

Family Matters: the Care  
and Protection of  
Children Affected  
by HIV/AIDS in Malawi

by

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Final revised version October 2002

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## Executive Summary

This case study is one of a number commissioned by the Save the Children Alliance as part of the Care and Protection of Separated Children in Emergencies project (CPSC). It was designed to complement a series of other studies which focused on children separated from their families in the context of armed conflict and forced migration. It was felt that the perspectives and experiences of children who live without their parents as a result of HIV/AIDS could inform and be informed by the experiences of war-affected children in various countries around the world. It was also hoped that in-depth information from children affected and infected by HIV/AIDS could provide some insight into how boys and girls understand the many facets of HIV/AIDS so that future interventions could be more effectively targeted.

This study particularly focuses on the work of COPE in Malawi, a programme of Save the Children USA which mobilises communities to respond to a range of issues stemming from the AIDS epidemic. Although this research was not an evaluation of this programme, it was hoped that, by using research methods which would elicit detailed information from children, it would be possible to formulate some conclusions for future interventions. In total, the study reached 165 informants in three communities, including many children from the age of 8 years and upward. A great deal of the research time was spent with children aged between 8 and 12 who participated in workshops which used a range of participatory techniques. Individual interviews and focus group discussions were also held with older children, guardians and other adult members of the communities.

This case study provides a description of the COPE programme and of the activities at the community level which stem from it: it examines the cascade model in which capacity building and training are undertaken at various levels based on existing government-endorsed District, Community and Village level AIDS Committees. The COPE programme model encourages and facilitates community ownership of the problems stemming from HIV/AIDS, an approach widely regarded as the most cost-effective and sustainable way to address the magnitude of the problem nationwide.

In Malawi and globally, the vast majority of children rendered parentless by AIDS are living within the extended family. This study examines the various reasons why such children are, or are not, taken in by their relatives. A remarkable discrepancy was found in the views of adults and children: while adults tended to believe that children should play no part in the decision-making around their care, children themselves expressed clear and well-considered opinions on the characteristics of the most suitable care arrangements, and these vary significantly from those of adults. While adults emphasised the material capacity of a family to care for an orphaned child, children were much more concerned about being cared for by adults who would love them and respect the honour of their deceased parents. This led to a strong preference for care by grandparents, even if this meant living in extremely poor material and economic circumstances.

One of the most striking findings of this study also illustrates a strong discrepancy in the views of adult guardians and children. In general, adult guardians articulated a strong belief that orphaned children have many behavioural problems and as a result are difficult to look

after. They were highly critical of children who complained of discrimination because they felt that an orphaned child should appreciate the financial challenges posed by their arrival in the household and should feel grateful for this act of generosity. In contrast, orphaned children revealed a startling pattern of abuse and discrimination at the household level, and some quite gross examples were cited. Discussions with guardians and children highlighted a vicious circle of misunderstanding which was often difficult to break: children brought into the substitute family high levels of distress, stemming from what might have been a long period of caring for, and eventually losing, one or both parents, in addition to coping with the strong sense of stigma which surrounds HIV/AIDS and orphanhood. In the substitute family, discussion of their late parents tends to be discouraged and they are expected to behave well and not to complain. From the child's perspective there is often a profound sense of isolation because no one is paying attention to their special needs for love and emotional support. This feeling of loneliness is compounded by a sense of being different from other children in the household, whom they believe to be treated more favourably. Sometimes they act out their feelings by behaving rudely or inappropriately, or by withdrawing from family members. The resentment which results from their less-privileged position is augmented by what many orphaned children see to be their unmet needs for patience, love and kindness as they work through their feelings of grief and sadness. The result is a cycle in which guardians feel unappreciated and therefore less inclined to be supportive to the orphans in their care, while the children themselves feel angry, alone and unjustifiably discriminated against.

In COPE-mobilised communities, it was reassuring to find that discrimination towards orphaned children was much less pronounced within the wider community. It was particularly interesting to find that children deployed a range of coping strategies which included, for example, approaching other families outside of their immediate household for specific needs, and many dropped out of school and sought paid work in order to meet their basic needs. They also sought help and support from their own peer networks, and occasionally neighbours.

In addition, this research revealed children's striking lack of knowledge about HIV/AIDS, though where community-mobilisation around HIV/AIDS was well-established, boys and girls had greater awareness of how to protect themselves from the disease. Many felt that AIDS awareness campaigns have been largely unsuccessful and children were highly critical of the hypocrisy of adults who failed to practise what they preached. However, boys and girls were supportive of the idea of peer education and felt that behavioural change was most likely to occur as a result of seeing someone dying of AIDS. In particular, some suggested that young people should be taken to talk to someone dying of AIDS if that person was able to talk openly about his or her experience. They were also appreciative of people who asked that their funeral be used to raise awareness of AIDS and to discourage risky behaviour. Boys and girls also emphasised the role of parents in AIDS education, and they had a range of other ideas on reducing children's vulnerability to HIV/AIDS.

## List of Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
CAC	Community AIDS Committee
CBCC	Community-Based Childcare Centre
CBO	Community-Based Organisation
CHAPS	Community Health Partnerships
CPSC	Care and Protection of Separated Children in Emergencies Project
CRC	UN Convention on the Rights of the Child
COPE	Community-based Options for Care and Empowerment
DACC	District AIDS Coordinating Committee
HBC	Home-Based Care
HIV	Human Immunodeficiency Virus
MOGYCS	Ministry of Gender, Youth and Community Services
NACC	Namwera AIDS Coordinating Committee
NGO	Non-Governmental Organisation
OCG	Orphan Care Group
OTSC	Orphan Technical Sub-Committee
PRA	Participatory Rural Appraisal
RAC	Residential AIDS Committee
SC-S	Save the Children Sweden
SC-US	Save the Children USA
TSC	Technical Sub-Committee
USAID	United States Agency for International Development
VAC	Village AIDS Committee
YTSC	Youth Technical Sub-Committee

## **Acknowledgements**

This research could not have been conducted without the generous logistical, financial, material and moral support of a number of different people and institutions. The staff of Save the Children USA in Lilongwe and Mangochi provided a great deal of assistance in the organising and undertaking of the fieldwork and the local dissemination of the research. Special thanks go to George Chiweyu, Novice Bamusi, Victor Katchika-Jere, Lucretia Kuchande, Vera Ngosi and Justin Opoku. The patience and enthusiasm of the Namwera AIDS Committee, Ngawo and Mpinganjira Village AIDS Committees, and members of the Area 18 Residential AIDS Committee were also very much appreciated. Their commitment to the prevention and mitigation of HIV in their communities is both encouraging and inspiring. Thanks in particular go to the staff of Save the Children Sweden in Pretoria and Stockholm, especially Thando Khaile, Lennart Reinius, Ulla Armyr and Ulrika Persson.

Co-researchers, Sylvia Namakhwa and Dean Kampanje-Phiri were instrumental in creating an environment in which children, families and communities felt able to express their views and experiences. All aspects of this research have benefited from their caring and thoughtful approach to the research and those who participated in it. As well, David Tolfree's assistance in the conceptualisation of the study, the analysis of its findings, and the structure and content of this report has been greatly appreciated.

Final thanks go to the community members, guardians, youth and children who chose to participate in the research and to share their opinions and perspectives with us. It is hoped not only that we have done justice to their views, but that they and others in similar situations will feel the benefits of the research process and its resulting interventions.

## Definitions and Understandings

Terms such as “child”, “orphan”, “vulnerable”, “fostering” and “community-mobilisation” are subject to a variety of different meanings.

This document uses the terms and definitions employed throughout the research process. The term “child” is used to refer to a boy or a girl under the age of 18. The terms “young people” and “youth” are used interchangeably to refer to males and females between the ages of 15 and 25. Since definitions of childhood and youth vary across communities and contexts, these definitions were determined in consultation with children, young people, and adults in the research communities.

For the purposes of this study, an orphan is defined as “any child who has lost one or both of their parents and is under the age of 18”.<sup>1</sup> This is the definition set out by the Malawi National Task Force on Orphans. It includes both paternal and maternal orphans, and uses the same upper age limit as the United Nations Convention on the Rights of the Child (CRC).

During the course of the primary research for this study, conceptions and definitions of orphanhood were explored in depth with children, guardians and other community members. Part of the aim of the study was to explore people’s own perceptions of children’s vulnerability as a result of the impact of HIV/AIDS on their families and communities. In those communities where local AIDS committees have been mobilised as a result of COPE intervention, children’s vulnerability has been more broadly defined. Local understandings of vulnerability tend to include not only orphans, but also those children who live with disabled, chronically or terminally ill parent(s) or those whose already-poor households have expanded as a result of taking additional children in. In some cases, certain orphaned children are seen as less vulnerable than other children, whose parents may still be alive (and perhaps not infected).

This report uses the term “vulnerable children” to refer to those boys and girls considered by communities to be most at risk of social, emotional, economic and health problems. The term is in many ways inadequate, because it does not recognise the agency of some children, who challenge their “vulnerability” in numerous subtle and overt ways. However, the expression is employed in order to highlight the contextual nature of risk and the recognition that having parents is not the only protective factor needed to ensure a child’s healthy development. This is discussed further in Chapter 5.

In Malawi, HIV/AIDS orphans and other vulnerable children live in a variety of different household arrangements. These include: living in a relative’s household, living with an unrelated individual or family, living by themselves without adults, and living in child-headed households (which may or may not include siblings).

For the purposes of this study, the term “fostering” is used to refer to situations where children are cared for in a household outside their extended family. “Agency fostering” is

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<sup>1</sup> National Task Force on Orphans (1996): “National Orphan Care Program 1996-1998”. Lilongwe: Ministry of Women and Children Affairs, Community Development and Social Welfare, UNICEF (Malawi & UNDP (Malawi)).

used to refer to the placement of a child in foster care which results from the intervention of government, or a community-based organisation (CBO) or a Non Governmental Organisation (NGO). The term “spontaneous fostering” is used to refer to those families who choose to take in an unrelated child without the intervention of a third party. These definitions have been used in past CPSC studies. However, there is no word for “fostering” in either Chichewa or Chiyao, the two local languages spoken in the 3 communities where this research took place. Local terms for this practice translate roughly to “taking in” a child.

The term “community-mobilisation” is used to refer to the process of supporting neighbourhoods, villages and other areas to identify and take action on shared social, economic and health concerns. This approach to working for positive change can be initiated by the community itself, or by external individuals or institutions. The aim of community-mobilisation is to strengthen the capacity of people to address their future needs and those of their neighbours, families, and friends.



## Chapter One: Introduction

Malawi is a small, densely populated country in southern Africa which ranks among the poorest countries of the world.<sup>2</sup> Poverty is a reality for the majority of its 10.5 million inhabitants, more than half of whom are under the age of 18.<sup>3</sup> Statistics of maternal and child mortality, health and nutrition indicate the inaccessibility of basic health and social services to more than half the population. The country's single major natural resource, agricultural land, is under severe pressure from rapid urbanisation and population growth. Susceptibility to natural disasters such as drought and heavy rainfalls make food security precarious. Currently,<sup>4</sup> an estimated 3.2 million people are facing acute food shortages due to the combined effects of reduced crop yields and declining purchasing power.<sup>5</sup> Already scarce food reserves are being used to make up for this shortfall, and the country's next harvest is predicted to reap only half of the required amount. In early 2002, the risk of famine was so great that the government of Malawi declared a state of disaster.

Coupled with this food crisis and the nation's enormous social, economic and environmental challenges is the fact that Malawi is one of the countries worst hit by the HIV/AIDS epidemic. HIV gained a silent foothold in the 1980s under the regime of Hastings Banda, which restricted dialogue on sexuality and HIV/AIDS. In 1999, the virus had spread to such an extent that an estimated 16.4% of people between the ages of 15 and 49 were HIV positive, with 46% of new infections occurring among youth 15-24 years old, the majority of these among females. The epidemic is almost solely responsible for a decline in average life expectancy from 52 years in 1990 to 37 years in 1999<sup>6</sup>. To date, the disease has had a debilitating effect on families, communities and the nation as a whole and is widely considered to be the most critical challenge to Malawi's development.

### HIV/AIDS and Children in Malawi

In Malawi, HIV/AIDS has a direct impact on many facets of children's lives. In 1999, UNAIDS estimated that there were nearly 400,000 boys and girls under the age of 15 whose mother or both parents had died as a result of AIDS. Moreover, it is widely estimated that the number of children in Malawi who are living with an HIV-positive parent exceeds the number of those already orphaned. These children may themselves be HIV positive, and/or be responsible for caring for, and eventually losing, a surviving mother or father<sup>7</sup>. Because the average family has six children, the burden on alternative caregivers when parents die is substantial. Problems faced by most orphaned children include lack of food, shelter, clothing and other material necessities; lack of access to health care and education; discrimination, stigmatisation, economic and sexual exploitation; and a lack of support and attention to their social and emotional needs. Property grabbing is also a considerable problem for some boys

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<sup>2</sup> According to UNICEF (2001), the average annual per capita income in Malawi is 200 USD.

<sup>3</sup> UNICEF Malawi (2001)

<sup>4</sup> mid-2002

<sup>5</sup> <http://www.reliefweb.int/w/rwb.nsf/vLCE/Southern+Africa+Humanitarian+Crisis>. Access date 15 August 2002.

<sup>6</sup> UNICEF Malawi (2001).

<sup>7</sup> Care for chronically ill adults is often left to women and school children. It appears that boys and girls both share these tasks, depending on the sibling make-up and birth order of children in the household.

and girls, whose livelihoods often depend upon the scarce resources which remain after their parents' death.

These significant and wide-ranging problems are particularly acute for orphaned children whose extended families have grown smaller: the sheer numbers of adults dying means that parents' siblings may themselves have died or fallen ill. Many families in this context are too poor to provide children with their basic material needs. Caring for nuclear and extended family members, and then for the children they leave behind, places great stress on family resources, which may have been limited to begin with. The unprecedented scale of the epidemic in Malawi has meant that the "problem of orphans" has reached a level where virtually everyone is directly or indirectly affected by increased pressures on traditional social and economic support systems. Adults and young people who are not ill or infected shoulder enormous responsibilities for the well-being of their larger, extended families. When resources grow too thin or non-existent, many orphaned boys and girls are left to fend for themselves and their siblings. It is not uncommon for children in such circumstances to drop out of school, to seek employment in the informal economy, and to become involved in petty crime. Girls, in particular, may marry early or engage in prostitution or exchange sex for material goods. In 2000, a national study on children and violence in Malawi found that orphaned girls were more susceptible to HIV/AIDS and more vulnerable to sexual exploitation and abuse than children in general.<sup>8</sup> Protection issues specific to orphaned and other vulnerable boys are to date not well understood.

Community and individual attitudes towards HIV/AIDS are often influenced by the public position of religious leaders and through religious teachings. Accordingly, in Malawi, efforts to prevent the disease and mitigate its impact are shaped by the approaches taken by the church and Islam at the local level. In those communities where condom use is discouraged, and where religious officials have declared that AIDS is a result of "immoral behaviour" and "sin", there tends to be less acceptance of HIV/AIDS, and higher levels of discrimination against orphans and those who have the disease. Religious institutions, especially the Church, have played different roles in different places, at times engaging in awareness-raising activities, and other times controlling the nature and content of the information provided to congregations. It is these inconsistencies which have to a large extent influenced the level of understanding, acceptance and knowledge of HIV/AIDS among children and adults in Malawi.

### **Traditions of Care for Orphaned Children in Malawi**

Orphanhood is not a new phenomenon in Malawi. Traditionally, children whose biological parents died were taken in by uncles or aunts or other members of their extended family. These relatives usually lived nearby, and in significant numbers. In matrilineal societies, children were typically cared for by their mother's brothers, and in patrilineal societies, by their father's brothers, though in practice it is the wives of these individuals who care for the children. Guardians were usually well known to the child before the death of the parents through a strong network of blood relations. Then, as now, child care was not seen as the sole responsibility of the child's biological mother and father, and most children grew up with more than two parents: the sisters of their mother, for example, were known as "junior" and

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<sup>8</sup> Kaponda, C.P.N. 2000.

“senior” mothers according to their birth order. Similarly, the “senior” and “junior” fathers were the elder and younger brother of the father, respectively.

These concepts of parenthood and family and their link to the structure of kinship relations are still predominant in both urban and rural areas of Malawi. However, it is widely agreed that before the AIDS crisis, caring for orphaned children was much easier: deaths of parents were few and families and communities were more able to deal with the needs of orphaned children. Participants in the three communities where this research took place commented that there used to be fewer orphans, and a smaller population in general. Despite sometimes high infant mortality rates, death in adulthood was less common than it is today. Furthermore, in the event of an adult dying, it was rare for an individual to leave behind a sick spouse and children. There was enough land to cultivate, healthy soil and big harvests were the norm, and there was usually a variety of foods available in adequate supply. In nearly all cases, taking in an additional child was not considered to be a burden.

Many adults involved in this study also commented that before AIDS, no one knew which children were orphans. Often boys and girls who were too young to remember their parents were raised as the biological children of relatives and were never told that they were orphans. Those children who were old enough to know their mother or father were not allowed to see their deceased parent or the coffin, nor could they participate in funeral or burial rites. When the coffin was carried through the village, children were told to hide so that no one would know it was their parent who had died. Death was rarely openly discussed with young children (under the age of about four years) and after a short period of mourning, boys and girls were expected to “forget their parents” and to feel fully integrated into their new household. Children learned not to speak of their biological mother and father and to proceed as if their guardians were their parents.

Today, the reality is different. Those most likely to die of AIDS are parents in their 20s, 30s, and 40s. In the rural areas where this research took place, past efforts to protect children from being known as “orphans” are no longer possible because, in the words of many,

*Today, it is only young people who have the strength to carry coffins*

Some very young children are still not told that they are orphans, but they frequently learn of their parentless status from peers, other children in the household and neighbours. Sometimes in a fit of anger, guardians themselves may betray their own efforts to keep the secret. At other times, children themselves know that they are orphans, but choose not to disclose this knowledge to their guardian. On two separate occasions in this research, children told us that they were orphans, yet discussions with their guardians revealed their belief that the child was unaware that the current carers were not the biological parents. Those children whose orphaned status is public knowledge or are old enough to remember their parents tend to keep their family name. Those boys and girls whose guardians have chosen not to disclose that they are an orphan may choose to give the child their family name.

Despite the high numbers of people dying, and the fact that being an orphan is no longer exceptional in most Malawian communities, children of all ages learn not to discuss their feelings of grief and sadness. Even though they are told that they can speak to their elders, many children do not, believing that elders will not understand or that they are too busy with

their own problems to focus on those of the child. Some speak to their friends, and this appears to be one of the most common support-seeking strategies for children, especially in urban areas. However, the absence and impossibility of open dialogue with their guardians means that many children develop an understanding of their circumstances that may not be true but cannot nevertheless be clarified because they have no one to talk to.<sup>9</sup> This sense of isolation leads many orphaned boys and girls to see themselves as burdens, and as “different” from other children. Young children may become withdrawn; those over the age of 10 or so may begin to behave inappropriately, in an effort to act out their frustration and draw attention to themselves.

Today, given the high rates of adult mortality owing to HIV/AIDS in Malawi, conceptions of orphanhood and support to orphaned children must be understood alongside awareness and acceptance of the disease. In those communities where HIV is common and its presence is openly acknowledged, orphaned children face less stigma than they do in those areas where there is little acceptance.

Both matrilineal and patrilineal traditions are found in different communities in Malawi. The following table depicts traditional practice with respect to the care of orphans in matrilineal and patrilineal communities respectively:

<b>Traditional Orphan Care Practices in Matrilineal Communities<sup>10</sup></b>	<b>Traditional Orphan Care Practices in Patrilineal Communities</b>
Husband moves to wife’s community when they marry	Wife moves to husband’s community when they marry
No bride price is paid	Bride price is paid
Children belong to their mother, and upon her death, to her relatives	Children belong to their father, and upon his death, to his relatives
Husband moves away from wife’s village in the event of her death. In some cases, he may stay to look after his children, but most men are told to move away and leave their children behind	Wife is made to marry her husband’s younger brother in the event of his death. If she refuses to do so, she is asked to leave the village and usually has little or no contact with her children, who remain with their father’s relatives
In the event of the death of the father, his relatives take the property. Only those items he specified to go to his children are left behind	In the event of the death of the father, his relatives take the property. His wife may be left with a few small household goods such as cooking utensils
Maternal uncles determine who the children are to stay with and preside over property sharing which takes place 30 days after the funeral	Paternal uncles determine who the children are to stay with and preside over property sharing which takes place 30 days after the funeral

### **Research on Orphaned and Other Vulnerable Children**

Concern for the situation of orphaned children in Malawi and elsewhere has led to an increasing body of information on the needs and circumstances of children infected and affected by HIV/AIDS. Globally, several studies have been conducted on community-based assistance to orphans and community perceptions of the problems orphans face. In Malawi, research on orphan care has tended to focus on responses at the family and community level. The majority of participants in these studies have been adults, and occasionally, young

<sup>9</sup> Ali, S (Undated)

<sup>10</sup> This table is adapted from Ali, S (undated).

people. To date, boys and girls have rarely been involved in the articulation of their specific needs for care and protection, especially those beyond their material and economic requirements. Their lack of participation has meant that the experiences and perspectives of HIV/AIDS affected children in Malawi, especially those between the ages of 8 and 14, have largely not been considered in programmes and policies to meet their needs. Even those programmes which are specifically targeted towards children and young people often do not involve them in decision-making at the strategic or programmatic level.

## **Chapter Two: Overview of the Research**

### **Purpose of the Research**

In early 2002, a study was commissioned by Save the Children to address the need to learn from the experiences of boys and girls who have been most severely affected by HIV/AIDS by using research methods which enable children to share and articulate their experience. This research was designed to complement a series of other studies on the care and protection of separated children in emergencies (CPSC). It was felt that the perspectives and experiences of children who live without their parents as a result of HIV/AIDS could inform and be informed by the experiences of war-affected children in various countries around the world. It was also hoped that in-depth information from children affected and infected by HIV/AIDS could provide some insight into how boys and girls understand the many facets of HIV/AIDS so that future interventions could be more effectively targeted.

Malawi was chosen as the site of this research both because of the scale of the epidemic there, and the desire among Save the Children Alliance members to learn from the COPE programme of Save the Children USA in Malawi. This programme has been widely recognised for its success in supporting families and communities to address and cope with the challenges posed by HIV/AIDS. Given the urgent need to respond to the magnitude and duration of the epidemic, it is essential to learn from those programmes which are working well. COPE is one such intervention.

Accordingly, this study had three main aims:

1. To describe and learn lessons from the child-focused community support work undertaken by the COPE programme of SC-US in Malawi
2. To understand better the care and protection needs of HIV/AIDS-affected children by learning from the experiences and perceptions of children, guardians and other community members in Malawi
3. To understand community perspectives, especially those of boys and girls, on the accessibility and effectiveness of HIV/AIDS messages

### **Principal Research Questions**

This study explored a broad range of issues as they pertain to family and community coping in the context of HIV/AIDS in Malawi. The following 7 questions were explored in depth throughout:

1. How do families and communities cope with the increasing number of HIV/AIDS-affected children within the cultural and socio-economic context of the research sites? And, more specifically, how do young people themselves take actions to manage their lives? What are the traditional approaches to the care of orphaned children? What are the differences in child caretaking between patrilineal and matrilineal families? What is the impact of age and gender on child, family and community coping?
2. How are traditional coping mechanisms changing as a result of the AIDS epidemic? Do

people think that attitudes towards HIV/AIDS have an impact on individual and community coping?

3. In what ways are the rights of orphaned and other vulnerable children being abused or neglected? Do children living with related and unrelated carers experience a different level of care and protection from other children in the household? In what ways are the lives of (non-orphaned) children affected whose families support or take in other children?
4. What steps can be taken to reduce the heightened risk of orphaned and other vulnerable children to HIV infection, to discrimination (ie: access to education and services, community support, relationships) and to an absence of protection?
5. Where families and communities have failed to provide adequate care and protection for orphaned and vulnerable children (e.g. where children are living on the street) what kinds of interventions can be both effective and sustainable over the long term?
6. How can agencies support community coping in an effective, culturally-appropriate and cost-effective manner?
7. What unintended impacts might external, agency-driven interventions have on coping patterns, and how can the negative influences be minimised?

### **Research Methodology**

This research took the form of a case study. The intention was not to evaluate the COPE programme, nor to conduct an assessment of the impact of different caretaking arrangements on children in a quantifiable way. Given the scope and the scale of the AIDS epidemic in Malawi, and the aim of this study to collect qualitative data on the experiences and perceptions of children, guardians and others, it was not appropriate (nor possible) to collect a representative sample whose findings could be generalised to the population level. It was hoped that the results would reveal new insights about how children, their guardians, community members and external agencies perceive and respond to the needs and circumstances of HIV/AIDS-affected orphans and other vulnerable children in Malawi. The findings are designed to speak to practitioners, policy-makers and others at the local, national and international level.

This study consisted of 3 main components:

#### **COMPONENT ONE: An examination of SC-US Malawi's COPE programme and the associated community-mobilisation work which is being undertaken in local communities.**

Much research has already examined and documented the various aspects of the COPE programme. In order to avoid any unnecessary duplication in this regard, the bulk of data for this component was collected through an examination of secondary sources such as programme reports, records and evaluations, past studies, and other relevant archival material. Many of these documents are listed in the references at the end of this report. Additional information was acquired through interviews with SC-US staff, members of

partner NGOs and CBOs and adults and children living in communities where COPE-mobilised activities have taken place.

**COMPONENT TWO: An examination of the experiences, perceptions and opinions of HIV/AIDS-affected orphans and other vulnerable children in Malawi, their guardians, and other community members.**

The majority of the data collection for this component of the study took place at the community level, through a variety of participatory techniques used to elicit people's own constructions and understandings of the issues of concern. The research process and methods used are described below.

**COMPONENT THREE: An examination of the perspectives of community members, especially children, on the accessibility and effectiveness of HIV/AIDS messages.**

Like the second component of this study, the majority of the information collected in this area took place at the community level through dialogue and various techniques derived from the Participatory Rural Appraisal (PRA) methodology.

Fieldwork took place in three communities in Malawi over a 4 week period in May 2002.

The following criteria guided the selection of research sites:

1. Urban and rural
2. Significant numbers of orphaned children of all ages
3. Presence of "spontaneous" fostering
4. Presence of different forms of fostering, ie self care, by relatives and unrelated individuals and families
5. Patrilineal and matrilineal kinship patterns
6. Duration or existence of COPE-mobilised intervention
7. Lack of "research fatigue"
8. Lack of previous consultation with children on topics of concern
9. Expression of interest and support from local AIDS committees
10. Adequate harvest or recent reception of food aid by SC-US or another external actor: given the food crisis which was devastating many of the communities in Malawi at the time of the primary research for this study, it was determined that for ethical reasons it would only be appropriate to conduct research in an area where people were meeting their minimum daily nutritional requirements.

Every attempt was made to meet all of these criteria in the selection of the research sites. However, a number of factors conspired to make it impossible to conduct the study in a solely patrilineal community (the urban community selected is both matrilineal and patrilineal). It is hoped that such a study will be undertaken in order to complement the data already collected and to provide another level of comparison essential to understanding the situation of HIV/AIDS affected children in Malawi and other countries in the region. It was also found that the chosen communities contained almost no children living with unrelated carers.



## **Research Process**

A core team of three researchers was involved throughout the period of data collection, comprised of two women and one man, all under the age of 30. Additional research assistance was provided by SC-US COPE staff members in each of the communities, thus bringing the research team to approximately 4 people per community. Most interviews and discussions were conducted in Chichewa, the most widely spoken local language in Malawi. Occasionally Chiyao or English were used, when these were the preferred languages of study participants.

Data for the three components of the study were collected from adults, young people and children above the ages of 8 years. In total, 165 people took part, including 75 children between the ages of 8 and 12 years. The bulk of the research time was spent with this latter group, who participated in day-long workshops in which a number of participatory methods were used, including games, story telling, drawing, singing, drama and ranking. Children were encouraged to construct and share with researchers a picture of their lives and the issues of greatest concern and importance to them. The methods employed elicited rich and varied data on the experiences and perceptions of orphaned and other vulnerable children about the joys and challenges of their daily lives; the problems they face and the strategies they use to overcome them; their views on the most appropriate care arrangements for children who live without their parents; their networks of support; their perceptions of community activities and suggestions for changes and new approaches to supporting children and HIV/AIDS affected families. Two workshops took place in each community (with separate groups of children)<sup>11</sup>. Community leaders gathered child volunteers who were not necessarily orphaned or made vulnerable by parents having HIV/AIDS. These children were then informed of the research, its purpose and process. Question and answer sessions were then held with children before they were asked to decide if they wanted to participate, and if so, to give their informed consent to do so.

Individual interviews were conducted with guardians, children (12-15 years) and young people in each of the three communities. Interviewers were unable to speak directly with orphans who they knew to be orphaned by parents infected with HIV/AIDS as COPE works to reduce the stigma of orphans and therefore could not single out these children. However, most of the data collected with people over the age of 12 years were derived from group discussions which were pre-structured and often involved PRA techniques and other exercises such as ranking and drama. Every attempt was made to consult equal numbers of males and females and to work within community norms of age and gender groupings. Overall, a gender balance was achieved. However, the largely male membership on the executive of the Village AIDS committees, and the predominance of female guardians in the study communities meant that it was not always possible to have equal representation of adult males and females in all research activities. Such issues were not a concern among children and youth; boys and girls participated in equal numbers throughout the data collection process.

In addition to the children's workshops, group sessions were held with the following people in each community:

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<sup>11</sup> Except in the case of Area 18, where a second workshop day was not possible.

- Members of the Community AIDS Committee, where possible
- Members of the Village AIDS Committee (or its urban equivalent)
- Members of Orphan and Youth Technical Subcommittees at the village/neighbourhood level
- Male youths (13-18 years)
- Female youths (13-18 years)
- Female guardians
- Male guardians

Research feedback meetings were held with each of the communities at the end of the fieldwork period in order to present the preliminary findings of the study and to discuss their implications for current and future interventions. COPE staff participated in these meetings in order to provide continuity and support to Village or Residential AIDS Committee members. Since formal consultation with children is new to the COPE programme, these feedback meetings also provided COPE staff with an opportunity to learn the views and experiences of children in the communities where the programme has been operating and to consider their comments as they pertain to programme design, implementation, monitoring and evaluation.

At the end of the fieldwork period, a half-day long workshop was held for Government, and international and national NGOs concerned with the situation of orphaned and other vulnerable children in Malawi. Preliminary research findings were presented and discussed, and participants were asked to evaluate the extent to which the findings supported or contradicted their previous experience. On the whole, it was agreed that the research substantiated a number of issues not yet formally documented, but nevertheless apparent to many. This workshop enabled the research team and COPE staff to contextualise the study's findings on a national scale, in addition to providing an added opportunity for data verification.

### **Characteristics of the Case Study Communities**

AIDS is a day to day reality in the three communities where this research was conducted and funerals have become a fact of life. During our week-long stay in each community, at least one and often two AIDS-related funerals took place. At times we had to reschedule our data collection activities because women were called away to care for a dying relative, to prepare a body for burial, or to contact distant relatives of a deceased or dying person. The constant struggle of families and friends to deal with the emotional, social and economic impact of the AIDS epidemic was ever present.

#### **Community One: Ngawo Village**

Ngawo is a remote rural village of approximately 1400 people in the Mangochi District of Malawi. It lies in the lush hills of the Namwera region, near the border with Mozambique. The dominant ethnic group in Ngawo is the Yao, a matrilineal tribe near Lake Malawi. Nearly all residents of the village are Muslim.

The majority of the village population engage in subsistence farming, and most live in extreme poverty. Few families have access to all of their basic needs: food, clothing, soap and other necessities are a constant requirement for people of all ages. Like most areas of Malawi, boys and girls under the age of 18 represent more than 50% of the population.

COPE-mobilised activities began approximately five years ago in Ngawo, when a Village AIDS Committee was established. From the outset, COPE's involvement in Ngawo village has been through the Namwera AIDS Committee (in Namwera, the Community AIDS Committee is called NAC). Namwera was one of the first areas in Malawi in which COPE intervention took place, and the relationship between NAC, COPE and the Ngawo Village AIDS Committee has been strong and mutually reinforcing.

AIDS has been a significant problem in Ngawo for approximately the last 10 years. Through the Village AIDS Committee, community-led initiatives for the prevention and mitigation of HIV are currently in place and there is widespread acknowledgement of the disease. At the time of this research, the community was supporting more than 100 orphans and all of these children are being cared for "spontaneously" by adult relatives. Some children had reportedly left the community to live with extended family members elsewhere or to fend for themselves in urban areas in other parts of the country. The whereabouts of these boys and girls was not known.

### **Community Two: Mpinganjira Village**

Mpinganjira is a rural village of approximately 1800 people, located about 10 km from Mangochi, the district's urban centre. The dominant religion in this community is Christianity (Anglican), and a smaller portion of the population practise Islam. The ethnic groups represented in the village are the Yao and Nyanga peoples. All village members practise matrilineal kinship patterns. Poverty is widespread in this primarily agricultural community; however, residents have relatively easy access to the urban-based sectors of Mangochi town, as well as the fishing grounds of nearby Lake Malawi. In this respect, Mpinganjira has a broader economic base than Ngawo and its geographic location next to a major highway means that communication and transport are more easily accessed.

COPE intervention in Mpinganjira was initiated very recently, through the Community AIDS Committee in the area. The Mpinganjira Village AIDS Committee was formed one week before this study took place, in early May 2002. Previously, an Orphan Care Group (OCG) was run by the Anglican Church. The newly-established Village AIDS Committee (VAC) is basically an expansion of the OCG to include the local Imam, business leaders and others. The OCG was initially formed because a number of people in the congregation were concerned about the extent of the problems facing orphans in the village. To date, activities have involved providing guardians with soap, flour and milk for orphaned babies, as well as cooking porridge for orphans on Sunday afternoons and occasionally distributing used clothing that has been donated to the church from outside the community. One member explained these activities in his comment:

*In this community, children lose their parents almost every single day. Most of the people who die are between the ages of 20 and 35 years old. But these people who are dying are ours. These orphans are ours. We can't just wait for someone to come along to help us. We have to do it ourselves.*

The number of orphans in Mpinganjira village is not yet known, as the VAC was in the process of conducting a census when this research was being carried out. Various estimates have been made at 200, 300 and 600. Nonetheless, it is generally agreed that there are large

numbers of orphaned and vulnerable children in the community, and that most families are suffering under the economic, social and emotional impact of HIV/AIDS.

All but one of the more than 50 children between 8 – 18 years from Mpinganjira who participated in this research were living with related adults, and all guardians interviewed had chosen to take in children. Such actions reflect adults' responsibility towards related children, and thus took place without agency or government intervention.

### **Community Three: Area 18, Lilongwe**

Area 18 is a small urban neighbourhood in Lilongwe, the capital city of Malawi, with a population of approximately 10,000. The area was originally built by the government in the early 1970s in order to house civil servants, many of whom have since purchased their houses and retired in the community. The income levels in the community vary from middle to lower. Like most urban areas in Malawi and elsewhere, the population of Area 18 is made up of people from all over the country. Consequently, numerous ethnic groups are represented, as well as adherents to both Islam and Christianity. Family kinship patterns are determined at the household level; both matrilineal and patrilineal traditions are practised.

COPE-mobilised intervention began in Area 18 in November 2001, when a number of concerned citizens formed a Residential AIDS Committee (a RAC is the urban equivalent of a CAC). COPE provided training to the RAC in the areas of orphan and home-based care, prevention, youth involvement and community-mobilisation. Since that time, the RAC has begun to sensitise the community on HIV/AIDS and its prevention, and youth members have developed and performed a series of dramas for children in local primary schools. Membership of the RAC includes the local chief, representatives of religious organisations and other concerned individuals.

While the absolute numbers of people infected and affected by HIV/AIDS are greater in rural areas, HIV/AIDS percentage rates in Malawi are highest in urban areas, where 14.4% of the population live.<sup>12</sup> Urbanisation has been taking place at a rapid rate over the past 15 years, and as a result the population of Lilongwe has more than doubled in this period. A census conducted by RAC members in Area 18 in November 2001 indicated there were 268 orphans in the community. Some of these boys and girls live "spontaneously" with adult relatives and others live in sibling-headed households. This latter living arrangement appears to be most common when the eldest sibling is above the age of 20.

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<sup>12</sup> UNICEF Malawi (2001). p. 94

## **Chapter Three: Save the Children USA's COPE Programme and Associated Community-based Activities**

### **General Overview of the COPE Programme**

The COPE programme of SC-US in Malawi began in 1995 as a pilot programme designed to mitigate the impacts of HIV/AIDS on communities, families and children. Initially, COPE activities took place in nine villages in Mangochi District, on the southern end of Lake Malawi. COPE staff worked with government, NGO, church and business people to implement a broad range of interventions, including identifying and monitoring orphans and other vulnerable individuals; organising structured recreational activities for children and young people; providing material assistance to orphans and AIDS patients living at home; training caregivers in home-based care; fundraising; HIV prevention activities such as drama groups for youth; developing community gardens to produce food and income to benefit vulnerable families; and establishing anti-AIDS clubs for children.

A 1996 evaluation found that most of the COPE activities were producing positive results in the areas of AIDS awareness, home-based care, and income generation. It was recognised, however, that in order for the programme to be sustainable, its staff needed to focus more on the facilitation of community-owned efforts and work more closely with existing structures, institutions and organisations at the community and district level. In 1997 COPE shifted its focus to address these concerns and also began to use its human and financial resources to invigorate the UNICEF and Government-endorsed village (VAC), community (CAC) and district (DACC) level AIDS committee structures. Staff began to work with individual committee members as well as the committees to strengthen their capacity to implement activities to assist families caring for orphans and/or terminally ill patients living at home. In addition, young people were trained in HIV prevention and families and communities were assisted in mobilising resources in order to sustain these activities in the long term.

Over the past six years, COPE has built on this community-mobilisation approach and has slowly adapted and expanded to cover four districts of Malawi, an estimated 9% of the national population.<sup>13</sup> Today, it is widely agreed that the programme has not only been successful in assisting communities to act on their own initiative, but that it has provided a model which has become an integral part of Malawi's overall response to HIV/AIDS at the local and national level. Plans are currently in place to further expand the programme within Malawi and to replicate the model in Ethiopia and with other members of the Save the Children Alliance in Mozambique.<sup>14</sup>

### **Components of the COPE Programme**

The COPE programme of SC-US in Malawi is based on the assumption that HIV/AIDS has diverse and wide-ranging impacts on individuals, families, communities and society as a whole. Intervention is thus designed to be multi-sectoral and the programme in its current form includes five key components which together form a "package"<sup>15</sup> of services for HIV/AIDS prevention, care and mitigation. These are orphan care, home-based care, youth involvement, prevention and community resource-mobilisation. Each of these components

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<sup>13</sup>Hunter, S (2002). This figure was estimated in January 2002.

<sup>14</sup> To date, Alliance partners include Save the Children Norway and Save the Children UK.

<sup>15</sup>Hunter, S (2002)

operates through voluntary village, community and district committee structures, called Technical Sub-Committees (TSC). While each TSC works relatively independently, all Village AIDS Committees have an executive committee composed of representatives of each of the different TSCs. Because the negative impacts of HIV/AIDS are inter-related, responses target various points on the prevention-to-care continuum. In this way, VACs are able to develop a variety of activities and services to meet the specific needs of vulnerable children and families in their community, including, for example, community-based child care centres, community gardens, youth-to-youth counselling and home care services for the terminally ill.

### **Links between COPE and other Programmes, Resources and Actors**

The COPE programme is linked to and co-ordinates with varying levels of government, NGOs and CBOs in an attempt to support and invigorate the 3-tiered AIDS committee structures. COPE works alongside VACs, CACs, largely through the provision of training in areas identified by members, including representatives from the Ministries of Agriculture, Health, Education and Women and Children's Affairs. In addition to community members, business people, NGOs, CBOs and faith-based organisations also participate on these committees. In recent years, there have been several examples of SC-US collaboration with these groups at the implementation, policy and advocacy level. Past partners have included World Vision International and the Adventist Development and Relief Agency, among others.

At the national level, COPE representatives sit on various HIV/AIDS-related task forces, such as the Malawi National Task Force on Orphans and the Task Force on Young People's Issues and Prevention of HIV. Members share experiences, pool resources, and engage in collaborative activities such as conducting a survey on wills and inheritance (1999) and a situation analysis of children and violence in Malawi (2000). In addition, since 2001, COPE has been involved in a national umbrella organisation for all NGOs implementing HIV/AIDS activities called the Malawi HIV/AIDS Participation Programme. Its purpose is to ensure quality of interventions, avoid duplication of services, document and disseminate best practices and act as a unified voice on implementation issues across the country.

In some cases, responsibilities for COPE-led operations have been handed over to other government or non-governmental actors at the local, regional or district level. For example, in early 2002, the Community Health Partnerships (CHAPS) in Mangochi District became responsible for integrating the various components of COPE programmes into the Government's District-wide health activities. CHAPS is a programme supported by SC-US and in this way, the organisation remains closely involved in the monitoring of further COPE-initiated interventions and advocacy efforts.

### **Description of COPE Activities at the Community Level**

By its very nature, the COPE programme looks slightly different in every community where interventions take place. While the process of community-mobilisation is replicated in each village or urban neighbourhood, the type and nature of the activities implemented depends on the specific needs and desires of each community.

In reading through the literature on COPE, it is sometimes difficult to picture exactly how the programme is implemented at the community level. In a nutshell, COPE works within the

VAC/CAC/DACC structure to mobilise communities to take action to mitigate the impact of HIV/AIDS in a 10 step, cascading process:

1. Staff begin by working at the district level to support or revitalise the DACC
2. COPE then works alongside the DACC to build relationships at the community level and form, familiarise and train CACs
3. COPE then assists the CACs to develop and orient VACs
4. Depending on the nature of the information required, COPE staff may then assist VACs and CACs to use PRA techniques such as focus group discussions and resource mapping to augment existing understandings of the problems facing the community
5. Once these committees are in place, COPE staff facilitate “*Tigwirizane*”, or Training for Transformation, workshops in order to raise awareness of HIV/AIDS and its impact, to encourage community ownership of HIV/AIDS-related problems, and to support the development of a range of activities aimed at alleviating the impact of the disease at the village level and beyond
6. As VAC and CAC members become more experienced and knowledgeable about the issues specific to their community, COPE staff begin to focus their efforts on supporting the development of 5 Technical Sub-committees: prevention, orphan care, home-based care, youth, and community resource-mobilisation (to date, the role of youth committees has been largely in the area of AIDS awareness)
7. Once TSCs have been formed, COPE provides orientation and training to each committee separately, so that they can begin to implement activities to assist those in greatest need
8. COPE staff then assist VACs to conduct a resource inventory, register the chronically ill, orphans and other vulnerable children, and to undertake a needs assessment of these target groups and HIV/AIDS affected households
9. Services provided may include some or all of the following<sup>16</sup>:
  - *Agricultural development* (training, provision of inputs, communal gardens)
  - *Income generation* (marketing, micro-credit schemes, management training)
  - *Education* (Community-Based Child Care Centres, assistance with school fees)
  - *Health* (home-based care for people living with AIDS, hospital referrals, training in nutrition and growth monitoring)
  - *Psychosocial assistance* (home visiting and assistance with household chores for people living with AIDS, integration of orphans and other vulnerable children into recreational activities such as football, counselling of guardians and children, child protection, succession planning using memory books)
  - *Prevention* (life skills, peer education, condom distribution, behavioural change)

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<sup>16</sup> This list is adapted from Hunter (2002)

- *Activities for youth* (prevention and training for youth to do preventive work themselves)
  - *Relief* (food, clothing)
10. Once these activities are up and running, and communities have begun to engage in fundraising to sustain them, COPE staff reduce their support and focus on assisting VACs and CACs to maintain, monitor and develop the programmes they have implemented.

## **COPE Intervention and the Daily Lives of Orphaned and Other Vulnerable Children**

The sheer number and variety of activities taking place on the ground make it especially challenging to see what COPE intervention actually means for the daily lives of orphaned and other vulnerable children in the communities where the programme is operating. At the time of data collection for this study, COPE-mobilised activities had not yet begun in Mpinganjira, and involvement in Area 18 was relatively recent. However, a description of the activities taking place in Ngawo, where a Village AIDS Committee has been active for approximately 5 years, may provide an example of the specific impact of COPE on children in one small, rural community.

Orphaned and other vulnerable children in Ngawo benefit from the following VAC-run activities:

**Communal Gardens and Seed Donations:** Guardians caring for orphans and households with sick and dying parents or other carers are provided, where possible, with produce to feed their households or seeds to grow their own vegetables. This assistance increases the food consumption and nutritional status of the children, both orphaned and otherwise, living in these households.<sup>17</sup>

**Community-based Child Care Centre:** A small nursery school has been established in the village in order to provide children between the ages of 3 and 6 years with the opportunity to learn and socialise with others. Children spend 5 half-days per week at the CBCC, where they play, sing, dance and engage in other early childhood educational activities. The CBCC is free for orphaned and vulnerable children, and communities make food contributions to the CBCCs. Some parents in the community also send their children to the centre, as it is seen as good preparation for primary school.

**Advice to Guardians:** VAC members speak individually and in groups with guardians in order to encourage them to be kind to the orphans in their care and not to overwork them; to understand the value of school and its role in ensuring the child's future; to love and treat orphans the same as biological children; to provide guidance to the orphans so that they will not engage in activities such as drinking and smoking marijuana. It is important to note that VACS are reluctant to contact guardians individually because such actions are considered to be intruding into their private affairs. They also worry about what might happen to the child if they appear critical of the guardian.

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<sup>17</sup> It is important to note, however, that many of the children who participated in this research commented that this food assistance did not always reach them, as some guardians tended to deny the orphan access to it and to feed their biological children instead.



**Structured Recreational Activities:** Orphans and other vulnerable children in Ngawo participate in activities such as football and netball. Adults and young people undertake casual labour in order to raise money to buy balls, and volunteer their time to referee games and organise other activities.

**Fundraising:** VAC members work together to buy clothing, food and school materials for orphans in the village.

**Monitoring of Children's Well-being:** VAC members have been trained in children's rights and the basics of child development. Volunteers try to be attentive to the behaviours of orphaned children in the village. When they become aware of a child who has dropped out of school, for example, VAC members will ask the boy or girl to explain what has happened, and will try to convince the child and/or the guardian to return the child to school. Girls who become pregnant and are sent away from their guardian's home are often traced and encouraged to sort things out with their guardian. Children under the age of 12 who run away to work on farms are also encouraged to return to the village and enrol in school. VAC members may discuss with guardians ways that they can augment their family income without having the orphan miss school. Cases of abuse are not frequently reported to VAC members, so there is little intervention to support children in this respect.

**HIV/AIDS Awareness and Prevention Activities:** In Ngawo, children aged 10 and up are involved in youth-to-youth education around HIV/AIDS. Some also participate in theatre groups to spread prevention messages about the disease. Condoms are freely distributed (although some children expressed difficulty in accessing them because the youth committee had finished its supply and they did not want to approach adults with this request).

In Ngawo, children were asked for their views on COPE-mobilised activities and the extent to which they were meeting their needs for care, protection and support. Most participating children felt that peer education on HIV/AIDS was changing the behaviour of some young people. They also felt that VAC-led efforts to sensitise the community on appropriate care for orphans had changed the way that orphans were treated by adults in public places, such as within the community and in schools. However, boys and girls expressed concern that discrimination and abuse at the household level was still a serious problem and most commented that orphaned children need a great deal more protection than they are currently receiving. Despite the comments of some VAC members encouraging children to seek assistance in the event of discriminatory or abusive treatment, the boys and girls who participated in this research did not feel comfortable to do so, in part because of feared reprisals from their guardians. Children felt strongly that the VAC should focus its efforts on sensitising guardians on how to care for orphans and tackle the widespread issue of the harsh and cruel treatment. These issues are discussed further on page 45f.

### **Cost-Effectiveness and Sustainability**

The underlying premise of the COPE programme of SC-US Malawi is that the appropriate role of an international NGO in responding to the needs generated by HIV/AIDS is not to provide direct care for affected individuals, but to mobilise lasting community responses to address these needs. However, the lack of adequate government resources at all levels, coupled with the extreme poverty of most of the communities in which the programme takes

place, means the implementation of supportive interventions is very difficult to sustain without adequate training and support and the input of external financial resources. Some of the serious constraints to sustainability at the community level include high levels of illiteracy among programme volunteers (at least 50%<sup>18</sup>); unavailability of basic drugs and supplies for home-based care volunteers; high rates of death and illness amongst adults between 25-40 years; and the lack of financial and material resources within the community to contribute to the costs of programme activities. Similarly, the massive workload associated with the CACs, many of whom are responsible for supporting up to 100 villages, means that many communities' needs go unmet and volunteer burn out can be high.

Despite these significant barriers to the cost-effectiveness and sustainability of the programme, COPE has made considerable efforts at the local, district and national level to overcome these challenges. Its dual focus on community capacity building on the one hand, and support to the VAC/CAC/DACC structure and other national efforts on the other, has enabled the programme to grow and flourish. Investment in the training of local leaders has helped communities to initiate change from within. Some COPE-trained communities have begun to develop and implement new interventions with resources mobilised by community members themselves; others have chosen to lead by example and to convince other communities to adopt the programme. Furthermore, national level advocacy efforts and integration of COPE into the government-supported AIDS committee structure at the local, district and regional level has ensured government support and participation in the programme, and allowed for its replication and continued growth.

When COPE first began in 1995, the DACC/CAC/VAC structure was barely operational. In its first year of implementation, the programme helped to establish 9 VACs. Since that time, several programme modifications have taken place in order to maximise the impact of COPE interventions. By 2000, a total of 4 DACCs, 17 CACs, and 208 VACs were formed. Current plans are in place to scale up the programme to 6 Districts, with the goal of reaching 15% of the Malawian population.<sup>19</sup>

Until recently, information on the costs and benefits of the COPE programme were not systematically recorded and examined. In the past, evaluators have argued that the programme "appears to be delivering very high benefits at an extremely low cost, but this subject needs more creative evaluation techniques that look at outcomes using cost benefit, cost effectiveness, or return investment models".<sup>20</sup> A retrospective study of these aspects of the programme was initiated in January 2002 to address this gap. Programme reviewers feel sure these efforts will substantiate their strong intuition that COPE is cost-effective and that it has had a significant impact on the health, economic and social well-being of the communities in which it works. A summary of the project's achievements to date is reproduced overleaf.<sup>21</sup>

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<sup>18</sup> Hunter, S (2002) p. 30.

<sup>19</sup> Phiri, S N, Foster, G, & Nzima, M (2001) p. 20; and Hunter, S (2002) p. 3.

<sup>20</sup> Hunter, S (2002) p. 22.

<sup>21</sup> This table is a modification of one produced by Hunter, S (2001) p. 10.

<b>COPE Achievements, 1995 - 2001</b>		
<b>Topic</b>	<b>COPE I: 1995-1996</b>	<b>COPE II: 1997-2001</b>
<b>Duration</b>	Phase 1: 1 year 5 months Phase 2: 7 months	4 years
<b>Organisational Accomplishments</b>	1 DACC 1 CAC 16 VACs (+ 5 post project) 249 youth clubs 458 trained care givers	4 DACCs 17 CACs 302 VACs 440 Youth Clubs 2495 trained care givers
<b>Persons/Households Served</b>	4456 total households 704 target households with 4154 members and 2409 children 1210 orphans registered 276 orphans assisted 56 home care patients assisted	Not estimated Not estimated  30,000 orphans registered 10,284 orphans assisted 2763 home care patients assisted
<b>Improvements in Health and Quality of Life</b>	Care for chronically ill improved in 95 out of 100 target households 9 CACs trained in market chain analysis 10 CACs trained in resource-mobilisation 39 children referred to under 5 clinics 45 children referred to hospital	99 VACs with community gardens 100 VACs linked to agricultural extension system 20 people trained on cassava grating machine 33,500 reached by HIV/AIDS prevention campaigns 17,935 condoms distributed on average by each VAC \$20,472 raised by CACs and VACs 12 CACs trained in market chain analysis 130 individuals trained in resource-mobilisation 271 patients referred to hospital
<b>Budget</b>	\$538,000	\$1.1 million
<b>Catchment Population</b>	Phase 1: 9 villages Phase 2: 16 Village AIDS Committees	Phase 1: 5 CACs in 6 districts Phase 2: 17 CACs in 4 districts
<b>% of Population Served</b>	1.1% of national population	12% of national population
<b>Cost per Person in Service Area</b>	\$6.75 US	\$1.45 US

## **Monitoring and Evaluation of COPE**

Currently, both qualitative and quantitative data are collected on the impact of the COPE programme in participating communities. Monthly, quarterly and annual reports by project staff describe programme activities, achievements and lessons learned. In the last few years, internal evaluations have been commissioned on an annual basis in order to explore specific issues of concern. In 2001, COPE began to involve participating communities in the documentation and monitoring of activities at the village level. Village AIDS Committees have been trained to gather data and maintain records on the vulnerable members of their communities and the numbers of people served by their interventions. This information is then fed to and consolidated by the Community AIDS Committees, who in turn pass it onto the District AIDS Co-ordinating Committees for the same purpose. This is now integrated into a programme-wide Management Information System (MIS) in order to assist in programme development and refinement, as well as the gathering of information on the long

term benefits of the COPE programme for children and families. These recent efforts to involve local communities in the monitoring and evaluation of activities came in part as a response to the concerns of external reviewers about the lack of efficiency in the collection of baseline data in earlier phases of the programme. It was felt that the absence of this information was limiting COPE's ability to measure change and to examine critically the effectiveness and sustainability of the programme at the community level.

In Ngawo, community members expressed widespread agreement that they have benefited a great deal from the involvement of COPE and NAC in the establishment and development of the VAC. They spoke highly of the work of the VAC and the fact that traditional and political leaders are now involved in community efforts to combat HIV. Perhaps most importantly, many villagers commented

*People can now say, "There is AIDS in our village"*

## Chapter Four: Care Options and Decision Making

### Options for the Care of Orphans and Other Vulnerable Children

In the three communities where this research was conducted, nearly all orphaned children were cared for by relatives. Of the more than one hundred and thirty children and young people who participated in the study, only one child was living with an unrelated guardian, and in this case it was a 14 year old boy in a rural community who was already living with his employer when his parents passed away. All others were living with members of their immediate or extended family; this was the case for boys and girls in the two matrilineal communities as well as for children in Area 18, where the urban melting pot has meant that kinship patterns are determined at the household, rather than the community, level.

In the matrilineal villages of Ngawo and Mpinganjira, it is customary for children whose mother has died to be taken in by members of her family, regardless of whether or not their father is alive and in good health. Children's options for care in these communities thus included living with their maternal grandparents, aunts or uncles, or with older, married siblings (although this option was rarely practised). While some of the children involved in the study in these two villages were not paternal orphans, none was living with their father: most men in this context had been encouraged to leave the community by the wife's family shortly after the death of the wife because they want him to go and find another wife. Children reported that it was rare for them to see or communicate with their fathers. In these two matrilineal communities, losing their mother (ie: being a "maternal orphan") left children in effectively the same position as those boys and girls who had lost both parents ("double orphans").

### Factors which Support or Undermine the Decision to Take in an Orphaned Child

Adults in all three communities where this research was conducted were asked to identify those factors which encourage or discourage people from taking in an orphaned or otherwise vulnerable child. The discussions which resulted were often very lively and a number of different reasons were identified and explored.

#### Reasons why Some Guardians Choose to Take in a Child

- **They have no choice:** The number one and most commonly cited reason why adults become guardians to orphans is because there "is no one else to do so", and guardians felt they have "no choice" in the matter.
- **The child is related to them:** Obligation to extended family means that people very often feel that they cannot refuse to take in the child of a relative, even when they do not have the financial resources required to care adequately for the child. This view was expressed by community members in both urban and rural areas.
- **Concern for the welfare of the child:** This view was clearly expressed by a woman in Ngawo, who commented: "If left on their own, (an orphaned child's) future will be doomed".

- **In order to remove the child from an abusive living situation:** Some people spoke of choosing to take in an orphaned child who was already being cared for by another guardian because they felt that the child was experiencing undue suffering.
- **To fulfil the wish of a dying parent:** All adults involved in this study said that it is impossible to ignore the stated wishes of a dying family member because of a sense of moral obligation and the fear that the deceased individual will come back to haunt those who have shirked their responsibilities.
- **In order to support the child to go to school:** Some people feel that they are the only one amongst their relatives who is able or willing to invest in an orphaned child's education. It is not uncommon for people to believe that "it is a waste to send a child who is not (their) own to school". This view comes from the belief that guardians will not benefit from the investment in the long term.
- **In order to relieve relatives who do not have adequate resources:** When it is obvious to an individual that s/he is in a better financial position to care for a child, that individual often feels a moral obligation to take in the child.
- **Long-term thinking:** Several men and women who participated in this research commented that helping a child in need in the short term is a wise investment because there are significant long term costs associated with not doing so. For example, supporting a related child to go to school was seen by some adults as a way to mitigate against the child's future unemployment and thus the need to provide the child with financial support long into adolescence and adulthood.
- **In order to get a share of the deceased parents' wealth:** The financial and material status of the deceased is a motivating factor for some people to take in an orphaned child. Some people believe that these resources will assist them to care for the child; others hope to gain personally from the pension, property, or belongings of the child's deceased parents(s).
- **In order to gain from the child's labour:** This reason spans the length of the spectrum from the need for additional hands to perform household chores to the desire to use the child as an unpaid domestic servant or, as some children deemed it, "slave".
- **In order to get registered for assistance:** Some guardians hope that by taking in an orphaned child they will be able to access money or other benefits such as farming tools. This reason is most common in those communities where orphans are registered and local or external actors target assistance according to these records.
- **The child is a girl:** Many people spoke of guardians' preferences for girls. Reasons for this preference included wanting assistance with domestic work, using a female orphan as the "wife" of the male guardian, and hopes of benefiting from the man a girl may marry later.
- **The child is between the ages of 3 and 6:** In many communities, young children are seen as having fewer problems because they are less aware of the differences between

their past and future care arrangements, and are perceived by guardians as not yet “trained” by their parents.

### **Reasons Why Some Guardians Choose Not to Take in a Child**

- **Poverty/lack of resources:** The number one reason given for why people choose not to take in an orphaned boy or girl was their perceived financial inability to care for an additional child. The extreme poverty of many families in the communities where this research took place meant that, despite the best of intentions, some adults felt simply unable to stretch their already-strained resources.
- **Deceased parents were on bad terms with the relative:** Some people choose not to take in the child of a family member with whom they were jealous rivals or with whom they have had strong disagreements.
- **“Umbombo”:** Many men and women spoke of the “selfish desire of some people to hoard their resources for themselves and their biological children”. Female guardians in Mpinganjira said such people were “greedy” and had “cold, animal hearts” because they were unwilling to share their wealth with another person’s child.
- **No perceived personal gain:** There is a perception among some adults that there will be no personal gain from investing in another person’s child: in such cases, guardians believe the child will never view them as parents and will therefore not feel obligated to assist them, in old age or infirmity.
- **The child is located a long distance away:** Some relatives live far from one another and are unaware when a child is orphaned. Others may not be able to afford the transport costs of bringing the child to their community.
- **The child is academically or otherwise gifted:** Some parents do not want to support a child who is known to be intelligent, for fear that the orphan will out-shine their own biological children at school and in future efforts to seek employment.
- **Assumption that the child is infected:** In some communities, a child whose parents have died of AIDS is assumed to be infected as well. In these cases, some guardians fear that the child’s illness will impoverish the household, and in some cases, bring shame and dishonour onto its members.
- **Assumption that the child has many problems:** Many of the adults who participated in this research felt that orphans in general are difficult to care for, not only because they have many emotional and behavioural problems, but also because they will not appreciate the efforts guardians will have to make to assist them.
- **Fear that the child will be discriminated against:** Some adults spoke honestly about their fear that they would not be able to treat an orphaned child equally with other, biological children in the household. Several women commented that it is in fact not possible to do so, because

*When a child is not your own, you cannot love them in the same way you love the children you have given birth to*

Coupled with the recognition of this fact is the fear that the orphaned child will tell others of their unequal treatment and neighbours and friends will judge the family harshly.

- **No obligation:** In matrilineal societies where the responsibility for caring for children falls with the maternal uncle, often family members on the father's side do not feel it is their duty to care for his orphaned children. When asked if the reverse of this situation occurred in patrilineal communities, participants said that widowed women are still considered to be the responsibility of their deceased husband's family. Therefore, support from maternal relatives is less likely to be called upon<sup>22</sup>.

### **Decision Making Around Children's Care**

In the matrilineal communities where this research took place, it is common for maternal uncles to decide who will be given the responsibility to care for their sister's orphaned children. One man explained that

*When a woman dies, her brother becomes the owner of her children, even if the father is still alive*

If there are no maternal uncles, then all maternal relatives are involved in the decision-making process. The village chief is usually involved in these discussions or informed of their outcome, before the final arrangements have been made. Similarly, in Area 18, it is typical for the relatives of the deceased parent to make such decisions. However, most adults who participated in this research said that choice is a luxury when it comes to selecting a guardian for an orphaned child: high levels of household poverty, illness and the inability of most family members to support another child means that there are rarely any real options to choose from. In these cases, children are placed with the "best of the worst" options available to them.

To date, children in all three communities have not been involved in the decision-making around their care. While some adults were interested to know children's preferences, most felt that boys and girls would not choose realistic options, even if they were asked. Others commented that children should not participate in these decisions because "it is not their place" and "they will get very confused about it all". One prominent member of a Village AIDS Committee bristled at our enquiries about the role of children in stating their care preferences:

*Children play no part in the decision-making about their care. This question is about the "democracy thing" and rights but things in this community are different. We don't go by that. Children are getting confused by these things. They have no choice, nor should they*

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<sup>22</sup> In a patrilineal community, wives remain part of the husband's family only if they choose another male relative in the family for marriage. If not they are disowned and the children remain the property of the husband's family



In contrast, orphaned and other vulnerable boys and girls in all three communities felt strongly that they should be consulted on such matters and suspected that adults had no idea of the different criteria that they used to assess the appropriateness of a potential guardian. In one particularly animated discussion, an 11 year old boy commented

*It is your life and you know who will care for you. You can see for yourself who will love you and who will treat you like a slave*

On another occasion, in a focus group discussion with girls between the ages of 13-16, one girl said

*We would like to be given a choice about where we live because we know best where we will be well-treated – but we are not asked*

Nearly all children expressed agreement with these and other similar statements. Some said that they sometimes want to refuse the arrangement made for them, but it is usually the only one available. They also fear that by refusing they will be sent away to live on their own, a situation viewed (at least initially) to be far worse.

The following discussion of adults' and children's care preferences highlights a major difference in the views of men and women and those of boys and girls. Adults tend to base their decisions in large part on economic considerations, whereas children appear more concerned with the atmosphere of their guardians' household: the vast majority of boys and girls involved in this research spoke of their desire to live with those who will love them, enable them to "feel free" and treat them equally with other children in the household. While adults, at least initially, recognised that orphaned children have specific emotional needs, in the end, most felt that children's basic material requirement came first. The extreme poverty of most families who participated in this study means that adults' focus on meeting children's daily needs for food take precedence over almost all other concerns. It is no wonder, therefore, that economic considerations dominate in adults' selection of guardians, and that these matters are ultimately viewed as more important than keeping siblings together, for example.

### **Adults' Preferences for Orphan Care**

Adults in Ngawo and Mpinganjira had strong views about the most appropriate person with whom children should live upon the loss of their mother. In general, those maternal relatives with the most money and/or the least number of children were considered to be the best guardians because the orphaned children would be well fed and would have the best chance of going to school. As one elderly male guardian in Mpinganjira commented

*(Choosing a place for an orphan to live) does not depend on who is who but on who has what*

This view that the economic situation of a relative is the most important factor in determining their appropriateness as a guardian was reflected in different ways in the two matrilineal villages where the research was conducted. In Ngawo, adults interviewed felt strongly that the institutionalisation of orphaned children was a last resort. While the Yao villages in

Namwera region are largely Muslim, there is a history of Christian missionary activity in the area, and there are two Christian orphanages within 10 kilometres of Ngawo village, one Baptist and another Catholic. Adults in Ngawo see the orphanage as a “European” environment in which children lose their cultural heritage, including for example, by learning to eat different food and practising a different religion from that of their relatives. They said that when children who have spent time in the orphanage return to the village to live,

*They are no longer Muslim and usually fall sick because of the change in food*

Several participants shared stories to support these statements.

Ultimately, adults in Ngawo believe that it is very important for orphaned children to stay in the village where they and their mothers were born. It is argued that doing so enables the child to participate in the VAC-run community based child care centre (CBCC) and to be monitored by Village AIDS Committee members and other concerned village residents. If a child is seen to be unhappy or to be getting into trouble, VAC members can intervene to assist the child and can support the child’s guardian to understand how best to care for the orphan. Keeping boys and girls in the village is viewed as an important means of maintaining a hand in the development and protection of orphaned children.

Adults in Mpinganjira share this same desire to protect and care for the orphaned children in their community. However, members of the newly-formed VAC believe that the best strategy for doing so is to establish an orphanage in the village. Most families in this context are extremely poor and parents are often unable to meet the material needs of their own biological children, let alone those of the sons and daughters of their siblings. As a result, orphans often move between relatives’ houses, and are therefore seen to be difficult to assist. Furthermore, VAC members expressed concern about the discrimination of orphaned children by guardians, and felt that the best way to avoid these problems and to ensure good quality care for children was to establish an institution where children’s basic needs can be assured. VAC members have stated their intention to seek funding for a community-run orphanage in which children would be housed and educated in their own cultural context.

The institutionalisation of orphaned children is currently a hotly debated issue in Malawi, in both rural and urban areas. In Area 18, members of the Residential AIDS Committee do not believe that orphanages are a suitable care option for children, in large part because institutions are perceived to separate children from their culture, tradition, community and family. Like adults in the two rural communities where this research took place, RAC members, guardians and other adults believe that living with relatives is the most appropriate option for the care of orphans in their community; the specifics of these arrangements depend on whether the family is matrilineal or patrilineal in custom. In practice, however, a significant proportion of the orphaned children in Area 18 do not live with members of their extended family because they do not know where to locate them: many children were born and raised in the neighbourhood by parent(s) who were civil servants. Rarely, if ever, have they visited the rural areas where their parents came from and as a result, few know how to contact their relatives. Some orphaned children in Area 18 do live with their aunts, uncles and grandparents, but these arrangements appear to be most common when these individuals are also urban-based and previously known to the child.

Unlike Ngawo and Mpinganjira, it is common for orphans in Area 18 to live with their siblings, especially if the eldest child is over the age of 16. RAC and other community members believe that this is a good care option for children because the eldest sibling is capable of maintaining a sense of family and connection to their deceased parents. It is also believed that young women and men of this age range usually try their best to care for their siblings as their own parents would have done. The adults who participated in this research stressed that this situation is only suitable if the children have the economic means to support themselves.

### **Children's Preferences for their Care**

Orphans and other vulnerable children in all three research communities expressed very strong views about the most appropriate options for their care and protection. Throughout the study, discussions about care options and preferences were highly animated and often boys and girls explored at length the pros and cons of living with different people, sometimes challenging one another with different situations in order to assert their views or to seek agreement with one another. These exercises took place with children between the ages of 8 and 18; different techniques were used with different age groups, but younger children often expressed opinions as strongly as older children, and all were equally vocal about their concerns.

In general, children agreed with the adults in their communities that living with unrelated families and individuals was not appropriate or desirable. Boys and girls of all ages were suspicious of people who chose to care for children who were not related to them. They expressed concern that such people would over-work and treat them harshly, physically, emotionally and sexually (in the case of girls). Children worried that because the guardian was not related to them, their own relatives would not be able to intervene to protect them. In the two rural communities, many children over the age of 12 suggested that they would rather live on their own than live with unrelated people. Others said that they would beg other family members to take them in order to avoid such a situation.

Outlined below are children's top five preferences for care. These choices reflect a strong level of consensus within the three communities where the study took place. While there was often discussion and debate amongst participating children, final disagreements were usually a result of the specific views or experience of a particular child. For example, those children without grandmothers often did not state a preference to live in such an arrangement, as doing so was obviously not a realistic option in their minds.

### **Children's First Choice for Care**

In all three research communities, orphaned and other vulnerable children's first choice for care was with their mother. This was the case for families in the matrilineal villages of Ngawo and Mpinganjira, but also for those children in Area 18 whose families are either matrilineal or patrilineal. Nearly all felt that their mother was the one who loved them most and could best care for them, regardless of her economic, health or HIV status:

*No one will ever love you like your mother; she gave birth to you so you are part of her*

*A mother will care for you better than anyone else*

*When a baby sees her mother, she feels very happy*

*She will give you advice and tell you to go to school*

*She will give you warm water for your bath*

*When you are wrong, she will forgive you*

*When you stay with other people, they will give you too much work*

The only exception expressed to the above views was in those cases where a child's mother was remarried to a man who was cruel to them. In these instances, children said that their step-father would tell their mother lies about them so that he could "turn (her) against (them)". Under these circumstances, boys and girls said that living with their mother was not an acceptable option.

### **Children's Second Choice for Care**

In the absence of their mother, almost all children in the three research communities said that the next best option for care was to live with their grandmother. Whether this woman was their maternal or paternal grandmother depended on the kinship practice of the household. Boys and girls commented that they would prefer to live in this situation even if their grandmother was elderly and they therefore had to perform a number of time-consuming and arduous tasks on her behalf. The primary reason for this preference was the widespread opinion that grandmothers give their grandchildren unconditional love and will always do everything in their power to meet the children's needs:

*Grandmothers will always look for food for you and share it equally*

*They will allow you rest when tired*

*She will get medical care for you when you are sick but others might make you work anyway*

*Grandmothers will try to care for you as they would their own children*

*Sometimes when you are sad, she will give you sweet potato*

*She will give you food, even when you have done something wrong*

*She will give you instruction about how life is different there*

*At other relatives' houses, guardians might say that they are failing to get rich because of you. A grandmother won't say this*

*She will not beat you every time you are wrong. She will talk to you instead*

Equally important, it was common for children in the two rural communities to comment that

*A grandmother will never remind you that your mother is dead or insult your mother because she was her daughter*

Instead, she will openly challenge the cruel comments made by others and defend the honour of her family. Many boys and girls said that in their grandmother's home, they do not have to compete with her other, biological children, for scarce resources. Children argued that even those grandmothers who have young children of their own do not give preferential treatment or distinguish between biological children and grandchildren. Finally, children appreciated the guidance a grandmother will give them on the performance of household chores and advice on life in general, believing that she always has their best interests at heart.

Many of the children involved in this study are currently living with their grandmothers, especially in the two rural villages. The majority of these families are extremely poor and are often living in extremely difficult circumstances. It was striking, however, to note that despite their often desperate poverty, and the fact that other family members may have greater financial resources, boys and girls still felt that they were living with the best person possible. Many commented that the children in their aunts' and uncles' houses had more to eat, but felt certain either that they would not have access to this food if they lived in that household, or that they would have to endure enormous amounts of discrimination and harsh treatment in order to benefit from it.

### **Children's Third Choice for Care**

When living with their grandmothers was not possible, boys and girls in all three research communities felt that the next best option for their care was with their unmarried older sister or brother. In practice, this caretaking arrangement appears much more common in Area 18, where households are quite frequently headed by unmarried siblings between the ages of 18 and 25. In this context, children felt that their siblings loved them and would treat them fairly:

*They will not ill-treat you because you are the same blood and there is nowhere else for you to go*

*They share the same parents so they will understand you*

Children said that this mutual affection and the desire to please their deceased parents would mean that their older siblings would never abandon them. Boys and girls in Area 18 also commented that in sibling-headed households, they had a say in family decisions, and were able to work together to share ideas and solve problems.

While participating children in Mpinganjira and Ngawo also prefer to live with unmarried siblings, this care option is rare in these two communities, where young men and women tend to marry at an earlier age than they do in urban areas. Girls in these villages, especially those who are not enrolled in school, are often married by their late teens, and sometimes as young as 12 or 13 years old. This practice seems to be particularly the case for orphaned girls, many of whom marry young as a survival strategy.<sup>23</sup> In this context, girls are viewed as making a

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<sup>23</sup> This practice is also common among war-affected separated children (and those with their families). See, for example, de Smelt, J (1998)

transition directly from childhood to marriage. Correspondingly, those orphaned girls who are not yet married are often not seen by relatives to be adult enough to care for their siblings. Similarly, some orphaned boys also marry in their teens. Those unmarried boys under the age of 18 tend to be viewed by relatives as inappropriate guardians, either because they lack income, are still in school, are engaging in “bad behaviour” such as drinking and drug-taking, or are untraceable because they have left the village to seek opportunities elsewhere.

### **Children’s Fourth Choice for Care**

Children in Area 18 said that living with their married brother or sister was the fourth best care option for orphaned children. The reasons they cited were similar to those which favoured living with unmarried siblings. However, siblings’ spouses were seen as potentially problematic because they may give preferential treatment to their own biological children and be cruel or abusive to the orphans under their care:

*Your brother’s wife may not buy you clothes. When her children are tired of their clothes, that’s when you will get them – all torn up and dirty*

*Your brother’s wife and your sister’s husband love to beat you*

The majority of boys and girls felt that married sisters are preferable to married brothers, because domestic gender dynamics mean that ultimately, it would be their sisters-in-law who would have the power to make their daily lives miserable through the provision of long and arduous household chores, especially when their brother was away from home. This sentiment was mostly expressed among children under the age of 13. Boys above this age preferred to live with their married brothers because they felt their blood ties would enable them to stand up and claim authority over their sisters-in-law as needed. Similar behaviour would not be possible in their brother-in-law’s house, regardless of how cruelly the child was treated.

Boys and girls in Mpiganjira and Ngawo also ranked living with married siblings as the fourth most desirable option for their care. But in these rural communities, where women are almost solely responsible for child care, being cared for by one’s older brother effectively means being looked after by his wife:

*Your brother may love you but his wife will treat you badly and insult you with foul language*

*If you refuse to do hard tasks she will chase you and tell you to go “where your mother went”*

The large majority of rural children who participated in this study did not want to be cared for by their sisters-in-law. They argued that competition with her biological children and resentment of the extra costs associated with caring for orphans on her husband’s side virtually guaranteed their mistreatment in their married brothers’ homes. Even in those cases where their brothers’ wives were kind and generous, children felt that their sisters-in-law would be influenced by their own relatives to favour their own biological children. While children also worried that their sister’s husbands would mistreat them, they felt that the

majority of their interactions would be with their sister, who would be less likely than their sisters-in-law to give preferential treatment to her own children. Children also expressed the view that their sister loved them and would ultimately find ways to defy a cruel husband's wishes.

### **Children Fifth Choice for Care**

Living with a young aunt was determined by orphaned and other vulnerable children to be their fifth choice for care. In all three communities, children felt that aside from their grandparents, their aunts were the only people in their extended family whom they could trust to care for them with love and kindness. In the rural matrilineal villages where this research was conducted, boys and girls identified this person to be their mother's younger sister. Children in Area 18 chose the aunt whom they knew best and who accorded with their household kinship practice; in some cases this was their mother's younger sister, in others, their father's. In most cases, children said that their young aunts were closer to them in age and would sympathise with their difficult and painful situation:

*Your aunt will look at you as her own child because you are her sister's child*

*If your (aunt's husband) buys food, she will give some of it to you*

*Your mother's younger sister will feed you if she has food whereas your uncle's wife will not*

*She won't beat you if you are tired from gardening or collecting water*

In the rural communities, boys and girls often commented that they already had established relationships with their mother's younger sister because she lived nearby and often cared for them when their mother was alive. Similarly, children in Area 18 felt that their young aunts would be more likely than others to treat them well, in part because she too would have benefited as a child from the care her older siblings (the child's parents).

### **Other Care Preferences**

The boys and girls who participated in this study did not have established preferences for whom they live with beyond the five above-mentioned categories of people. In their view, choices at this stage depended on the personality of the guardian and the openness of their spouse and children to having a new child move in with them. Most felt that even if their father were alive, living with him would be very difficult because he would soon remarry and want to start a new family. His wife will not want to care for his children from a previous marriage, and "may even try to poison you". This sentiment was widely expressed in both matrilineal and patrilineal contexts. Similarly, aunts and uncles are often not seen to be desirable guardians because of the likelihood that they or their spouses will mistreat the child:

*Uncles might beat you, deny you food and treat you harshly*

*Uncles might want to buy you a dress, but his wife will tell him not to*

*Your sister's husband may deny you food*

*Your uncle's wife will give pocket money to her own children but will tell you to go ask your dead parents if you want money*

*Your uncle's wife will punish you too much*

With a few exceptions, most children felt that the only reason these individuals would take them in would be to benefit from their labour. Children frequently mentioned the potential for exploitation and harsh and cruel treatment in this context, and many shared stories with one another of things they or their friends had experienced.

In Ngawo, where there are two nearby orphanages, children had strong views about the unacceptability of this care option. All agreed that in these institutions, children are given new clothes, bicycles, are able to go to school, and are allowed to play freely. One 11 year old boy commented that “*children in the orphanages do not know hunger*”. Despite these obvious benefits, boys and girls in this community were unanimous in their belief that living in an institution was the worst possible situation:

*Staying in (an orphanage) is temporary, but your grandmother or sister will never leave you*

*(Staff of the orphanage) go on holiday and then you are left alone with no one to care for you*

*In the orphanage you would feel like you were staying away from everybody and you would be so lonely*

*They can chase you from there at any time. When you are too old, they make you leave, but you have nowhere to go*

*When you grow up in the village, you can get married. If you stay in the orphanage this can't happen*

*If you get married and it doesn't work you can go back to your family, but not to the orphanage*

*Some uncles may be harsh, but it is still better to be with them. When they get married, they may still keep you*

It is interesting to note that although children recognise the superior material situation associated with living in an orphanage, their concerns about companionship, feeling a sense of belonging and membership, and preparation for adulthood override the benefits of such things as food, clothing and going to school.

The boxes overleaf summarise children's preferences for care in rural and urban situations respectively.



**Rural Children's Preferences for Care  
(Ages 8-12)**

**Mpinganjira and Ngawo villages  
(matrilineal)**

1. mother (if not remarried)
2. grandmother
3. unmarried older sister or brother
4. married older sister
5. mother's younger sister

**Urban Children's Preferences for Care  
(Ages 8-12)**

**Area 18, Lilongwe  
(patrilineal and matrilineal)**

1. mother (if not remarried)
2. grandmother
3. unmarried older sister or brother
4. married older sister or brother
5. mother or father's younger sister

### **Adults' Perceptions of Children's Preferences for Care**

AIDS committee members, guardians and other community members in Ngawo, Mpinganjira, and Area 18 were all asked with whom orphaned children most prefer to live. In both Ngawo and Area 18, most adults interviewed said that they did not know children's preferences, aside from staying with relatives. Some believe, as one woman told us that

*Children only care what they eat, not where they stay*

In Mpinganjira, it was widely felt that children prefer to stay with their grandmothers, in part because "life is easier with a grandmother – children can do their own thing and never get disciplined for it". But adult community members also cited many of the reasons given by boys and girls, especially with respect to children's desire to be well-treated and to have their mother's honour and character defended. One elderly woman guardian made an analogy between dogs and their owners, saying

*If you treat a dog well, they will follow you around and do as you ask because they love you and you love them. It is the same thing with children and their grandmothers*

It is interesting to note that grandmothers themselves, while often elderly and very poor, rarely complained of being burdened by the care of orphans in the way often expressed by other, younger, guardians. In general, they felt that the only way they could ensure the decent treatment of their grandchildren was to take them into their homes. Many of these elderly women (and sometimes men) were financially dependent on their adult children before these children fell sick and died. Most are having to cope with a major shift in traditional intergenerational relationships and responsibilities, as they are now looking after their children's children at a time when they would normally themselves have been looked after.

Discussions with children about their favoured care options indicated clear preferences and identified issues which they considered to be of primary importance in the selection of their guardian. The opinions expressed were for the most part markedly different from those of the adults who are expected to operate in their best interests. Community members were surprised to learn that boys and girls had such strong, and often well thought-through views. While many believe that orphaned children should have no say about whom they live with, others were genuinely amazed by the divergence of their opinions and those of children. This research highlighted that, despite the best of intentions, adults do not always reflect the

perspectives and experiences of children in an accurate or appropriate manner. Children's views are essential to understanding why certain living arrangements are more preferable than others so that interventions can be targeted to support boys and girls in the best way possible.

## **Chapter Five: Vulnerability and Orphaned Children's Needs**

### **Conceptions and Definitions of Children's Vulnerability**

In the three communities where this research was conducted, AIDS committee members, guardians, children, youth and others felt that children's vulnerability did not depend only on their orphaned status. Vulnerability in these communities is defined in part by parental loss, but also by parental disability and illness, poverty, social exclusion, abuse, exploitation and school enrolment. Accordingly, some orphaned children are considered less vulnerable than a child whose parents may be alive, but who may be unwilling or unable to provide care. Orphans who live with caring families and whose basic needs are met are not considered vulnerable, largely because such an environment will "help them to forget their parents", an expression frequently used to indicate an orphaned child's ability to cope with the loss of the mother and/or father. None of the participants in the research conceptualised children's vulnerability as in any way dependent on the age or gender of a child. However, occasionally participants expressed concern about the susceptibility of orphaned girls over the age of 12 to sexual abuse and exploitation, to early marriage, and to reproductive problems as a result of pregnancy-related complications.

Throughout the research, there was a general reluctance on the part of participating adults to identify or create a distinction between the needs and problems faced by boys and girls of different ages. As a result, to date there has been little focused attention and action on the specific needs and desires of children in different circumstances. This concentration on the general needs of orphans and other vulnerable children was common amongst VACs, guardians and other adults in the three communities where this study took place.

In the villages of Mpinganjira and Ngawo, all of the orphaned children in the community are known to concerned adults and members of the AIDS committees. This is particularly the case in Ngawo, where the small size of the population and the recognised role of the Village AIDS Committee enables members to assess the vulnerability of orphaned children on a case-by-case basis. However, in urban Area 18, where community-mobilisation to date has been very difficult to achieve, and people are more spread out and spend less time in the community, it has been difficult for the Residential AIDS Committee to undertake an assessment of the needs and circumstances of orphaned children. It is hoped that this report will provide a small step in this direction.

It is interesting to note that so far RAC members in Area 18 have been hesitant to approach households because a large number of orphaned boys and girls in the community are not known to them. Members expressed their discomfort with visiting unknown children, especially those living without adults because they feared asking children about their problems when they do not feel they have the resources to assist them. However, the children and young people from Area 18 who participated in this study expressed a desire to have adults visit them, even if they had no material goods to offer. Many children and youth felt they could benefit from the advice of an unrelated and caring adult. They also said that such visits could "make (them) feel less alone" and therefore provide them with a much-needed morale boost. These differences in the expectations of children and those adults who want to assist them seem to arise in part from a lack of communication across generations and families.

Efforts are currently under way in all three communities to address the problems of orphaned and other vulnerable children. Aside from recreational activities for children and young people, the majority of work to date has focused on the provision of children's and families' material needs. This prioritising of needs is understandable given the scale and scope of the problems that many people are facing. However, very little attention has been paid so far to the emotional and social needs of children in these three communities. This tendency to focus on economic and material well-being may be due in part to a lack of resources such as time, people and money at the community level. It may also reflect people's expressed belief that if you provide children with all of their basic needs then they will be able to "forget their parents". Furthermore, some participants in the research expressed discomfort with exploring the psychological and emotional well-being of orphans under the care of related guardians, for fear of being seen to "interfere in the affairs of another household". These issues are discussed further on page 61f.

### **Material Needs of Orphaned and Other Vulnerable Children**

Poverty is a reality for the majority of AIDS-affected children in Malawi, both orphans and those whose parents are living with HIV. It is estimated that approximately 67% of the country's rural population is poor as compared to 55% of people living in urban areas, and that women and children are the majority among these populations.<sup>24</sup> This general trend proved true in the three case study communities where this research was conducted.

When adult community members and guardians were asked what they considered to be the specific needs of orphans and other vulnerable children in their community, the overwhelming response was material support. In Ngawo and Mpinganjira, boys and girls lack adequate food, clothing, shelter, soap, bedding, school fees, pens and notebooks. Given the very high rate of poverty in these communities, these needs are shared among the majority of children in both villages, whether they are directly affected by HIV (ie orphaned and/or living with terminally ill parents) or not. The difference between the circumstances of children with healthy parents and those without is that orphaned children in this context often appeared to lack these items even when other children in the household did not.

Many of the children in Area 18 also suffer from a lack of material and financial resources. However, in relative terms, the majority of children in this community are financially better off than those in the two rural villages where this study was also conducted. This difference may be due in part to the greater and more diverse opportunities for income-generation characteristic of urban areas. It may also be a result of the consistent, albeit modest, income of the average household in Area 18. Some orphaned children in this context do not lack basic material requirements because their parent(s) earned a pension as a civil servant or because their deceased parents' illnesses did not deplete the family's resources. Others may be able to avoid losing their property to the relatives of their deceased parent(s). In such cases it is not uncommon for a group of siblings to move to a small flat and use their family home as a rental property in order to provide a small income for food and basic necessities. Rarely, however, are children in these circumstances able to do more than merely survive: school fees, uniforms, and supplies, as well as household rent, electricity and food, are often unattainable for boys and girls in this context, who commonly leave school soon after their parents die in order to reduce household expenditure. Some may seek employment as

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<sup>24</sup> UNICEF Malawi (2001). p. 10.

domestics (boys and girls from age 8 onwards), prostitutes (girls from age 13) or seeking customers for local buses (boys from age 14); others choose to stay at home, waiting for things to change.

Different perspectives on children's needs emerged in the research from discussions with VAC members, guardians and children. These views will be presented below and then analysed in the final section of the chapter.

### **Parents', Guardians' and Other Adults' Perceptions of Children's Needs**

Aside from material and financial support, guardians and other community members identified orphans and other vulnerable children as having two significant and related needs. These are the need for parental guidance, and the need for love and support. These two issues were raised in all three communities where this research was conducted, and were widely agreed to be problems of utmost concern.

The majority of adults who participated in this study believe that relationships between parents and children in Malawi have changed in recent years, and not for the better. Many commented that it is increasingly difficult to "control" children, in large part because of children's exposure to Western culture, which in adults' opinion has had a negative influence on parent-child relationships in their communities. Others felt that the sexual promiscuity of young women and men has led to children having younger and younger parents, many of whom are not perceived to be mature enough to raise sons and daughters. Adults believe that these two factors taken together have resulted in both boys and girls behaving badly and parents not taking responsibility for their children. This view was particularly prominent in Area 18, where many of the vulnerable children in the community do have mothers and/or fathers, but have nonetheless been able to drop out of school, become involved in street life and/or engage in other risky behaviour. In this case, adults blame parents for their selfish engagement in their own activities and for not intervening to discipline or protect their child. Many view boys and girls in these circumstances as being particularly susceptible to HIV. It is also feared that, if orphaned, the unruly nature of their behaviour and their lack of previous parental guidance will make these children especially difficult for guardians to care for.

Orphaned children are considered to be in special need of parental guidance and love. Parents are seen to play a crucial role in the promotion and monitoring of their children's emotional and physical well-being. In the absence of parents, adults believe that boys and girls are exposed to a number of serious risks to their health and security. In this way, child-headed households are viewed by adult research participants as unacceptable living arrangements for orphaned children in Malawi, except in those circumstances where the head of household is over the age of 18. Guardians, it is argued, have a responsibility to protect and teach children, through providing for their basic needs, instructing them in appropriate tasks and behaviours, disciplining them as required and providing support to them as they adjust to life without their parents. In the communities where this research took place, it was rare for guardians or other adults to articulate this support in an overtly affectionate way, particularly for children over the age of 9 or 10. Rather, "love" was seen as providing for the basic needs of a child. Giving food when hungry, buying school supplies and involving the child in family life were all considered ways of showing love and support to orphaned children. Open discussions with orphaned children about the death of their parents are not common; the large majority of

guardians interviewed had never spoken directly to the child in their care about his or her sense of loss and the process of grief and adjustment.

While all adults involved in the research agreed with the vital nature of these needs, many identified barriers to their provision. In particular, community members felt that orphaned children, in general, have many problems and are badly behaved. As a category of children, orphans are seen by many adults to be extremely difficult to look after because “they see themselves as victims” for whom all perceived injustices, large and small, have been perpetrated against them on the basis of their orphan status. One example given included instances where the biological children in the household were attending school at the time that the orphaned child moved in. Because of the limited resources of the household and the fact that the orphan’s arrival was unplanned and therefore not budgeted for, it was not immediately possible for the guardian to send the orphan to school. Adults, in this case, felt that it was unfair of the child to claim that they were being discriminated against. Instead, they felt that the child should understand the financial challenges posed by their arrival and be appreciative of the guardian’s agreement to take them in.

Another example of an instance in which adults felt that orphaned children made unjust claims of poor treatment included those occasions when household chores were allocated to them. Many guardians expressed frustration with boys and girls who complained if they were given tasks that were time-consuming or difficult to perform, even if they were accustomed to undertaking these same responsibilities when they were living in their parents’ home.

Many adults resented what they described as orphaned children’s sense of constant persecution and discrimination. They argued that boys’ and girls’ fixation on “equal treatment” and their invariable complaints and refusal to comply with requests and expectations meant that orphans were very difficult to discipline. Consequently, many guardians lose patience with children’s disrespectful and disobedient conduct and as a result stop giving them guidance and begin to ignore them. This dynamic further reinforces the tensions in the household and the child’s sense that s/he is not loved. In the end, the child is free to go anywhere and do anything, no matter how dangerous or inappropriate. Sadly, the all-too-common lack of communication between orphaned children and their guardians can lead to the further vulnerability of an already vulnerable child.

### **Orphaned and Other Vulnerable Children’s Perspectives on their Needs**

The orphaned children who participated in this study view themselves as fundamentally different from the boys and girls in their community whose parent(s) are alive, including those whose parents may be ill or dying:

*Other children in the village have access to better clothing and food than I do because I am an orphan*

*My life is better than that of other orphans, but I am envious of those with parents. They have love; they have love*

*There is a difference in our way of life. We have to do everything for ourselves: find food, get money, do piecework*

Participating children identified three significant and related areas in which they felt their lives were notably unlike those of their peers. These were: unconditional love and forgiveness; freedom of expression; and discrimination and stigmatisation.

### **Unconditional Love and Forgiveness**

The majority of orphaned and other vulnerable boys and girls between the ages of 8 and 18 in all three research communities believe that parents are the only ones who will give a child unconditional love and forgiveness. As a result, many orphaned children, in particular those who have lost both parents or are no longer in touch with their remaining parent, see themselves as extremely disadvantaged vis à vis other children in their community. Boys and girls of all ages shared numerous examples of situations in which they felt their parents would have treated them with love and kindness but their guardian did not. These included not being allowed to rest when sick; not being provided with medical care even when it was freely available; being denied food for no apparent reason; being punished harshly for small mistakes such as dropping a piece of laundry; and being made to feel like a burden for merely existing. Further, many youths, especially males, commented on the inability of orphaned children to ask advice and seek encouragement from the only people whom they could trust to have their best interests in mind. Some spoke of how they wished they did not know they were orphans because, in the words of one 15 year old girl

*It causes me great distress to know that I do not have a mother*

### **Freedom of Expression**

Many of the children who participated in this research commented that being an orphan meant that they were never free to express themselves or their needs:

*We can never say what we are really feeling*

*Guardians do not understand you because you are not their own child.  
They don't want to help you grow up well*

*No one helps me to solve my problems because no one cares to know  
what they are*

*If I said what I wanted, like to wash clothes instead of dishes, I would be  
yelled at or beaten and chased away*

Because of this sense that they are an unwelcome burden to their guardians, many children felt that they needed to make their presence as inconspicuous as possible so that they would be allowed to remain in their guardian's household. Some boys and girls commented that they try to avoid making small requests for things like a pen or notebook because they do not want to give their guardian any opportunity to physically or verbally abuse them. Similarly, one 13 year old girl said

*If you enquire about something, you are shouted at ... you decide never to ask a  
question again*

A number of children said that this inability to express themselves meant that an orphan could never “feel free” in a guardian’s home and therefore had to find other ways to meet their needs.

### **Discrimination and Stigmatisation**

Cruel and unfair treatment were the dominant themes in nearly all discussions and activities with children and young people in the three communities where this research took place. Orphaned boys and girls shared at length their experiences of discrimination and stigmatisation at the household and community level.

### **Discrimination at the Household Level**

All children and young people who participated in this research agreed that orphaned children in their communities experience enormous amounts of discrimination and harsh or cruel treatment within the household, both at the hands of guardians as well as biological children and others. Some of the specific forms of this discrimination are listed in the following box. Many children commented that the bulk of this cruel treatment was delivered by their female guardian.

It is interesting to note that many guardians reported that orphans often feel victimised to such an extent that they are unable to differentiate between discrimination and the inability of their guardian to meet all of their needs. While this claim may certainly be true in some instances, the following examples suggest that boys and girls are not always misinterpreting or exaggerating the brutal way they are treated in some households. Furthermore, many illustrate quite extreme emotional abuse.

#### **Forms of discrimination and harsh or cruel treatment against orphans in the household identified by children in all 3 research communities**

- Child is treated as an unpaid domestic worker, and made to do all of the household chores while the guardian’s biological children are able to rest and play at leisure
- Child is the only one in the household who does not attend school
- Child is denied food, while others eat
- Child is told that in order to eat, they have “to pay back the family in work”
- When eating, child is asked, “did your dead parents buy this food for you?”
- When child requests assistance with a task or problem, s/he is told “we are not the ones who killed your parents, so don’t ask us for help”
- Child is made to cook and serve food to the family, then told to wait in the kitchen until the family has finished eating to see if there are any remainders
- Child is sent on a long errand at meal time so that the family can have adequate time to eat in his/her absence. On return, there is no food remaining for the child
- When child has made a mistake, s/he will be shown the grave of their deceased parent(s) and told to dig it



- Child is made to sleep outside, often without a mat or blanket
- Guardian locks food in the bedroom when leaving the house so that the orphan will not eat it
- Child is given a long list of chores to start at bedtime so that s/he is awake long into the night. Guardian then wakes the child very early to cook for the family
- Child is told that they are causing too many problems and that they will “kill” the guardian, like they “killed their own parents”
- Girl is sent out to find a husband so that “someone else will be responsible” for her care
- Girl is told to “go and find some soap” (a euphemism for becoming involved in prostitution or the exchange of sex for material goods) so that she “can earn her keep”
- Biological children give the orphaned child all of the work that they have been personally assigned. When the guardian returns home, these children claim responsibility for the completion of both their tasks and those of the orphan. The orphaned child is then beaten for being “lazy and doing nothing”
- Child is told not to touch the guardian’s belongings because his/her “mother did not buy it for you”

## Family Dynamics

The above discussion of adults’ and children’s perceptions of their needs highlights the vicious circle that is responsible for creating the difficult relationships common to many guardians and orphaned children under their care. When boys and girls lose their parents, they are not encouraged to speak of them. They are expected to move into a new household and to behave like a “good” child who is polite, never complains, is respectful of elders, and who takes on household chores willingly and sometimes without being asked. The grief and sadness many children feel but cannot openly express leads them to feel isolated because no one appears to be paying particular attention to their special needs for love and support. This sense of being different from the other children in the household contributes to their sense of victimisation at having lost their parents. Sometimes they act out their feelings by behaving rudely, refusing to undertake chores, or by physically fighting with other children in the household. At other times, they withdraw and spend as little time as possible at home, in order to avoid a situation which they feel to be untenable. This distancing of themselves from their guardians is a self-protection mechanism which results in numerous misunderstandings.

By “being difficult”, orphaned children contribute to the stereotypes held by guardians that orphans have many problems and are hard to care for. Most of the guardians who participated in this research are very poor and are often unable to meet the material needs of their family. As a result, taking in an additional child is considered to be a burden, yet obligation to family means that the guardian cannot overlook his/her responsibility to care for a related child. This sense that the orphan is exacerbating the economic problems of the household often means that the guardian feels they are doing the child a favour by taking them in. They feel therefore, that the orphan should be grateful for this act of generosity and expect that the child will respond by behaving well and not commenting on the discrepancies they see between their situation and those of the biological children in the household, who may attend school, wear better clothes, or do fewer chores. Some guardians involved in this study said that this preferential treatment of biological children was natural; in the words of a female guardian in Area 18

*When a child is not your own, you cannot love them in the same way you love the children you have given birth to*

Many orphans recognise that their guardians expect them to be grateful for even the most negligible of assistance. But children do not feel that they should be held responsible for the death of their parents. They cannot help the fact that their parent(s) died and do not want to be made to be thankful for a situation which they view to be both dreadful and entirely not of their own making. They attribute this need to accept always being second best to the other children in household to their status as orphans. The resentment which results from their less-privileged position is augmented by what they see to be their unmet needs for patience, love and kindness as they work through their feelings of grief and sadness. The result is a cycle in which guardians feel unappreciated and therefore less inclined to be supportive to the orphans in their care, while the children themselves feel angry, alone and unjustifiably discriminated against.

Interventions to support orphaned boys and girls need to engage with the reality of this situation. Perhaps most importantly, they need to recognise that many guardians do not feel that it is possible to treat an orphan in the same way as a biological child. To date, advice to guardians has focused on treating all children equally, without acknowledging that many people do not believe this is possible. Until these concerns are openly discussed and guardians can be honest about these views, this vicious circle of misunderstanding and poor communication between guardians and children will continue, with potentially disastrous implications for the emotional, physical and social well-being of orphaned boys and girls. Communities need to have frank dialogue about these issues in order that families, friends and neighbours can begin to work together to address them. Children's participation should be an integral part of these discussions. The box below provides some illustrations of the perceptions of one group of children regarding the components of a "good" home:

**A "Good" Home  
Girls 13-17 years  
Area 18**

*Where there is love – that is the most important thing*

*Where there is food and each child gets an equal amount*

*Where no one insults you*

*When you look forward to being there at the end of the day*

*Where people do things together*

*Where there is no discrimination between children*

*Where no one talks about who is an orphan and who is not*

*Where you are allowed to go to school*

## Chapter Six: Children, Communities and Support Networks

### Discrimination at the Community Level

In general, children described experiencing far less discrimination within the community than at the household level. This was especially true in Ngawo, and to some extent Mpinganjira, where older children commented that advocacy on the part of AIDS committees and religious leaders had made a positive impact on the way that orphans are treated by teachers and other unrelated adults. However, this level of public acceptance experienced in the two rural villages where the study took place was rarely expressed by boys and girls in Area 18, who spoke of sometimes feeling overlooked, poorly treated and stigmatised by community members. Some school-going children in this community commented on the insensitivity of teachers to the challenges in their lives. In particular, one 12 year old boy gave an example of how his teacher frequently spoke in class about AIDS and inevitably mentioned that the child was an orphan and that both his parents had died of the disease. Another 15 year old girl spoke about how her neighbour always brings visitors over to “meet the orphans” next door.

Children also spoke of discrimination and stigmatisation at the hands of their peers. It was generally agreed that orphaned children have as many friends as other children and that friends and acquaintances whose parents are alive are normally kind and supportive of their orphaned peers. However, some boys and girls above the age of 12 commented that it is in times of conflict and stress that their friends say brutal things to them. In Ngawo, for example, a focus group discussion with girls between the ages of 13-18 led to several participants sharing stories about arguments with female friends, who, in the heat of anger, had made cruel and painful comments. One girl recounted how she listened to an angry friend shout a list at her of all her relatives who had died of AIDS. Similarly, a 15 year old boy in Mpinganjira commented that when arguing with his friends, some have directed him to his parents’ graves and told him to “go and get help from them”. Young children in Area 18 often reported being taunted by peers for “bringing bad luck”, or for wearing dirty or tattered clothes.

One group of children were invited to produce a spider diagram<sup>25</sup> to illustrate the things that made them happy and the things that made them sad:

#### Spider Diagram of Children ages 8-12 years in Mpinganjira

##### Things that make me happy

Clean clothes  
Having food  
Going to school  
Eating bananas  
Drinking Fanta  
Having a notebook  
Playing football  
Eating meat  
Birth of a baby  
Weddings  
Eating rice

##### Things that make me sad

Being beaten  
Being falsely accused  
Having no food  
Being denied food  
Having stones thrown at me  
People insulting my parents  
Being sick  
Being shouted at  
Having no pen  
Funerals  
Failing exams

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<sup>25</sup> A spider diagram is a way of compiling a list of ideas, each one drawn as the legs of a spider drawn on a large sheet of paper

Initiation  
When people come back from a long trip  
Listening to music  
Traditional dancing  
Listening to funny stories  
Prayers

When not allowed to go to school  
Being made to find money  
Accidents  
When things are broken  
People using obscene language at you  
Fighting

### **Children's Strategies for Dealing with Discrimination and Other Problems**

Adults and children who participated in this study agree that discrimination of orphaned children takes place most often at the household level. Boys and girls whose material and emotional needs are not being met by their guardians employ a number of different strategies for addressing their problems. These strategies differ according to the age, gender, and birth order of the child.

In general, children under the age of 10 or so are seen as least able to remove themselves from the difficult circumstances in which they find themselves. Most adults interviewed said that young boys and girls do not know how to solve their problems so they tend to persevere and try to be as "good" as possible so that their guardian will begin to love and treat them fairly. Often very young children in this context choose to "suffer in silence" and not cry or attract attention to themselves as a means of avoiding trouble:

*If I was being treated harshly, I would persevere and live with it (boy, 10, Mpinganjira)*

*If I was treated very badly, and I had somewhere to go, I would leave.  
But probably I would just stay and put up with it (girl, 9, Ngawo)*

Some children describe singing songs to themselves that their parents once sung to them, as a way of feeling connected to those who have died. When hungry, young boys and girls may also wander from house to house throughout the community in the hopes that someone will take pity on them and give them food. Others share tasks with supportive or kind children in the household in order to reduce their workload. While often not recognised as such, these practices are nevertheless important coping mechanisms for young orphaned children whose material and emotional needs are not being met by their guardians and other responsible adults.

Orphaned children over the age of 11 or 12 also employ a number of different strategies for avoiding severe household conflict and meeting their basic needs. Many boys and girls of this age end up dropping out of school. They do this because they have no money to pay tuition fees or because they are expected to contribute to the household, either in terms of domestic or paid labour. There is great similarity in the strategies used by boys and girls in the three communities where this research was conducted.

In the two rural villages, boys in this age range tended to seek piecework in order to support themselves, and in some cases, their younger siblings. This work often involved gardening, making bricks, and in the case of Mpinganjira, fishing in nearby Lake Malawi. Boys in Area 18 tended to seek work getting customers for local buses or by becoming involved in begging and petty theft. Some boys (and girls) as young as 8 years old in this urban community also seek work as domestics in order to find a place to live and to earn enough money to survive.

It was commonly stated that from age 12, boys in rural areas may run away, and often become involved in drug and alcohol use. Since these boys were no longer in the communities where this research took place, it was not possible to ascertain the various ways in which they acquire the money to survive and pursue these habits. There is a real need for research and programmatic work to look beyond the category of “orphans” in communities and to explore the needs and circumstances of parentless children living on the street, as sex workers, farm labourers and in other situations. Once orphaned children leave their communities, they tend to fall between the cracks of programme and advocacy efforts.

Girls above the age of 12 years also engage in piecework in order to acquire money to support themselves, their guardians or ill parents, and their younger siblings. Some find work in gardens, others sell vegetables or roadside snacks. Adults and children in all three communities also reported that it was common for orphaned girls in difficult circumstances from age 12 onwards to become involved in prostitution or the exchange of sex for material goods such as soap or flour. Female youths in rural and urban areas commented that it is often guardians who encourage girls to sell sex or to find a Sugar Daddy.<sup>26</sup> Others said that many girls “find men” on their own, both as a means of acquiring money and material goods, but also in an attempt to find affection and have fun. Early marriage is also a reality for many girls in this context; 15 years was purported to be the lower age limit for a girl to marry in Area 18, and 12 years was estimated for the girls in the rural villages. One 14 year old girl in Ngawo commented that

*Early marriage won't change. It will never stop, especially because so many of the women in this village were themselves married before 15. As long as families can't meet the needs of their children, girls will have to marry young, even before they have breasts*

The reality of this phenomenon struck home when, during the course of one focus group discussion with female youth in a rural area, a girl who looked to be about 15 years old walked by. She had a small baby on her back, and a toddler walking beside her. She was accompanied by a man with greying hair. One participant leaned inside the circle and quietly pointed out that this girl was an orphan, and that she was with her husband and two children, on their way to work in the fields.

### **Orphaned and Other Vulnerable Children's Support Networks**

In Mpinganjira, Ngawo and Area 18, children between the ages of 8 and 12 were asked to draw the most important people in their lives. Workshop facilitators then spoke at length with children so that boys and girls could explain their drawings and the reasons for choosing certain people over others. In general, the support networks for children in the two rural villages were quite similar, while those of urban children were different in the following ways:

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<sup>26</sup> A Sugar Daddy is a man, often in his 40s or 50s, who, in exchange for sex and (sometimes) companionship, will pay a girl's school fees, buy her clothes, food or other material items. Sugar Daddies tend to seek out girls between the ages of 12-15 (and sometimes younger) because they are suspected to be virgins and therefore believed to be uninfected by HIV.

**Main Themes from Children's Support Network Drawings  
Ages 8-12 years**

<u>Rural</u>	<u>Urban</u>
Support networks contain many adults; all are relatives, both male and female.	Support networks contain few adults, aside from guardian, who is usually female and a relative.
Networks are smaller, with fewer people providing more.	Networks are larger, with more people providing less.
Networks are strong with relatives outside the immediate household.	Networks are weak with relatives outside the immediate household
Provision of food is a key element in children's social networks.	Older siblings play a crucial role in meeting the child's emotional, physical and material needs.
Relatives outside the household contribute to meeting a child's emotional and material needs. Friends rarely appear on drawings.	Friends play an important role in the provision of emotional and material support, especially for girls
Relationships with guardian's biological children tend to be relatively close and strong.	Relationships with guardian's biological children tend to be characterised by cruel and abusive treatment.

In general, this study revealed a significant and important difference in the coping strategies of young orphaned children in rural and urban areas. In their efforts to meet their basic needs for food and clothing, children in the rural villages where the research took place tended to approach supportive family members who were living outside their immediate household. While they might sleep in one house, they would eat, get clothing or school fees and play all in different places. This strategy of approaching specific people for specific needs was less apparent in the support networks of children in Area 18, whose networks with those relatives outside their immediate household were often weak or non-existent, reflecting both isolation from their extended families as well as closer networks of unrelated people. For those boys and girls who knew the members of their extended families, most said that these relatives did not visit them regularly and that they did not feel comfortable to share their problems with them. As a result, children tended to rely almost exclusively on those family members with whom they lived on a day-to-day basis. When these relationships were difficult or unsupportive, young children would turn to their friends for assistance with their material requirements, as well as their emotional needs for sympathy, consolation, advice and protection from the cruelty of others.

Gender differences in these strategies did emerge: boys tended to seek out companionship in form of activities such as football, but were less likely than girls to sit and "share secrets" and discuss their problems with their friends. In these cases, boys reported not telling their problems to anyone. The differences in the strategies of boys and girls under the age of 12 also emerged among those in adolescence.

Discussions with children between the ages of 12 and 18 also indicated the supportive role played by friends. This was equally true for boys and girls in the rural and urban areas where the research took place. However, in rural areas, children in this age range used a three-step approach which involved first approaching their guardians (if they felt comfortable to do so), then various supportive members of their extended family, and finally their friends. In Area 18, children did not employ the second step of approaching family members outside their household. In the event that their guardians were unable or unwilling to listen to them, or to

assist them with their needs, most boys and girls would seek out their friends. Occasionally neighbours were also approached, but this was rarely reported, as most children felt that

*(These people) have their own problems and wouldn't understand mine* (girl, 14, Area 18).

The importance of peer networks cannot be overestimated and interventions to support orphaned and other vulnerable children need to recognise and build on the strong relationships that exist between children themselves. Throughout this research, it was often mentioned by guardians, AIDS Committee members, and others that children's friendships consist entirely of play. One woman commented

*Children don't care who they play or eat with, only that they get to play and eat*

There was little or no recognition at the community and programmatic level of the substance of children's relationships with their peers, and the supportive role that children can perform for one another. This view was especially widespread as it pertained to young children. Some adults recognised the role friends play in the lives of older adolescents. Still, it is interesting to note that even though the vast majority of guardians said that the orphans in their household never came to them for advice or to talk about their problems, most felt that children's needs for social support were being met by their guardians, and if not, within the extended family network. The feeling was that if children were not taking advantage of these networks, then they were either not seeking support from anyone, or they did not have problems large enough to warrant "*malagizo*" (advice or guidance).

## **Chapter Seven: Access to and Effectiveness of HIV/AIDS Information**

### **Children's Awareness and Understanding of HIV/AIDS**

In all three case study communities, children above the age of 10 were aware of HIV/AIDS and its consequences. "AIDS is a virus that kills" or "AIDS is a virus that lives in the blood. It can kill you," were some of the comments frequently made by boys and girls between the ages of 10 and 16. Children cited a series of different ways in which they acquire information about HIV, most often through radio, drama, songs, anti-AIDS clubs in schools, posters, and religious sermons (Christian and Muslim). In Ngawo, peer education was also cited. None of the children involved in the study mentioned their parents, guardians or other family members as sources of information about AIDS, regardless of whether or not relatives were infected or had died as a result of the disease.

Our research indicated that while children below the age of 10 years had heard of HIV/AIDS, they often did not know what the illness was, how it is transmitted or how it can be prevented. All knew, however, that "you can die of it". On the whole, adults in the three communities where the study was conducted said that children of this age do not need to know about AIDS because they are not yet believed to be aware of their sexuality nor are they considered to be sexually active. Young children are not only seen as incapable of understanding the nature of the disease, but it is widely felt that this information is not necessary for children who have not yet reached puberty.

One of the striking issues to emerge from this research was the fact that while all of the participating children (above age 10) and young people were able to describe AIDS as a fatal sexually-transmitted disease, the minority were able to discuss the illness beyond repeating slogans from radio and other sensitisation campaigns. Very few could speak knowledgeably about HIV, beyond the fact that it is the result of "immoral behaviour" and that abstinence is the best way to avoid contracting the disease. In Ngawo, where the Village AIDS Committee has been active for 5 years and youth have been trained and are involved in educating others about HIV/AIDS, condoms were seen as the next best option in terms of prevention. In this village, there appeared to be very little discomfort with discussing condoms and other means of practising safer sex, including masturbation as an effective way for teenage boys to act on their sexual desires. But in Mpinganjira, where until very recently all anti-AIDS activities have been organised from within the community without assistance or training from COPE or other external actors, condoms are highly frowned upon, in large part because of the significant influence of the village Anglican church, which does not promote their use. When asked how HIV could be prevented, most of the children in this community described the need to abstain from sex until marriage and to avoid sharing toothbrushes and razor blades. None of those interviewed mentioned condoms as a means of prevention. When condoms were directly discussed, most young people commented on their unreliability and the fact that they often have small holes in them and can break easily. Many children and youths in this community seemed to feel that condoms were not a realistic option for the prevention of HIV/AIDS. What is striking is that the young people who chose not to use condoms and argued abstinence to be the only way to prevent HIV were the same people who said that sexual activity was a mainstay of their peers' activity.



In all three communities, regardless of their perceived acceptability as a means of protection, children and young people strongly believe that condoms have promoted promiscuity among young people. Many children said that advertisements for condoms “make you want to try sex” and that they make “sex look like a lot of fun”. Some said that more children have sex, and at an earlier age, than they did before condoms were made so popular. A number of adults expressed similar views; some shared stories, for example, of finding a condom while emptying the pockets of their 8 year old son’s trousers. When approached about it, the child quoted the ubiquitous advertising campaign, saying that “you should never go anywhere without a *Chisango* (the most popular brand of condoms in Malawi)”.

### **Children’s Perspectives on the Efficacy of HIV/AIDS Awareness Efforts**

Many children in this study expressed the opinion that most of the AIDS awareness campaigns in their community are not effective. This view was most widely held among young people above the age of 14 in Mpinganjira and Area 18, although some young people in Ngawo also expressed similar feelings. Several reasons were given for the ineffectiveness of these messages. First, some said they were “sick of hearing about AIDS” and that they no longer listened to the public awareness campaigns, which were “everywhere”, “always saying the same thing”. Second, it was explained that young people feel angry and distrustful of adults who tell them to abstain from sex; they resent the fact that adults, many of whom have had “lots of fun” in their youth, are now selfishly telling children that they cannot “enjoy life”. A third and related reason is the belief that those who pass on anti-AIDS messages may not practise what they preach. Young men in particular expressed disillusionment when they witnessed or heard of the promiscuous activities of those adult men who had warned them of the dangers of sexual activity. Boys in one community felt that these men were only trying to scare them so that they could “keep all the girls to themselves”. In this case, male AIDS educators were viewed with suspicion because they were seen as “trying to eliminate the competition” for female sexual partners from young men in the community. Finally, in all of the research communities, children and young people over the age of 12 felt that plays and other drama activities about HIV/AIDS and its consequences were entertaining and funny, but that their messages are not taken seriously by children or adults. While young people said that theatre did help to raise awareness of the disease and its consequences, most felt that the approach was completely ineffective in changing people’s behaviour.

When asked what activities or approaches were successful in encouraging behaviour change, children and young people commented on three main strategies. The first was peer education, which was widely felt to be an appropriate way of learning about HIV/AIDS. At the time of our research, Ngawo had a well-established youth-to-youth education component in the work of the Village AIDS Committee, and the RAC in Area 18 had also recently mobilised interested youths to be trained as peer educators. While children in Mpinganjira had not participated in any peer-led activities, they nonetheless expressed an interest in this approach to AIDS awareness and felt that learning from, and having the support of other children and young people would enable them to “be good” and to “resist temptation”. This might be an important intervention point for the provision of social support to orphans and other vulnerable children as well as an effective educational model.

Second, children in this study said that knowing someone who had died of AIDS made the reality of the illness hit home for them. Seeing the suffering and misery that AIDS brings not only to the infected individuals, but also to their family and friends, was a powerful incentive

for children to accept the reality of the illness and to heed its prevention messages. Some spoke of the depletion of family finances that results from the significant and unrelenting costs of caring for dying family members (and paying for their funeral). Associated with this was the inability of affected families to adequately feed other members, to look after their gardens and other income generating activities or to pay school fees and other educational costs. Throughout the research, children said that AIDS awareness campaigns would be more successful if boys and girls were able to meet people with AIDS who would talk openly about the disease and its consequences. A group of boys in one community, for example, suggested that a respected male elder in the village should take a small group of boys to the home of a person who is dying. The boys thought that this experience would assist children and young people to protect themselves if they were able to ask the person living with AIDS a number of questions and to speak with other family members. They said it would be especially helpful if this person were a member of their own community.

Third, children mentioned AIDS funerals as another effective means of discouraging risky behaviour and promoting behaviour change among boys and girls of all ages. Over the last few years in Malawi, some people living with AIDS have decided that when they die, their funerals should be used as an opportunity to raise awareness about HIV/AIDS. It appears that this practice is becoming increasingly popular, especially in those communities where many people are dying and there is widespread concern that more and more people are becoming infected with the virus. In the same way that visiting or knowing a dying person with AIDS is seen as having a powerful impact on young people, AIDS funerals are viewed by children as a very effective means of educating the community, in part because it was the wish of the deceased to use their funeral as an opportunity to save the lives of those in their community. In addition, some children felt that the practice in some communities of not speaking of AIDS as the cause of death was counter-productive. They said that acceptance of the disease is still quite low and as a result it is common for family members, clan heads and religious leaders to say that a person “was sick for a very long time...”, rather than saying that they died of AIDS. Young people in this research clearly wanted the prevalence and danger of the illness to be acknowledged openly, and not seen only as a topic of a play or a lesson in the classroom.

Perhaps the most challenging observation made by children and young people in the three research communities was the widespread belief that anti-AIDS messages are not realistic for the majority of poor children in their community. In the view of many girls and young women between the ages of 13 and 20 years, telling children to abstain from sex is meaningless as long as girls are forced to sell sex to feed themselves and their family, or are exposed to sexual exploitation and abuse in circumstances such as domestic work and early marriage. Furthermore, this same group mentioned the tendency of some parents to ask their teenage girls to “go and get some soap” or “go and find us some food for supper”, euphemisms for having sex with a man in exchange for basic necessities such as soap or a bag of maize flour. Some felt angry about the hypocrisy of these same parents, who, when their daughter later falls ill with AIDS, feel ashamed of her and complain that she is aggravating the already desperate poverty of the family because of the costs associated with her care, both in terms of time and money.

Boys and young men appeared less sympathetic to (or perhaps not cognisant of) the pressures felt by girls and young women in their community. Instead, they tended to comment on the

need of many boys to “fend for themselves” from a very young age, usually by dropping out of school, doing piecework, stealing and begging. In so doing, they argued, it is common to fall among a “bad crowd” and to use drugs and alcohol as a means of passing time and abating hunger. They say that under these circumstances, it is difficult to make smart decisions, such as abstaining from sex or using a condom; others say the lack of concern for HIV/AIDS reflects the sense of hopelessness of some and a sense among others of being “untouchable” or immortal. One 13 year old girl in Mpinganjira commented on the differing levels of acceptance and awareness of HIV/AIDS among those children who attend school and those who do not:

*When you go to school it is easy to know about AIDS. But when you are out of school, it is more difficult. Children out of school often think we are making it up because we are jealous that they have money from working. They say that AIDS does not really exist, that we are wrong. But we know the truth from books, and books do not lie. AIDS is a big problem here*

### **Boys’ and Girls’ Suggestions for Ways to Reduce Children’s Vulnerability to HIV/AIDS**

Children involved in this research made a number of suggestions about how to reduce the vulnerability of children to HIV/AIDS, especially that of orphans and those boys and girls whose parents are disabled or not in good health. Given that the participants were themselves affected or infected by HIV, it is important to consider their perspectives and suggestions. Many proposals centred on parents and guardians and their obligation to provide for the needs of their children so that a child is not forced to engage in risky behaviours in order to meet his or her basic needs. This view was widely held among participating children. In addition to their role in providing children with their basic material and financial requirements, boys and girls felt that parents and guardians could reduce the likelihood of their children contracting HIV in the following ways:

- by being kind and not abusive to children
- by listening to their sons and daughters and giving them advice (*malagizo*)
- by talking openly about AIDS;
- by ruling out promiscuity through punishing their daughters for exchanging/selling sex (suggested by girls between ages of 13-18)
- by encouraging their children to go to school

It was widely agreed among participating children that all adults had a responsibility to behave in this way, and because most adults in the community are parents, realisation of these suggestions could have wide-ranging impacts on the reduction of children’s vulnerability to HIV/AIDS.

Children and young people also felt that they could assist one another to stop the spread of AIDS and reduce their own susceptibility to contracting the disease. They made a number of suggestions for things that children could do for each other, including:

- providing open and accurate information about HIV/AIDS through peer education
- providing condoms on a free and anonymous basis (Ngawo)
- encouraging each other to go to school

- soliciting funds to support orphans
- establishing income generating activities such as kitchen gardens for children so that they do not have to engage in risky survival strategies
- caring for one another, especially through befriending orphaned children and defending them when others insult or are cruel to them
- sharing resources such as food, paper and pens, regardless of the amount
- setting up activities such as sports and community work in order to keep one another busy so that “sex is not on our minds”
- giving children clothing that older ones have outgrown

### **Adults’ Suggestions for Ways to Reduce Children’s Vulnerability to HIV/AIDS**

Adult guardians and other community members, including chiefs, religious leaders, teachers, health workers, business people and others also felt that there were specific things that could be done in order to reduce orphaned and other children’s vulnerability to contracting HIV. In general, adults’ suggestions mostly centred on the need to reduce poverty in their communities. Many proposed:

- the need for credit facilities
- provision of agricultural inputs so that families could grow more food for consumption or sale
- implementation of an irrigation scheme
- provision of libraries where children can access information on HIV/AIDS
- donations of material goods such as blankets, bedding and clothing

Child-focused suggestions included establishing income-generating activities for young people and setting up vocational training centres for youth (both orphans and others) so that they can learn skills by which to earn a living; and providing recreational activities for children such as sports and singing clubs. It is interesting to note that there were no marked differences in the views of adults in Ngawo, where the Village AIDS Committee has been long-established and very vocal in its work, and those in Mpinganjira and Area 18, where the local-level AIDS committees are still in their initial stages. The similarity of responses may indicate both the exposure and/or participation of all three communities in the larger national and regional debates on strategies to support children and families in AIDS-affected communities. It may also indicate that those communities without a long history of external intervention have nevertheless thought through some of the potential ways of reducing poverty and HIV/AIDS rates. Perhaps it is as a result of the desire to implement their suggestions that they have decided to establish local AIDS committees. Support should be given to communities to build on their experience and expertise in order that they can implement and develop programmes to further assist those children and young people who are at greatest risk of contracting the HIV/AIDS virus. Many of these children are orphans, many are not.

## Chapter Eight: Conclusions

This study has attempted to examine the situation of children affected or infected by AIDS or otherwise placed in difficult circumstances in some of the most profoundly affected communities in Malawi, and in particular to deploy research methods which would facilitate children's articulation of their needs, problems, resources and ideas. Despite the widespread food crisis which had a huge impact on the country at the time of fieldwork, guardians, children, youths and other community members generously shared with the researchers their perspectives and experiences. The result is a greater appreciation for the complexities of the care and protection needs of orphaned and other vulnerable children in Malawi.

Throughout this study, a remarkable discrepancy was found in the views of adults and children respectively. These differences of opinion occurred in a number of areas. Adults tended to believe that orphaned children should play no part in the decision-making around their care, that they would not choose realistic options and that they would become confused if asked their opinion. Most adults did not know what children's preferences were and some actually felt that children did not mind where they lived so long as they were fed. On the other hand, the children involved in the research were anything but confused in their ideas about alternative care arrangements and they displayed clear and well thought-through ideas on the characteristics of the most suitable carers. Boys and girls felt strongly that they should be consulted in decisions about their care. While adults emphasised the material capacity of a family to take in an orphaned child, children placed more emphasis on being cared for by adults who would love them and respect the honour of their deceased parents. Children were much more concerned with the atmosphere in the guardian's household and they expressed a desire to live with people who would love them and treat them equally with other children in the household. This led to a strong preference for care by grandparents even if this meant living in extremely poor circumstances. Perhaps surprisingly, grandmothers, who were often old and very poor, rarely complained about being burdened by the care of orphaned children in the way that younger guardians frequently did.

Where this research showed agreement between adults and children was in the view that care for orphaned children by unrelated adults was neither appropriate nor desirable, and only one such case was encountered during the fieldwork for the study. Most adults and children suggested that children were even more vulnerable to discrimination, harsh or cruel treatment and exploitation in this context than they were in the homes of relatives, a remarkable statement given the considerable extent of these problems expressed by children living with extended family members. Boys and girls expressed the fear that their vulnerability in unrelated households would be even greater because their relatives would not be able to protect them; in the two rural communities, many children said that they would rather live on their own than with unrelated people. The majority of children involved in this research believed that living in an institution was the worst possible solution, despite their awareness of the material advantages of institutional care.

Contrary to popular assumptions, this study revealed that extended family care for orphans is not always trouble-free and that related guardians do not necessarily respond appropriately to the needs and rights of parentless children. High levels of discrimination and harsh treatment in the household, coupled with the inability of many families to meet their basic needs for

food and other necessities, has created a situation in which many children's basic rights are not being met.

Guardians frequently revealed that they found the orphaned children to have many behavioural problems and to be difficult to look after. Some were honest enough to acknowledge that it is not possible to treat a child who is not their own in the same way that they would treat their own, biological children. Many were highly critical when children complained of discrimination, and rather expected them to be grateful for the fact that another family had taken them in. Orphaned children, on the other hand, revealed a startling pattern of abuse and discrimination, and some quite gross examples were cited: one child, on making a mistake, was shown the grave of the deceased parent and told to dig it, while other examples were given of girls being sent out to "find some soap", a euphemism for earning money for essentials by selling sex. It was clear that many orphaned children living with related families did not have their basic needs met when other children in the household did.

Discussions with guardians and children throughout the research process highlighted a vicious circle of misunderstanding which was often difficult to break: children brought into the substitute family experience high levels of distress, stemming from what might have been a long period of caring for, and eventually losing, one or both parents, in addition to coping with the strong sense of stigma which surrounds HIV/AIDS and orphanhood. In the substitute family, discussion of their late parents tends to be discouraged and they are expected to behave well and not to complain. From the child's perspective there is often a profound sense of isolation because no one is paying attention to their special needs for love and emotional support. This feeling of loneliness is compounded by a sense of being different from other children in the household, whom they believe to be treated more favourably. Sometimes they act out their feelings by behaving rudely or inappropriately, or by withdrawing from family members. The resentment which results from their less-privileged position is augmented by what many orphaned children see to be their unmet needs for patience, love and kindness as they work through their feelings of grief and sadness. The result is a cycle in which guardians feel unappreciated and therefore less inclined to be supportive to the orphans in their care, while the children themselves feel angry, alone and unjustifiably discriminated against. In communities with a longer history of COPE-mobilised activities, the discrimination experienced in the wider community was much less pronounced than that experienced within the household.

Child protection concerns have played a very minor role in the support of orphaned children who are cared for within the extended family network, and even in COPE-mobilised communities there is a reluctance for volunteers to become involved in the actual care and protection of children living with relatives. In the urban community in which the research was conducted, it was interesting to note that while members of the Residential AIDS Committee were hesitant to visit children not already known to them, the children themselves expressed a desire for visits even if the visitors had no material goods to offer them: boys and girls in this context welcomed the possibility of support and guidance.

It is clear from this study that taking care of children who have lived with and eventually lost their parents, often under extremely difficult and distressing circumstances, is not the same as caring for one's own biological children. Just as orphaned children have special needs and problems, so do guardians, who may not know how to cope, and hence may do so by

inadvertently making an already difficult situation worse. Some form of facilitative intervention within these stressed households is clearly needed.

On the other hand, children's remarkable resilience also showed through the research: young people employ a wide range of strategies for coping with exceptionally difficult circumstances, often making good use of their networks both within the extended family and among their peers, with some differences between children living in urban and rural contexts respectively. Paradoxically, many guardians expressed the opinion that most children's needs for social support were being met by guardians even though, in practice, children rarely came to them for advice or to talk about their problems. The importance of peer networks was generally not recognised either at community or programmatic level.

One possible future direction for programme planning may be to promote networks of support both for guardians and for children. It was highly significant that in communities with a longer experience of COPE-mobilised activities, children experienced far less discrimination within the community than at household level. These factors combine to suggest that children may benefit greatly from the mobilisation of young people with a similar experience in order that they may learn from each other's experience and benefit from mutual support. Similarly, guardians who are struggling with the practical and psychological difficulties of caring for an additional child - and moreover one who brings considerable behavioural and attitudinal problems - may derive considerable benefits from the support and guidance of others struggling with similar issues, especially if this is supported by adults with more extensive knowledge of child development and children's needs.

The study sought to elicit the views of young people on the effectiveness of HIV/AIDS awareness efforts and it was clear from them that campaigns in the community are generally not effective. Children did, however, have some constructive ideas for future developments, including the importance of peer education, the role of parents and guardians in HIV/AIDS education and the need to learn from people with AIDS if they were willing to talk openly about their experiences and the consequences of the disease. They also thought that funerals could sometimes remind people of the need to avoid risky behaviour. Boys and girls were highly critical of adults who failed to lead by good example, and in particular they were angry with guardians who preached abstinence from sex but then encouraged girls to sell sex and then complained if the girl fell ill and hence aggravated the already desperate poverty of the family.

One factor to emerge from the study is that, while all children need to be seen as vulnerable to HIV/AIDS, children who have lost their parents to the disease may be at particular risk. Many children living with relatives did not have their basic material needs met and many were forced to drop out of school and fend for themselves, sometimes resulting in behaviour that posed further health risk - e.g. selling sex, stealing and begging and using drugs and alcohol to pass time and abate hunger. Ensuring that the basic needs of orphans are met may be highly significant in minimising the danger of them contracting the virus that has already rendered them parentless.

Attention to the concerns of children must to be incorporated into programmes designed to meet their needs. Boys and girls have a powerful role to play in the improvement of their own lives and those of their peers, siblings, families and communities. When the results of this

study were fed back to adult members of the local community there was frequently a great deal of surprise that children's perspectives were well thought-through and so different from their own. Interventions need to build on children's own experiences and opinions with respect to their care as well as the prevention of HIV/AIDS. We need to learn from children themselves about the positive aspects of their existing coping mechanisms and strengthen the capacity of peers and adults to provide them with support. In short, we need to put children, as well as AIDS, at the heart of programmes to support orphans.

The COPE programme of Save the Children USA in Malawi is ideally suited to support this process. Its foundation in the local realities of the communities in which it works and its long and proven record of mobilising people to mitigate the impact of HIV/AIDS provides a strong basis from which to build on these issues. The success of the programme at the community level is in large part due to the appropriateness and relevance of existing activities to the daily lives of the most vulnerable families and children in the community. Open dialogue with children will augment the success of these ventures, and provide important insights into new and alternative ways of addressing the needs of orphaned boys and girls. Through the use of appropriate, child-focused and participatory methods, we can learn from children different things from those we learn from adults. In so doing, we can gain a fuller picture of their lives and thus improve our capacity to assist them to assist themselves.



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