most vulnerable children; increasing family capacity to provide for children's needs; increasing community support for vulnerable children and families; helping children stay in school and prepare to support themselves; ensuring protection and care for children; addressing threats to psychosocial well-being and development; and ensuring access to health services.

The paper concludes by highlighting the importance of operational research and programme evaluation. While much is known about the scope and nature of the problems that HIV/AIDS is causing, there is still much to learn. Solid programme evaluations and operational research can help to fill this knowledge gap and provide guidance for future programming.

Williamson, J. (2000). *Finding a way forward: Principles and strategies to reduce the impacts of AIDS on children and families*. Washington DC: USAID.

Williamson, J. (2000). *What can we do to make a difference? Situation analysis concerning children and families affected by AIDS*. Washington, DC: USAID.

This article discusses the importance of situation analysis in the process of formulating interventions for children and families affected by HIV/AIDS. The argument is that for interventions to be effective and resources to be well used, it is essential that interventions are developed with a clear understanding of the factors which are most significant and how they relate to each other in causing or mitigating problems.

Williamson, J. (2001). *Definition of orphan (CABA - Children Affected by AIDS)*. <http://www.synergyaids.com/caba>,

Williamson, J. (2003). *A family is for a lifetime: Part I: A discussion of the need for family care for children impacted by HIV/AIDS*. UNAIDS.

Williamson, J. (2003). *A family is for a lifetime: Part II: An annotated bibliography*. UNAIDS.

Williamson, J. & Donahue, J. (2001). *A review of COPE Program and its strengthening of AIDS committee structures*. Washington, DC: Displaced Children and Orphans Fund and War Victims Fund Contract.

Williamson, J., Lorey, M., & Foster, G. (2001). *Mechanisms for channeling resources to grassroots groups protecting and assisting orphans and other vulnerable children*. Mutarem, Zimbabwe: Family AIDS Caring Trust.

This paper briefly describes several types of mechanisms that have already been or could be used to channel resources to grassroots groups protecting and assisting vulnerable children in countries seriously affected by HIV/AIDS. Most of these approaches were identified in April 2001 by a group of experts in children's programming from Zambia, Zimbabwe, Malawi, South Africa, and Ethiopia who met in Cambridge, Massachusetts, in The United States. No one of these approaches is likely to be the best choice in every situation. Each has potential advantages and limitations, which must be considered in relation to a given context. These are not mutually exclusive options. In a given situation, two or more mechanisms may be needed, in parallel or working together. Also, this list is not intended to be exhaustive.

- Woelk, G. (1997). *Do we care? The cost and quality of community home-based care for HIV/AIDS patients and their communities in Zimbabwe*. Harare: SAfAIDS.
- Wood, G. & Mason, B. (2001). *The impact of HIV/AIDS on orphaned children in Kwa-Zulu Natal*. <http://www.togan.co.za.cindi/fullreport.htm>.
- World Bank (1997). *Confronting AIDS: Public priorities in a global epidemic*. New York: Oxford Economic Press.
- World Bank (2003). *Ensuring education access for AIDS orphans and vulnerable children: Participant module*. Washington, DC: World Bank.
- World Bank (2003). *World Bank workshop on orphans and vulnerable children*. Washington, DC: World Bank.
- World Health Organization (2003). *Global health sector strategy for HIV/AIDS*. Geneva: World Health Organization.

Conscious of the need to define and strengthen the role of the health sector within a broad multi-sectoral response to HIV/AIDS, the World Health Assembly adopted a resolution in May 2000 (WHA53.14) requesting the Director General of WHO to develop a strategy for addressing HIV/AIDS as part of the United Nations system-wide effort to combat the pandemic. The resulting Global Health-Sector Strategy (GHSS) for HIV/AIDS described in this document is only one of a number of important initiatives that have emerged since the United Nations Special Session on HIV/AIDS in 2001, and has been developed by WHO, in consultation with a wide range of stakeholders, in a spirit of renewed determination. The World Health Assembly will consider this GHSS document in May 2003. The global community in general and the health sector in particular now have an exceptional opportunity to redouble their efforts against a devastating global pandemic and to show what can be achieved through bold leadership and concerted action.

The aim of the Global Health-Sector Strategy (GHSS) is to strengthen the response of the health sector to the challenges posed by HIV/AIDS as part of an overall multi-sectoral effort. Within this overarching aim four specific objectives have been identified:

- To advise health ministries on the core components of an effective health-sector response to HIV/AIDS;
- To support health ministries in developing the policy, planning, priority-setting, implementation and monitoring frameworks needed to generate such a response as part of overall national strategic plans;
- To enhance and promote the comparative advantages, expertise and experience that health ministries can contribute to national strategic planning for HIV/AIDS;
- To help the health sector to meet the goals contained in the United Nations General Assembly Declaration of Commitment on HIV/AIDS.

In support of these objectives the strategy describes the support that WHO will offer, outlining a series of steps, issues and action points for health ministries and others in the health sector to consider, especially during the development or updating of national strategic plans for HIV/AIDS. The strategy can be used on a section-by-section basis to review policies and actions on specific topics – for example, priority-setting; human resourcing; or the allocation of roles and responsibilities.

- World Vision (2002). *Summary of OVC programming approaches*. World Vision International/HIV/AIDS Hope Initiative.
- Yamba, B. (2002). *Support to orphans and other vulnerable children in their communities. SCOPE-OVC (Strengthening Community Partnerships for the Empowerment of Orphans and other Vulnerable Children) Zambia experience*. Paper presented at the workshop on Children, HIV and Poverty in southern Africa. Pretoria: HSRC/SARPN/Save the Children.

The HIV/AIDS situation in Zambia has had serious effects on the population. One of the negative impacts of the pandemic has been the increase in the number children being orphaned. The current Ministry of Health HIV/AIDS figures indicate that approximately 20 per cent of the Zambian population between the productive ages of 15 to 35 are HIV positive.

With the number of HIV/AIDS related deaths still on the increase, the number of children being left behind with one or no parent is increasing. The current orphan estimates in the country lie between 650 000 to 1 000 000. This figure is expected to rise to around 1.5 million by the year 2010. Culturally, Zambians have a very strong extended family system, which requires its members to take care of children whose parents have died. Zambians live in a collective, rather than an individualistic, society, implying that problems affecting one, affect all around them. It is therefore very clear that communities and households surrounded by problems brought about by an increase in the number of orphans are bearing the brunt of this epidemic as they struggle to fulfill their family obligations of caring for the orphans. Seventy per cent of Zambians are currently living below the poverty datum line. This does not help the situation. The increase in the number of deaths has seen a lot of households absorbing other children and therefore thinly distributing the meagre resources to cater for their natural and orphaned children. This makes even the non-orphan children vulnerable. SCOPE-OVC is a CARE International Zambia project funded by Displaced Children and Orphans Fund of USAID, through Family Health International. Established in January 2000, SCOPE-OVC project has been implementing activities to mitigate the impact of orphans and other vulnerable children in their households and communities. Rather than implementing activities directly at community level, SCOPE-OVC enhances the capacities of district and community networks and organisations. This is done by mobilising, scaling up and strengthening community and district-level responses that support OVC within their communities.

Yamba, B., Simasiku, M., & Kalala, T. (2003). *Using Participatory Learning for Action (PLA) as an effective community mobilization methodology for the identification of community resources for orphans and vulnerable children support programs*. Presented at the XIV International AIDS Conference held in Barcelona, 7–12 July, 2002. [Available online: <http://www.aids2002.com/Home.aspl>].

Well mobilised communities will identify and effectively allocate locally available technical, material, human and financial resources that will address the problems affecting orphans and other vulnerable children. *Project*: SCOPE-OVC (Strengthening Community Partnerships for the Empowerment of OVC) Project has been using PLA tools to sensitise communities in 12 districts in Zambia to identify problems affecting OVC and establish ways to harness local resources for the children's support. PLA tools clustered as diagrams, interviews, maps or observation enables broader community participation in discussing issues. It helps break the gender, age, researcher/respondent, and the outsider/insider boundaries to brings out facts that may ordinary not be discussed. Researchers, acting as facilitators, only guide the whole exercise and leaves the community members to discuss the issues. This instils ownership of a problem from the start. The project has used tools like the resource maps, pie and venn diagrams to help communities pinpoint place and type of resource available in the community. Triangulated by transect walks and interviews, community resources are thus distributed effectively. *Lessons learnt*: 43 communities have used PLA and identified resources that have benefited needy children. These have included personnel for skills training, services such as home-based care programmes for linkages, infrastructure for use as community schools or children's corners. Small business ventures for financial support. Communities have also been able to understand roles and responsibilities of key players in the community leading to improved service provision. PLA helps people break the silence around an identified issue and raises awareness on available local resources. In Project Planning, communities should not always be seen as beneficiaries but also as key players and should be involved from the onset.