# O R P H A N   A L E R T

*International perspectives on children left behind by HIV/AIDS*

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## AFXB's global action for orphans and vulnerable children

The Association François-Xavier Bagnoud (AFXB) has made the rescuing of children in need its mission since its inception in 1989. AFXB has actively supported and promoted children's rights, health and human rights, and pediatric HIV/AIDS initiatives in more than a dozen countries.

In Brazil, Colombia, India, Thailand, and the United States, AFXB has established eight François-Xavier Bagnoud Houses for young children suffering from HIV/AIDS. Staff providing tender loving care and the best therapies available help the children in these Houses live longer, happier lives.

In Rwanda, AFXB helped the residents of a community torn by ethnic conflict to draw together to rebuild their homes and care for their orphaned children. At present, 1,505 families are benefiting from a program that promotes income-generating activities. Some 2,000 primary school children from the community are receiving assistance for their schooling. In Kigali, Rwanda's capital, AFXB has recently launched a program to provide support for HIV-positive mothers and for foster families caring for over 200 children who have AIDS or whose parents have died from the disease.

In Uganda, AFXB supports income-generating activities for families who welcome approximately 3,200 AIDS orphans into their homes. Links with local schools ensure that school fees are waived in exchange for support for building new classrooms. Recently, AFXB has begun to work in Alexandra township, near Johannesburg, South Africa, to develop programs to assist AIDS orphans.

In Montevideo, Uruguay, AFXB has reached out to more than 600 street children and young people from poor neighborhoods with workshops and training in human rights, healthy sexual development, and employment opportunities. In Goa, AFXB supports care for 86 children of sex workers and provides boarding for more than 150 children. In Thailand, AFXB took the lead in liberating hundreds of young women from brothels. Afterwards, the Association set up a program in Burma/Myanmar to help more than a hundred former sex workers learn another profession to earn a decent living for themselves and their families.

The François-Xavier Bagnoud International Pediatric HIV Training Program at the University of Medicine and Dentistry of New Jersey has imparted skills in pediatric AIDS care to more than 100 health care workers in two dozen countries. AFXB is supporting research for a vaccine derived from the blood of HIV infected people. This research is led by Dr. James Oleske, the holder of the François-Xavier Bagnoud Chair in Pediatric Allergy, Immunology, and Infectious Diseases at UMDNJ.

To champion the rights of children and to advance the understanding that health is a human right fundamental for sustainable development, AFXB established the François-Xavier Bagnoud Center for Health and Human Rights and its endowed professorship at the Harvard School of Public Health. The Center staff research, analyze, and promote the relationships between health and human rights, with special attention to children. The Center also publishes the Journal of Health and Human Rights, organizes international conferences on themes central to its purpose, and sponsors fellowships for scholars conducting relevant research.

AFXB is an active member of the NGO Group for the Convention on the Rights of the Child. At its November 1996 session, the United Nations Economic and Social Council granted the Association the designation "special consultative status."

The central focus of AFXB is children orphaned by HIV/AIDS. The Association's president, Albina du Boisrouvray, travels around the world to raise awareness about the catastrophe to come: up to 100 million children orphaned by 2010. AFXB is currently leading the first global civil society petition to draw attention to the orphan crisis. Individuals wishing to be part of this effort can sign on www.fxb.org.

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## A letter from Albina du Boisrouvray

*Dear global civil society of the village Earth:*

More than a decade ago, the death of my son, a helicopter rescue pilot named François-Xavier Bagnoud, turned my own life into a rescue mission of sorts. Inspired by his love for people and his commitment to action, I established the Association François-Xavier Bagnoud and the FXB Foundation. Together they have worked towards combating the HIV/AIDS crisis and eradicating poverty, championing global recognition of the inextricable link between health and human rights.

For most of the last ten years, the world was in denial about the disastrous spread of the HIV/AIDS pandemic. Governments, businesses, and those of us in global civil society failed to appreciate the pandemic's enormous scale, its complex causes, and its catastrophic consequences. All too many were unwilling to listen to the prophetic predictions made by the late Jonathan Mann and his staff at Harvard's FXB Center on Health and Human Rights and by the Global AIDS Policy Coalition, established by FXB, warning us to act on the basis of irrefutable data and incisive analysis.

Now, the world is beginning to remove its blinders. But some of us, like frogs in a well, can still only see a small slice of the darkening sky that poses such a threat to the planet. And that dark sky is much more than a global public health crisis. It is a social crisis that is tearing apart the fabric of communities and societies. To quote Dr. Geoff Foster, "In the body, HIV gets into the defensive system and knocks it out. It does that sociologically too. It gets into the extended family support system and decimates it."

It is also an economic crisis that is robbing countries of their workers, entrepreneurs, and teachers in the prime of their lives. And it is a security crisis that may soon lead orphaned and abandoned children to become criminals, soldiers and agents of violence, both responsible for and vulnerable to the abuses that erode the foundations of society.

The HIV/AIDS pandemic is rooted in social and economic realities. HIV/AIDS spreads rapidly in societies without strong education and health care systems, and without equality of rights and opportunity. It is driven by poverty and conflict. We have to understand how the lack of empowerment of women and adolescents, the lack of literacy and education, and the trampling of human rights fuel this epidemic. When HIV/AIDS ravages communities, it makes women and young people even more vulnerable, leaving them disempowered and defenseless targets of abuse.

Most troubling of all, AIDS leaves behind huge numbers of orphaned children: some 100 million in this decade, most desperately poor and struggling to survive. Our failure to reach out to them is a screaming scandal in our planet of interconnections and pockets of huge affluence.

We must reel these children back into society, into caring communities and loving families to enable them to gain access to support, education, HIV prevention, and health care. When they need medicine, it must be provided. When they are sick, they have a right to be cared for. When they die, they must be able to die with dignity, surrounded by love. Our programs of compassion must be based on rights: the rights of these children, enshrined in the Convention on the Rights of the Child and ratified by all but two nations of the world – one without a government, Somalia, and one with the strongest government of all, the United States.

From my vantage point as the founder of a small but influential NGO implementing micro projects with macro implications in more than a dozen countries, I see oases of hope everywhere. I am constantly heartened by the courage of those on the front line – health care workers, community organizers, people bravely living with AIDS, and the family members and neighbors who open their homes and hearts to orphaned children. Their commitment and dedication are exemplary.

Every citizen of our global co-op must learn from these examples and become involved. We must save these children and keep them and ourselves from falling into an abyss of poverty, sickness, despair, and violence. HIV prevention and treatment have to be top priorities. The search for new medicines and health care delivery systems must continue. But we are more than just medical missionaries. We are not just fighting a disease, but the poverty, malnutrition, wars, homelessness, and denial of human rights that are the root causes of the disease.

We are all in this together, each a colorful piece of the mosaic that forms the whole picture. And it is precisely this mosaic, a palette of innovative solutions, that is needed to reintegrate orphans and to prevent a global disaster.

To reweave torn social fabric, we need to end the discrimination within communities and to strengthen the invisible heroes that are the grassroots volunteers, mostly women. And we have to bring in the missing building blocks of society by leveraging the solidarity and generosity of the affluent parts of the planet. In the mode of Doctors Without Borders, what about Teachers Without Borders? What about Retirees Without Borders, drawing on the great skills and knowledge of those who live longer in good health?

As we act now, we have to act smarter, working with people, not just for them. We have to find ways to help those who are already helping the vulnerable. The orphans of the AIDS crisis in many cases do not need expensive medication. They can survive and thrive if supported by community-based initiatives that help guardians, extended family, and neighborhood networks to provide love and caring. Almost any development initiative to improve education, nutrition, income generation, sanitation, and health can make a difference.

Love is a word we rarely hear from international agencies and top-down strategists. Compassion seems to imply soft-mindedness when, in fact, it is the only

way to mobilize the resources needed to help those who have nothing. And children live on love the way flowers live on sun and water. The Native American poet Joy Harjo said it beautifully: "I believe love is the strongest force in the world, though it doesn't often appear to be so at the ragged end of our century, and its appearance in places of drought from lovelessness is always startling."

At FXB, we are demonstrating daily that practical bottom-up projects grounded in the experience and wisdom of indigenous cultures can work. We have combined research, training, education, and advocacy in small but potent efforts. We help caregivers to offer attentive care delivered with tenderness. We are as concerned about the quality of our services as their quantity.

You can get involved with FXB with the click of a mouse. Visit our continuously evolving website at www.fxb.org to find out about the range and depth of our work. Sign our online petition, the first global civil society petition of its kind aimed at showing governments, businesses, and the affluent that the world's people demand a higher level of engagement in the AIDS crisis. We are focusing our attention on where the power and money are. We are saying: Invest it to save lives. We are seeking help to fund orphan projects that are making an important difference. What better investment can all of us make in the future of the global community?

In a world driven by globalization from above, we promote globalization from below, treating the earth as a co-op in which we are all stakeholders. Like the little boy who put his finger in the dyke, we can put our minds and hands to work stopping the further erosion of social and economic systems that put the most vulnerable of us at risk. In fighting for humanity, we ultimately become more human ourselves.

Write to me via www.fxb.org and let me know how you are going to help.

*Albina*

# Foreword

The HIV/AIDS orphan crisis is one of the greatest humanitarian and development challenges facing the global community. The 'orphan epidemic' is still in its infancy. In the years and decades ahead, the impacts of HIV/AIDS on children, their families, and their communities will grow far worse, expanding to dimensions difficult to imagine at present. The crisis demands and deserves massive action by individuals and institutions throughout the global North and South.

To date, the international response has been paltry. In recent months, though, the UN Security Council, the US government, global media, and other central players in global politics have begun to pay attention to the AIDS orphan crisis. Powerful media portrayals of the suffering of orphans and their caregivers have been complemented by disturbing strategic analyses of the threats to regional and global security posed by high rates of orphaning. Key elements that have been missing from many recent accounts of the crisis, however, are substantive insights from community-level research and concrete examples of promising responses.

The Association and Foundation François-Xavier Bagnoud have been assisting children orphaned by HIV/AIDS and advocating on their behalf for more than ten years. FXB has developed this volume to serve as a resource for a broad range of readers interested in orphan issues. *Orphan Alert* is intended to be accessible and useful both for those who are already deeply involved in efforts to assist orphans and for those who are just beginning to learn about the orphan crisis.

This volume is comprised of two sections, each containing three articles. Through the articles compiled here, FXB seeks to fill gaps in present discourse and to advance knowledge and practice in the field.

## Section 1: New studies

The first section presents the initial findings of several studies commissioned by FXB for this volume. Each study discusses key dimensions of the orphan crisis at ground level in HIV/AIDS-affected communities. The studies cover urban, semiurban, and rural communities. Three countries in three different stages of the evolution of the orphan crisis were selected for the studies: Uganda, with a mature HIV/AIDS pandemic and a heavy orphan burden; Ethiopia, with a younger, rapidly expanding pandemic and orphaning already at crisis levels; and India, where HIV is spreading quickly and silently and AIDS-related orphaning is not yet occurring at large scale.

In the first of these articles, Neil Monk presents the findings of research conducted in rural villages of Uganda's Luweero district. He makes the compelling argument that the current methods used to calculate and project orphan numbers seriously underestimate the actual number of children orphaned in HIV/AIDS-affected areas. He contends that these numbers also fail to take into account the many other children who are rendered vulnerable because of the disease. He suggests an alternative mode of calculation based on a more relevant and inclusive definition of orphans.

For the second article, Marta Segu and Sergut Yohannes coordinated research in Bahir Dar, a town of 135,000 in central Ethiopia with high rates of HIV prevalence and AIDS-related orphaning. The article includes a revealing account of the situation of child-headed households in Bahir Dar. The article also discusses the strong consensus among the government and nongovernmental agencies at work in the town on how to respond to the growing orphan crisis.

The third article summarizes the findings of studies undertaken in three areas of India. India, with its billion people and grinding poverty, will soon become the next epicenter of the AIDS orphans crisis. To survey the orphan situation in the early stages of the pandemic's emergence, FXB supported studies led by Joana Chakraborty, Mellary Chrisstie, and John Zomingthanga in three very different areas of the sub-continent: rural villages in the northwestern state of Rajasthan, the medium-sized capital of the

northeastern state of Mizoram, and the sprawling city of Calcutta. Collectively, the India studies offer a pre-crisis snapshot of the Indian orphan situation and indicate that there is serious cause for concern.

**Section 2: Innovative views from the field**

The second section offers experience-based perspectives from leading practitioners in the field of care for orphans of HIV/AIDS. FXB is honored that these leaders accepted invitations to contribute articles that distill their experience implementing cutting-edge approaches in the field. The insights these articles offer have important implications for all organizations involved in promoting care for children affected by HIV/AIDS.

In the first article, Mulugeta Gebru of the Jerusalem Association Christian Homes (JACH) and his colleague Rebecca Atnafou discuss the hard lessons learned by orphan care organizations in Ethiopia. In response to the orphan crisis engendered by war and famine during the 1980s, JACH and numerous other organizations built orphanages to house vulnerable children. JACH was one of the first agencies in the country to recognize the negative impacts of orphanages on children's development and the unsustainability of an orphanage model of care. In their article, the authors detail why and how JACH shifted from an institutional approach to a community-based approach, explaining the obstacles they faced and the ways these obstacles were overcome.

In the second article, Louis Mwewa draws on his experience as coordinator of Zambia's Children in Need Network (CHIN) to discuss the value of building networks of child-focused organizations. CHIN's provision of training, information, and a forum for discussion has strengthened the policies and practices of a wide array of Zambian organizations. By enabling a disparate group of child-oriented groups to unite and speak with a single voice, CHIN has played a vital role in placing children's issues on Zambia's national agenda.

Stanley Phiri of Malawi concludes the section and the volume with an inspiring article about the women and men in AIDS-affected communities who take responsibility for caring for orphans and other vulnerable community members. Based on his experience as manager of COPE, a pioneering program to mitigate the impacts of AIDS on children and families, he identifies the qualities essential for effective orphan care activists – both those in communities and those who work to build communities' caring capacities.

**Toward action**

The enormity of the HIV/AIDS orphan crisis must not paralyze the global community. Rather, recognition of the magnitude of this unfolding disaster should galvanize decisive action. A number of the articles in this volume discuss promising initiatives that are helping orphans and other children who have been rendered vulnerable by HIV/AIDS. The overall message that emerges from the articles is not one of resignation and despair, but one of determination and hope.

In Ethiopia, orphans as young as eight are looking after their brothers and sisters. In Uganda, grandparents, aunts, and uncles have opened their homes to orphaned children. In Malawi, communities have organized themselves to provide ongoing care and support to orphans and chronically ill adults. In Zambia, organizations have banded together to make vulnerable children a national priority. Across Africa and other affected regions, children, communities, and countries are coping with the crisis. Their efforts can and should be reinforced by carefully targeted assistance from abroad.

The millions of children being orphaned by HIV/AIDS are not only a human tragedy, but also a grave threat to stability, security, and markets in heavily affected areas and beyond. Action to assist these children is a matter of both strategic imperative and moral responsibility. The human family must not abandon the children left behind by HIV/AIDS.

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# Underestimating the magnitude of a mature crisis: Dynamics of orphaning and fostering in rural Uganda

## Neil Monk

### Summary

In February 2000 research was conducted in nine rural villages in Uganda's Luweero District. The aim of the research was to examine in depth the nature and dynamics of the orphan crisis in a heavily HIV/AIDS-affected area. In particular, the study sought to address two questions:

- Who are the orphans and vulnerable children in the area?
- Who is caring for these children?

The research revealed that the definition of 'orphan' used by UNAIDS and other agencies excludes many children whose lives are severely affected by the HIV/AIDS pandemic. By excluding children who have lost their father, young people between the ages of 15 and 18, and non-orphaned children living in households that foster orphans, the UNAIDS definition fails to recognize many of the children rendered vulnerable by the pandemic. This failure means that current estimates of the number of children who will be orphaned by HIV/AIDS grossly underestimate the scope of the impacts of the disease on children. Data from this study suggest that current estimates of the number of children orphaned by HIV/AIDS should be multiplied by a factor of at least four to reflect the actual number of children made vulnerable by the pandemic.

### Location

Luweero District is located in the kingdom of Buganda, in the south-central region of Uganda. Buganda's people comprise about one-fifth of Uganda's population. Luweero has had a high number of orphans for a number of years, beginning with the period of civil war between 1979 and 1986 which followed the end of Idi Amin's rule. The conflict was especially intense in the area around Luweero. This 'orphan epidemic' has been perpetuated and exacerbated by the HIV/AIDS pandemic. AIDS mortality in Luweero District is slightly higher than average for the country, but below that of the most severely affected districts, e.g. Masaka and Rakai Districts in southwest Buganda.

### Methods

The study was undertaken in two sub-counties of Luweero District, Butuntumula and Makulubita. In this area, 15.6% of children are orphans, compared to a national average of 11.6%. These sub-counties were chosen because the AFXB orphans project active in the area was able to provide the initial statistical data from office records. Interviews of households caring for orphans took place in seven villages of Butuntumula sub-county and in two villages of Makulabita sub-county. A total of 152 households were interviewed.

### Findings

Both orphans and their caregivers can be grouped into several categories. The main categories of orphans are maternal orphans (those who have lost their mothers), paternal orphans (those who have lost their fathers), double orphans (both parents deceased), and 'virtual' orphans. The major categories of fosterers are widows and widowers, grandparents, young couples, and orphan household heads. Each category faces a unique set of challenges and constraints, discussed below.

### Categories of orphans

**Table 1. Orphans by deceased parent**

|  | PATERNAL ORPHANS | MATERNAL ORPHANS | DOUBLE ORPHANS |
|---|---|---|---|
| Total # | 453 | 118 | 161 |
| % of total | 61.88 | 16.12 | 22.0 |

*Source: AFXB records*

***Paternal orphans***

The following case study presents an example of how paternal orphans can effectively lose both parents when their father dies.

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**Case Study 8/22 - Katiiti Village**

This household was comprised of a widow and five of her grandchildren, all paternal orphaned siblings.
1.  Boy, 12 years old.
2.  Girl, 7 years old.
3.  Boy, 5 years old.
4.  Girl, 4 years old.
5.  Boy, 2 years old.

They had been orphaned for just over one year. The widowed grandmother was struggling to grow enough food to feed them all, and could not afford school fees.

The guardian reports that she has to take care of these children as she has lost all her sons to AIDS, and there is no other paternal family. The mother of these children is reported as being alive and well and living close by. However, she gives no support and has no contact with her children.

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**Table 2. Single orphans not living with surviving parent**

|  | PATERNAL ORPHANS | MATERNAL ORPHANS |
|---|---|---|
| Total # | 246 | 59 |
| % of total | 54.30 | 50 |

*Source: AFXB records*

Many paternal orphans in the study were found to be in a position where they could be regarded as 'virtual double orphans,' as they had lost both parents with the death of their father. In many cases this is the result of the tradition of patrilineage, which holds that children should be sent to paternal relatives immediately after their father's funeral. However, from interviews with guardians, a number of other factors that can cause 'absentee mothers' emerged.

➢ The mother may marry a new husband who refuses to adopt her children. His refusal could be justified by the custom of patrilineal descent, which gives the new husband some grounds to for arguing that the woman's children are someone else's responsibility. In such

cases there may be a period of 'second phase' orphaning for the children, first losing their father and then having to be fostered into another household at a later date, when their mother remarries.

➢ The paternal family may claim the children as theirs against the widow's wishes. Ugandan statutes should prevent this, but many people in rural areas are unaware of their legal rights or unable to enforce them.

➢ The widow may consider the children to be better off with other relatives, rather than living in a widow-headed household.

➢ The widow may have to go away in search of work and may be unable to take her children with her. In some cases this may be a temporary situation, ending with a reunion of children and mother at a later date.

➢ The widow may simply make a selfish decision to desert her children. In such cases the tradition of patrilineage makes it much easier for a mother to do so.

The Luweero study also showed that those paternal orphans who remain with their mothers are among the most vulnerable children of all, as they are left to survive in a widow-headed household. Life after the death of the household's breadwinner is often exceptionally difficult for widows and their children. Remarriage is made difficult if the widow is left with children in a society where, due to the tradition of patrilineal descent, men do not expect to have to foster children from another patrilineage.

If widows have retained their children, this is often a sign that there is no paternal family left to take on the orphans. Therefore extended family support is likely to be seriously diminished, if any exists at all. The following case study outlines the problems of a widow-headed household, and of paternal orphanhood.

**Case study 3/17 – Kabanyi Village**

The household head had been widowed for less than a year. She lived with her three paternal orphans.
1. 11 year old girl.
2. 3 year old boy.
3. A baby boy.

It is hard to comprehend how this family was surviving. They had only a small plot of land, about ten square metres, on which a few cassava plants struggled to grow in very poor quality soil. The three year old showed signs of extreme malnutrition, while the baby seemed barely alive at all. They had received a government hand out of 3 kg of flour the previous month, but had no idea what they would eat when this ran out.

The widow was unable to work, as she had lost all the fingers of both hands to leprosy. The 11 year old girl had dropped out of school, as there was no money for fees, but had been unable to find work outside the household. The 'home' was a tiny mud construction, just large enough for all of them to squeeze into at night.

The household was not receiving any assistance, from either the extended family or the local community. The widow said she felt 'totally defeated.'

*Maternal orphans*

While this study indicates that paternal orphans are the most vulnerable group of single orphans, maternal orphans should not be ignored by any orphan analysis. This research found that 50% of maternal orphans were living away from their father. Maternal orphans and their guardians face a range of serious problems. The loss of the mother causes emotional problems for her bereaved children, as well as for the father. The mother will also have carried out a number of tasks and performed many roles which will have to be undertaken by surviving members of the household. This may mean that children will have to take on greater responsibilities, perhaps affecting their abilities to study at school. It may also mean that the father will have to adjust his own work pattern to fill in the gaps left behind by his wife.

The following case study presents a typical pattern, in which a widower's livelihood changed as a result of losing his wife.

**Case study 6/9 - Butuntumala Village**

The household head had lost his wife a year before. He was left with five maternal orphans.
1 & 2. 10 year old twin girls.
3. 8 year old boy.
4. 7 year old boy.
5. 5 year old boy.

The father had been working as a driver, while his wife looked after cultivation and managed a small shop. After her death, he had to give up his driving job, which was much more lucrative than the shop, because it took him away from home for long periods of time. This was no longer possible because he had to look after his children on his own.

*Virtual orphans*

There were a number of children in the research area who, although not orphans according to the strict definition of the term, were subject to similar hardship as that experienced by orphans. The research found two categories of children who can be described as 'virtual orphans.'

First, there are those children who, although both parents are still alive, have been fostered by another household. Often these children were found in the care of grandparents who already suffered the strain of having fostered orphans. It was not always possible to ascertain the reason for this. In some cases, the children had been abandoned by parents who were still living. In other cases, it was reported that both parents were sick with AIDS. Thus, for many AIDS orphans the true point of orphanhood may occur *before* either parent has died.

**Table 3. Household occupants by age**

| ADULTS 18 yrs + | ORPHANS < 18 yrs | OTHER CHILDREN | TOTAL CHILDREN |
|---|---|---|---|
| 325 | 383 | 342 | 725 |

*Data from the field survey of 152 households*

Second, there are those children who live in households in which their own parents have fostered orphans. In the 152 households interviewed for this research there were 342 non-orphaned children living with the 383 orphans (see table 3 above). In the majority of cases there was no distinction between levels of care given to orphans and the care given to the guardian's own biological

children. All children in the household suffered the same economic effects caused by the increase in number of dependents in the household. Thus distinguishing between 'orphan' and 'non-orphan' children in the same household disregards the true impact of the orphan crisis, as many non-orphans are equally affected.

## Categories of fosterers

The constraints faced by widows and widowers have already been outlined in the sections on paternal and maternal orphans respectively. However it should be noted that many widows were found to have fostered other children, in addition to their own single orphans. The following tables show guardians by relationship with orphans, indicating a high prevalence of grandparent fostering.

**Table 4. Guardians who foster paternal orphans**

| | GRAND PARENT | SURVIVING PARENT | UNCLE/ AUNT | SIBLING | OTHER |
|---|---|---|---|---|---|
| # | 82 | 116 | 26 | 7 | 3 |
| % | 35.04 | 49.57 | 11.11 | 2.99 | 1.28 |

*Source: AFXB records*

**Table 5. Guardians who foster maternal orphans**

| | GRAND PARENT | SURVIVING PARENT | UNCLE/ AUNT | SIBLING | OTHER |
|---|---|---|---|---|---|
| # | 21 | 33 | 11 | 0 | 0 |
| % | 32.31 | 50.77 | 16.9 | 0 | 0 |

*Source: AFXB records*

**Table 6. Guardians who foster double orphans**

| | GRAND PARENT | SURVIVING PARENT | UNCLE/ AUNT | SIBLING | OTHER |
|---|---|---|---|---|---|
| # | 59 | 0 | 21 | 10 | 0 |
| % | 65.56 | 0 | 23.33 | 11.11 | 0 |

*Source: AFXB records*

## *Grandparents*

**Case study 6/29 - Butuntumala Village**

There are nine people living in this household. The household head is a 55 year old widow who has eight orphaned grandchildren living with her. One is a double orphan girl, 15 years old. The others are all maternal orphans whose father has deserted them and left them with his wife's mother.

The case study presented above is a typical example of the fostering burden faced by many elderly people in Luweero. Tables 4, 5, and 6 demonstrate the frequent occurrence of grandparent fostering.

Grandparent guardians and the children in their care face a number of serious problems. In rural Uganda, the elderly would normally expect their adult children to take care of them in old age. However, in areas where there is high AIDS mortality there are many cases of elderly people who not only outlive their children, but have to take care of their orphaned grandchildren. The problems for the orphans are many. Elderly guardians may not be capable of providing for either the emotional or material needs of their wards. Furthermore, if the guardians die before the orphans mature, those children will experience a second phase of orphanhood, which is demonstrated in the case study below.

**Case study 4/18 - Lusenke Village**

In this household the husband, 28 years, and wife, 22 years have four children of their own and have fostered a ten year old orphan boy.

He is a paternal orphan, nephew to the other children's mother. He was orphaned seven years ago, but has been in this home for two years. He was previously fostered by a grandmother who died when he was eight years old.

This highlights a large potential problem with grandparent fostering. This child has experienced two phases of orphanhood, first losing his parents, then losing his foster guardian. As numbers of grandparent fosterers increase, it is likely that this problem will increase in the future as well.

A major problem that occurs with grandparent fostering is the situation termed 'dependency regeneration:' the burdening of some households with a constant flow of young children to care for. The HIV/AIDS pandemic has had an especially profound effect on this situation, as it not only creates large orphan numbers, but robs many families of most adults in the traditionally non-dependant (15—50) age group. The following case study demonstrates dependency regeneration as a result of high AIDS mortality.

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**Case study 1/2 - Ggayaaza Village**

The household head is a man of 52 years, who lives with his 42 year old wife, and a total of 17 children.

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### Young couples

Younger married couples also have specific problems when having to cope with fostering. Often they will have less land, smaller houses, and fewer resources than more established families. This is typified by the case study below.

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**Case study 6/1 - Butuntumala Village**

In this household there are six people sharing a single room, rented within a large house. They are a young couple with a 3 year old girl and a 1 year old boy.

They have also fostered a 9 year old boy and a 7 year old girl. The husband is their paternal uncle;. Their father has died from AIDS, and their mother is ill.

The young family, too crowded in a single room, was planning to move to a larger home. Now, with older children in the room, the problems of crowding are much worse. However, the financial constraints of having to put these orphans through school mean that the family can no longer afford to move.

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Some cases were found where very young couples had taken on orphaned relatives before having any children of their own. Thus, they are faced with child care costs before starting their own family.

### Orphan household heads

Orphan-headed households are subjects of much attention in Uganda. However, although 5% of orphans in Butuntumala and Makulubita sub-counties were reported as in the care of either a brother or sister, only one of those visited during the field work was found to be headed by a sibling under 18. Nevertheless, this single case does demonstrate the problem that can occur when children are orphaned and there is no adult available, or willing, to take care of them.

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**Case study 3/18 – Kabanyi Village**

The head of this household is a 17 year old paternal orphan boy. He lives with his two brothers, 14 and 12 years old.

After their father died, ten years ago, their mother remarried, leaving the three brothers, then aged 7, 4 and 2 years, in her deceased husband's home, watched over by their grandmother who lives in the same village.

The older brother now works as a charcoal maker, and his younger brothers assist him in return for money for their school fees. However, they are rarely able to attend school because of the amount of work that they have to do, and the older brother, who was not able to go to school himself, wonders if the money would not be better spent elsewhere.

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Households in which orphans are fostered by adult brothers or sisters face several particular problems. Having to care for young dependents at the beginning of one's adult life may create difficulties in finding work, as travel may be impractical. Capital needed to establish a home, develop land, or fund income generating activities may be consumed for child care costs. The following case study demonstrates how the marriage of an orphan head of household creates a young family that already has four dependents.

**Case study 2/14 - Bamugolodde Village**

There are six people in this household, a 20 year old man, his 19 year old wife, and his four maternal orphan siblings. Although the father is still alive, he is too elderly to care for the children without their mother and so has left them with their adult brother. Thus, this young newly wed couple find themselves with four children.
1. 15 year old girl
2. 13 year old boy
3. 11 year old girl
4. 9 year old boy

This causes a number of problems, as the couple have only just married and were not expecting such a mature family so quickly. These problems could increase if the couple have children of their own.

## Conclusion

For the purpose of better understanding who orphans are and who cares for them in HIV/AIDS-affected communities, this study disaggregated both orphans and their guardians into several different groups. While all the groups face some similar challenges, each group also faces unique difficulties. It is hoped that the preceding analysis of these difficulties can inform the design of interventions intended to assist these groups.

The research revealed that one of the most vulnerable groups of orphans was paternal orphans, although they are not included in the UNAIDS definition of orphans. Paternal orphans constituted the majority of the study's orphan population, 62.74%. In the research area, paternal orphanhood often caused the loss of both parents to the child, as mothers had to leave their paternal orphans in the care of paternal relatives. In cases where paternal orphans remained with their mothers, they subsequently experienced the poverty of living in a widow headed household, and they sometimes lost inheritance rights.

Another group of at-risk young people excluded from the UNAIDS orphan definition is orphans aged 15 or over. This study found that the period of dependent childhood is often longer for orphans than for nonorphaned children. This is partly because of delays to schooling caused by

the initial stages of orphanhood, and may also be caused by the trauma of parent loss.

The Government of Uganda, for census purposes, defines orphans as all children below 18 years who have lost one or both parents. The definition includes paternal orphans as well as maternal and double orphans. Results of this study show this defintion to be much more appropriate.

This study found that poverty is exacerbated for many fostering households due to increased dependency ratios. In only two of the 152 households interviewed was any difference found between the way in which orphaned and non-orphaned children were treated. In each of the other 150 households, all children were treated the same, regardless of biological parentage or duration of stay. Therefore, the numbers of children living in orphan fostering households is a more accurate reflection of the true extent of the orphan crisis than the numbers of orphans alone.

In conclusion, those seeking to calculate the number of children impacted by HIV/AIDS would be well advised not to consider only those children defined as 'orphans' by UNAIDS. They should also include paternal orphans, orphans up to 18 years of age, and non-orphans who live in fostering households and thus suffer the same hardships associated with increased household dependency as orphans within the household.

If the UNAIDS definition is used to enumerate orphans in the research area, 279 children are identified. If the approach outlined above is utilized, the number rises to 1,386 AIDS-affected children: an increase by a factor greater than four. The programming and policy implications of this dramatic increase are far-reaching.

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# A mounting crisis:
## Children orphaned by HIV/AIDS in semiurban Ethiopia

## Marta Segu and Sergut Wolde-Yohannes

This is a preliminary report from a study examining the situation of orphaned children in Bahir Dar, a city of approximately 130,000 people in central Ethiopia that has been heavily impacted by HIV/AIDS. Using focus group discussions and in-depth interviewing, researchers gathered data from three groups:

- Orphaned children heading households (twenty children in four focus groups)
- Family and non-family adult caregivers of orphans (nineteen caregivers in five focus groups)
- Governmental and nongovernmental organizations that promote care for orphans (five organizations interviewed individually)

This report presents background to the study and initial findings of both the focus group discussions held with orphan household heads and the in-depth interviews with governmental and non-governmental organizations.

### The Ethiopian context

Ethiopia is one of the world's poorest countries, with a per capita income of US$120. According to the UNDP Human Development Report for 1997, Ethiopia is ranked 172 in the human development index of 174 countries. Life expectancy is only 43.3 years. Over the past three decades, Ethiopia has experienced a number of severe droughts and a prolonged civil war with Eritrea that resulted in extreme poverty in most parts of the country. The poverty that most Ethiopians face has been aggravated in recent years by the advent of the HIV/AIDS pandemic.

### The HIV/AIDS pandemic in Ethiopia

The sheer number of Ethiopians affected by HIV/AIDS is overwhelming. Since the start of the epidemic, an estimated 2.5 million people living in Ethiopia have been infected with HIV, i.e. one in every thirteen adults. In the most affected urban areas, the ratio of infection is closer to one out of every six adults and almost half of the HIV-infected people are women. The Ministry of Health had reported 51,781 cases of AIDS nationwide by the end of 1997. Officials admit that this number of cases is an underestimate and believe that the true number of cases was as high as 400,000 by the end of 1997.* The number and rate of infections have continued to rise.

In November 1999, it was estimated that Ethiopia had the 16th highest HIV/AIDS prevalence rate among sub-Saharan African countries. About 90% of reported AIDS cases are adults between the ages of 20 and 49. The peak ages for AIDS cases are 20-29 for females and 20-39 for males. Because of the country's high fertility rates (6.3 children per woman), the number of children born with HIV is very high. The government estimates that over 140,000 children are infected with HIV, giving Ethiopia one of the largest populations of HIV-infected children in the world.

There is growing concern about the number of children who are losing one or both parents to the disease. According to the Ministry of Health, in 1998 the country was home to almost 700,000 orphans. The majority of these orphans lost their parents to AIDS. This number of orphans is expected to reach 1.8 million by 2009.

### The impacts of HIV/AIDS on Ethiopian children and society

No statistics can adequately capture the human tragedy that orphans are facing in Ethiopia. For those children that have lost their parents to AIDS, grief is only the beginning of their troubles. When AIDS takes a parent, it usually takes a childhood as well. Children must witness death and suffering. The death of a parent threatens their psychosocial and physical well-being. Children lose love, affection, and nurturing. The loss of a father or both parents often results in loss of income and property rights.

Children who grow up without parents may be left impoverished and unprotected.

According to a 1999 address by the President of Ethiopia, the AIDS epidemic "undermines the efforts to build the country's economy and prevents the government from helping people to make a decent life. It deprives the children of their parents, the men and women of the country of their ability to care for their families, and the country of the enterprise and ingenuity of a whole generation."

## HIV/AIDS and orphans in Bahir Dar

Bahir Dar, capital of the Amhara Region, is located 570 km northwest of Addis Ababa. Bahir Dar, which literally means "by the sea side," is situated on the southern shore of Lake Tana, the source of the Blue Nile River. It is one of the most rapidly growing cities in Ethiopia, attracting many migrants due to the substantial tourist industry and the lack of economic opportunity in surrounding areas. The city is divided into 17 *kebele* administrative districts. Its current population of 130,000 lives in approximately 26,000 households.

Bahir Dar typifies the Ethiopian situation of HIV/AIDS and AIDS orphans**.** Based on government surveillance data, the Ministry of Health estimates the adult HIV infection rate of the city to be 13%. The office of the Labor and Social Affairs Department of West Gojjam Zone estimates that the adult HIV infection rate is 20%.

Estimates of the number of orphans supported by organizations in Bahir Dar vary from 278 to 620. This number represents a very small proportion of all orphans residing in the city. For instance, one organization estimates that the number of orphans living on the streets is 3,000. This number is far less than the number of orphans who live with caregivers or by themselves in orphan-headed households.

A representative of the Organization of Social Service for AIDS stated: "The number of orphans in Bahir Dar town is increasing…we and other organizations cannot reach the exact figure because of social and psychological factors…But we, as members of the community, know that many children have become orphans and abandoned because of HIV/AIDS."

*In these days, so many children in Bahir Dar die from lack of food and shelter. The city council has to arrange funerals of people found dead along the streets, and children constitute half of them.*

*Social Affairs Department official*
*Bahir Dar Special Zone*

The current health infrastructure of the city – one clinic, one health center, and one hospital run by the government – cannot meet the growing health demands of the population. Government social services, meager before the arrival of the pandemic, are now vastly overburdened and underresourced. Even the extended-family network, a social safety net that accommodated orphaned children for centuries, is unraveling under the strain of AIDS.

## Child-headed households

In many areas of Bahir Dar, the fraying of family safety nets is driving orphans to assume the role of head of household at a very young age. The focus group discussions revealed that children as young as eight years of age are taking care of their younger siblings. The following table shows the composition of the focus groups convened by researchers.

**Gender and age range of child household heads in focus groups**

| GROUP | M | F | TOTAL | AGES |
|-------|---|---|-------|------|
| 1 | 3 | 3 | 6 | 12-15 |
| 2 | 2 | 3 | 5 | 11-15 |
| 3 | 4 | 1 | 5 | 8-16 |
| 4 | 2 | 2 | 4 | 10-15 |

*Neighbors do not want us to join them…because we are identified as children whose parents died of HIV/AIDS and there is a rumor that we are infected with the virus…People talk about us negatively everywhere and we feel ashamed.*

*Orphan household head*
*Group 1*

Orphan household heads not only struggle with survival but also have to deal with grief, prejudice and social exclusion on a daily basis. The children interviewed were

constantly busy trying to meet the basic needs of their three to six siblings. Tasks for which they took responsibility included:

- doing household chores
- bathing siblings
- washing siblings' clothes
- supervising siblings' school attendance
- providing siblings with moral support
- steering siblings away from delinquent behaviors

> *My sister and I take care of our siblings by taking turns based on school shifts…We wash their clothes, we prepare food…and we advise them of the importance of living together in harmony with neighbors.*
> *Orphan household head*
> *Group 1*

All of the orphan heads of households who participated in the discussions were involved in petty trade activities to generate income for the family. The income generating activities varied according to gender. For males, the most common activities were those that took place on the city's streets: shining shoes and selling cigarettes, candies, sugar, chewing gum, and groundnuts. Girls usually generated income from activities that could be undertaken at home or in a local market: selling prepared spices, local beer, firewood, and food items including potatoes, tomatoes, and onions.

> *Sometimes when we are selling our goods, people disturb us and refuse to pay…then we quarrel with them to secure our money.*
> *Orphan household head*
> *Group 1*

In taking care of their siblings, orphan heads of households encountered a wide range of problems. The most common problems identified by focus group participants were:

- shortage of income to fulfill basic needs, including food and clothing
- obstacles to their and their siblings' attendance of school, including inability to pay school fees and purchase school materials and uniforms
- lack of access to health care
- stigmatization and rejection by community members
- lack of moral support
- lack of assistance with household tasks

> *We are used to sharing very small amounts of food…We usually give the large portions to the young ones. When there is no food at all, we miss meals.*
> *Orphan household head*
> *Group 3*

These orphans struggling to meet their families' needs sought supplemental support to enable them to care better for their siblings. However, they rarely received assistance from outside sources. The participants in the focus group discussions indicated that the following forms of assistance would be most helpful:

- payment of school fees
- provision of educational materials, including school uniforms and supplies
- counseling and moral support
- financial assistance
- vocational training and skills to help them support themselves

> *I know many people taking care of orphans…because we are so many that the government alone cannot help all of us.*
> *Orphan household head*
> *Group 4*

**Organizations promoting orphan care**

In-depth interviews were conducted with five organizations in Bahir Dar that provide or support care for orphaned children: three government departments, a church-based institution, and a NGO. The three government organizations were the Health Department of Bahir Dar Special Zone, the Labor and Social Affairs Department of West Gojjam Zone in Bahir Dar, and the Social Affairs Department of Bahir Dar Special Zone. The two nongovernmental agencies interviewed were the Bahir Dar Michael Orphanage (affiliated with the Ethiopian Orthodox Church), and the Organization of Social Service for AIDS.

All five organizations identified the same priority needs of orphans in Bahir Dar:

- limited financial resources
- shortage of housing
- difficulty attending school because of lack of funds for fees and materials
- inadequate access to health care
- lack of vocational and skills training
- lack of employment opportunities

In recent years, organizations in Bahir Dar have been shifting away from residential care for orphans and towards support of orphans in community-based settings. Only one of the five organizations interviewed, the Bahir Dar Michael Orphanage, provided residential care for orphans. However, recognizing that "we could not provide…the love and affection that a family provides to a child," the facility was emphasizing provision of "financial and material support to street children and orphans living with their relatives and by themselves in the community."

While each of the five agencies employed different approaches to assisting orphans and their caregivers, researchers found that their actions were guided by two common understandings. First, all the agencies agreed that the best way of responding to the orphan crisis was by helping the community to care for orphaned children. Michael Orphanage staff stated: "The organizations [currently] supporting orphans cannot solve even 1% of the problem. Ways in which orphans can be supported within their communities must be looked at...It is possible to enable the community to help the destitute of its own." Staff of the Organization of Social Service for AIDS stated: "The community should take care of orphans…of course the necessary support and facilities should be fulfilled for the community."

The government representatives expressed opinions similar to those of the NGO personnel. A representative of the Bahir Dar Special Zone Health Department stated: "Orphan children need many things apart from their health requirements. And these needs cannot be met by the efforts of a single NGO. It is better, I think, that the community itself care for them." The Bahir Dar Special Zone Social Affairs department concurred: "The problem [of orphaned children] requires the coordinated effort of all bodies…to this effect community-based programs should be designed."

The second understanding shared by all agencies was the recognition that the orphan crisis required a broadly inclusive, cooperative response. An official in the Social Affairs Department of Bahir Dar Special Zone stated: "The responsibility for taking care of the orphans cannot be given to a single organization or institution. It rather requires the integrated efforts and activities of all bodies. The problem is a social problem."

The Organization of Social Service for AIDS remarked: "All these [government and nongovernmental] organizations should work in close collaboration." Staff of the Labor and Social Affairs Department of West Gojjam Zone in Bahir Dar agreed: "Taking care of orphans is the joint responsibility of different parts of the system…it is expected that society should support its orphans."

**Conclusion**

The rapidly growing number of orphans in Bahir Dar is a cause of grave concern for individuals and organizations in Bahir Dar. The HIV/AIDS pandemic is creating a lost generation of children not only in Bahir Dar but across Ethiopia. An especially vulnerable group among orphans in Bahir Dar is children living in sibling-headed households. The organizations interviewed agreed that the best way to assist these and the thousands of other children made vulnerable by HIV/AIDS in Bahir Dar was through working together to help communities care for and support their children in need.

*\* All figures on national prevalence cited in this report are drawn from the Ethiopian Ministry of Health's Ethiopia HIV/AIDS 1998 Report and the 2000 report HIV/AIDS: The Situation in Ethiopia by Partners Against HIV/AIDS in Ethiopia.*

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# A looming crisis:
# Orphans in India before the impacts of HIV/AIDS

## Joana Chakraborty, Mellary Chrisstie, and John Zomingthanga

The Indian subcontinent is becoming a new epicenter for the HIV/AIDS pandemic. With the virus now spreading quickly through a population approximately double that of sub-Saharan Africa, India will soon be facing a calamity of disastrous proportions. Concern is growing in the region and the world about how India, a regional superpower with nuclear weaponry, will cope with the instability and insecurity that AIDS and its impacts may engender.

India seems to be in the stage of the pandemic's evolution in which eastern and southern Africa found themselves a decade ago: HIV prevalence rates in many areas are already high and rising rapidly, but the impacts have not yet begun to emerge fully. The heavily affected countries of Africa are reaping the bitter harvest of their failure to act decisively ten years ago: millions of adults are falling ill and dying, and millions of children are being orphaned. Unfortunately, India is likely to suffer the same consequences in the decade to come, and for many years thereafter.

To establish a baseline for subsequent research, AFXB commissioned three studies of the number and conditions of Indian orphans in the early stages of the pandemic's development. The studies were conducted in early 2000 in three very different parts of India: rural villages in Rajasthan, in the northwest corner of the country; the medium-sized town of Aizawl, capital of the northeastern state of Mizoram; and Calcutta, an enormous city in eastern India. This article summarizes the findings of these studies.

### RAJASTHAN

Rajasthan is a predominantly rural state of some 50 million people, situated on the Pakistani border. India's National AIDS Control Organization reports that its HIV prevalence is low relative to other states. A large proportion of Rajasthan's highly illiterate population migrates to other areas of India in search of employment.

In Rajasthan, researchers conducted surveys in two rural areas: one outside Jaipur and the other near Jodhpur. In the first village, fifteen of the 825 households interviewed had lost a father only. No households surveyed had lost a mother or both parents. The major causes of death among fathers were asthma, heart attacks, cancer, and tuberculosis. It was unclear whether HIV had caused any deaths.

In the second village, three of the 200 households interviewed had lost one parent. One household had lost both parents. Cancer was the major cause of death in this village.

Overall, orphaning rates seemed to be low in rural Rajasthan. Those children who were orphaned had been absorbed into the households of extended family members. The studies suggest that there is still time for Rajasthani society to prepare for the orphan burden to come.

### MIZORAM

Mizoram is one of the smaller Indian states, with a population of approximately 700,000. It neighbors Manipur, a state with among the highest HIV prevalence rates in the country. Mizoram shares a border with Burma/Myanmar. Drug trafficking and drug abuse are major problems in Mizoram, due partly to its proximity to poppy-producing areas.

The Mizoram study was conducted in the state capital, Aizawl, a town of approximately 200,000 people. The city has five orphanages, accommodating fewer than 500 children. By examining records and interviewing staff, the researcher collected data on orphans at the two largest orphanages: one with a capacity of 180, and another with a capacity of 250. Data were collected on a total of 130 randomly

selected orphans: 70 males and 60 females.

**Table M1. Age groups of orphans**

| AGES | # | % |
|---|---|---|
| 5 years and below | 14 | 10.8 |
| 6 to 10 years | 37 | 28.4 |
| 11 to 14 years | 79 | 60.8 |

**Table M2. Place of birth of orphans**

| PLACE OF BIRTH | # | % |
|---|---|---|
| Outside Mizoram* | 23 | 17.7 |
| Mizoram urban | 40 | 30.8 |
| Mizoram rural | 65 | 50 |
| Unknown | 2 | 1.5 |

*Includes Burma/Myanmar and neighboring Indian states*

Most of the orphans about whom information was secured were 11 to 14 years of age. Only about 11% were 5 years old or less. Exactly half of the study population came from rural Mizoram. Another third came from urban Mizoram. Almost 1 in 5 orphans came from outside of Mizoram state. They originated in both Burma/Myanmar and other Indian states.

**Table M3. Duration of stay in orphanage**

| DURATION OF STAY | # | % |
|---|---|---|
| Over 10 years | 0 | 0 |
| 6 to 10 years | 48 | 36.9 |
| 1 to 5 years | 73 | 56.2 |
| Less than 1 year | 9 | 6.9 |

The majority of the orphans in the sample had lived in the orphanages between 1 and 5 years. Slightly more than one-third had stayed for 6 to 10 years. Only 7% had been living in the orphanages for less than a year.

**Table M4. Reasons for admission to orphanage**

| REASONS FOR ADMISSION | # | % |
|---|---|---|
| Loss of parents | 33 | 25.4 |
| Born out of wedlock | 19 | 14.6 |
| Divorced parents | 61 | 46.9 |
| Extreme poverty | 9 | 6.9 |
| Unknown | 8 | 6.2 |

Surprisingly, only one in four children were living in the orphanages because their parent/s had died. Some 47% had been placed in the institutions following their parents' divorce. Another 15% were in the orphanage because they had been born out of wedlock. It seems that the orphanages in Aizawl were being used as 'dumping grounds' for children who were inconvenient, stigmatized, or very poor.

**Table M5. Children's age at time of parent's death**

| CHILDREN'S AGE | # | % |
|---|---|---|
| Less than 1 | 8 | 24.2 |
| 1 to 5 years | 21 | 63.6 |
| 6 to 10 years | 4 | 12.2 |

**Table M6. Causes of parental death**

| CAUSE OF DEATH | # | % |
|---|---|---|
| Known | 14 | 42.4 |
| Unknown | 19 | 57.6 |

Of the 130 orphans in the sample, only 33 had been placed in the orphanage because of parental death. The researcher was unable to determine from the incomplete records available if one or both parents were dead. About two-thirds of the children had been orphaned between their first birthdays and their sixth. Another quarter had been orphaned before the age of one. Records revealed the causes of only 14 of the 33 parental deaths. The major causes found were cancer, jaundice, and accidents.

**Table M7. Parental problems leading to placement in orphanage**

| PARENTAL PROBLEMS | # | %* |
|---|---|---|
| Alcohol | 29 | 22.3 |
| Drugs | 5 | 3.8 |
| Alcohol and drugs | 2 | 1.5 |
| Mother is sex worker | 3 | 2.3 |
| Mother mentally unsound | 10 | 7.7 |

*% of all orphans in sample*

The researcher discovered that at least 49 of the orphans in the sample had at least one parent with a problem that could inhibit the parent's ability to care for the child. More than a quarter of the children had a parent with a substance abuse problem – addiction to drugs, alcohol, or both. Ten of the children had mothers who were declared mentally unstable. Three of the children had mothers who were sex workers.

The data from this study of children in two Mizoram orphanages is not adequately

systematic or representative to allow extrapolation. However, it raises important questions. Why are so many children in orphanages not 'orphans' in the stricter senses of the term? Why are so many children being institutionalized instead of being absorbed into the extended family? What are the consequences for children and society of high rates of substance abuse? Finding answers to these questions can help Mizoram prepare for the large increase in rates of orphaning and numbers of orphans that will follow the spread of HIV/AIDS.

## CALCUTTA

The city of Calcutta is known around the world for the desperate poverty of its streets and slums. Calcutta is the capital of the state of West Bengal, which borders Bangladesh. The city's population, currently more than 12 million, continues to grow as migrants arrive from neighboring villages, states, and countries. Today, before HIV/AIDS has begun to orphan children at large scale, many thousands of orphaned children already live on Calcutta's streets.

The study conducted in Calcutta sought to investigate the reasons that orphans ended up on the street and the conditions of their lives there. Researchers conducted interviews with 700 children from a 'privileged' subgroup of Calcutta's vulnerable children: children who were working. A separate study surveying street children without a source of income – the vast majority of children on Calcutta's streets – is underway.

### Living conditions of the street children

It was observed that many street children in Calcutta suffer from malnutrition and ill health. They are extremely vulnerable to abuse and exploitation. Many of these children spend all day on the street. They sleep by themselves or with other children in small shacks called 'jhupries,' in empty sewer pipes, in garbage dumping sites, in railway stations, or on open land. A fortunate minority are able to return to the slums around Calcutta to spend the night.

Girls living on the street are in an especially difficult situation. There is no facility for

regular bathing. While many of them have attained puberty, the majority of them do not have access to toilets or restrooms. Many do not have access to health care. Very few male or female street children receive treatment of any sort when they are sick.

### Findings

These findings are based on the 150 surveys analyzed to date from the 700 total surveys conducted. Table C1 presents the demographic profile of the children interviewed. Some 58% of these children are between the ages of 11 to 13 years; 41% are 14 years old. Approximately 77% of them are male, and 23% are female.

The overrepresentation of males can likely be explained by the state education policy which affords free mandatory schooling to girls through secondary school, but does not do the same for boys.

**Table C1. Demographic data (total #150)**

|  |  | # | % |
|---|---|---|---|
| **Age** | 14 years | 62 | 41 |
|  | 11-13 years | 87 | 58 |
|  | 9-10 years | 1 | 1 |
|  |  |  |  |
| **Gender** | Male | 115 | 77 |
|  | Female | 35 | 23 |
|  |  |  |  |
| **Religion** | Hindu | 125 | 83 |
|  | Muslim | 25 | 16 |
|  |  |  |  |
| **Place of Birth** | Calcutta | 139 | 93 |
|  | Outside Calcutta | 7 | 5 |
|  | Bihar, Bangladesh Sri Lanka, Nepal or Unknown | 3 1 | 2 <1 |

Nearly all of these children (93%) were born in Calcutta. Almost all of them have been living in Calcutta since birth. However, most have lived in different locations in the city. Table C2 shows that 69% have lived in the same location for only 2-3 years, 21% for 4-5 years, and only 1% of them have lived in one place for six years or more. The majority of the children in the sample (59%) have 3-5 siblings, 21% have 1-2 siblings, and 15% have no siblings.

**Table C2. Length of stay in Calcutta and siblings**

| | QUESTIONS | # |
|---|---|---|
| | | |
| 1. | **How long living in Calcutta?** | |
| | a. since birth | 139 |
| | b. more than 5 years | 10 |
| | c. less than 5 years | 1 |
| | | |
| 2. | **Living in same location?** | |
| | a. 2-3 years | 103 |
| | b. 4-5 years | 32 |
| | c. more than 6 years | 15 |
| | | |
| 3. | **How many brothers and sisters?** | |
| | a. 0 | 22 |
| | b. 1-2 | 33 |
| | c. 3-5 | 88 |
| | d. 6 or more | 7 |

**Table C3. Information regarding parents**

| | QUESTIONS | # |
|---|---|---|
| | | |
| 1. | **When father died?** | |
| | a. alive | 48 |
| | b. not known | 14 |
| | c. 1-2 years | 17 |
| | d. 3-5 years | 65 |
| | e. more than 6 years | 6 |
| | | |
| 2. | **When mother died?** | |
| | a. alive | 12 |
| | b. not known | 10 |
| | c. 1-2 years | 29 |
| | d. 3-5 years | 92 |
| | e. more than 6 years | 7 |
| | | |
| 3. | **How father died?** | |
| | a. cardiac problem | 17 |
| | b. accident (car/bus) | 17 |
| | c. TB | 18 |
| | d. liver problem | 17 |
| | e. not known/ alive*/other | 81 |
| | | |
| 4. | **How mother died?** | |
| | a. accident (car/bus) | 16 |
| | b. TB | 14 |
| | c. malaria/fever | 35 |
| | d. cancer | 35 |
| | e. suicide/killed | 12 |
| | f. not known/ alive*/other | 38 |

*45 fathers and 12 mothers are alive, but abandoned the children*

Table C3 indicates that many children were abandoned by their fathers and/or by their mothers. Out of 150 children, 45 fathers left their children. Three fathers are living on the sidewalk or in a slum and are raising their children. These fathers earn their living by begging, rickshaw pulling, and running a street side stall, respectively. They have not remarried. Some 8% of the children were abandoned by their mothers. Remarriage or new girlfriend/boyfriend were the major causes of child abandonment.

Major causes of death among the fathers were cardiac problems (11%), accident (11%), TB (12%) and liver problems (11%). Causes of mothers' deaths included cancer (23%), malaria/fever (23%), accident (11%), TB (9%), and suicide/killed (8%). Less than 2% of mothers died of cardiac, neurological, liver, or gynecological problems.

Table C4 shows that some 29% of the children interviewed live with their relatives. About 22% live at their work place and 28% live in the slums or on the sidewalk. None of them are currently going to school; 47% of them went to school previously. Interestingly, 47% of these children do not suffer from chronic illnesses. Approximately 16% suffer from respiratory problems, followed by dermatological (13%), ear/nose/throat (11%),and orthopedic (5%) problems.

**Table C4. Living conditions/ health problems/education**

| | QUESTIONS | # |
|---|---|---|
| | | |
| 1. | **Live with?** | |
| | a. Relative (2 w/ father) | 44 |
| | b. Employer | 24 |
| | c. Mosque | 6 |
| | d. Workplace | 33 |
| | e. Other (Slum/Sidewalk) | 43 |
| | | |
| 2. | **Ever gone to school?** | |
| | a. Yes* | 70 |
| | b. No | 80 |
| | | |

*None currently go to school.*

All of these children work. Many girls are employed as maid servants or babysitters. The 13-14 year old boys tend to work at the car/cycle repair shops, tea stalls, markets

and sweet shops. Table C5 presents the different types of work in which the children are involved.

**Table C5. Work of children**

| WORK PLACE | # |
|---|---|
| Baby sitter/servant | 22 |
| Car repair shop/ cycle repair shop | 18 |
| Tea stall | 18 |
| Food stall/market | 13 |
| Meat shop/ fish market | 13 |
| Sweet shop | 11 |
| Grocery shop | 5 |
| Sweeper | 4 |
| Nut stall/potato chip sales | 8 |
| Restaurant/ canteen | 6 |
| Vegetable vendor | 7 |
| Miscellaneous | 25 |

*'Miscellaneous' includes: newspaper sales, rickshaw puller's helper, garment shop, shoe shining, haircutting, sales assistant, cleaner, and assistant to restaurant cook.*

This study found that 29% of the children interviewed lived with their relatives. They most often live with grandparents or uncles. Girls in the sample were more likely to stay with their relatives than boys, who became independent at an early age (11-14 years).

The majority of children interviewed were sleeping either on the streets, with their employers, or in the workplace. The researchers surmise that the large number of children living on the streets is due partly to the lack of an intact extended family network. Many of the residents of Calcutta are migrants from other parts of India. When adult residents die, their children lack the relatives that children in more rural and traditional areas could turn to.

The researchers were surprised to discover that abandonment rates were quite high among this population. Discussions with Calcutta residents suggest several reasons for this. When a parent dies, the other parent may feel unable to cope with the family pressure and poverty and may consequently choose to eschew responsibility. Mothers sometimes leave their children to be with men who offer a promise of better living. Also, some children

run away to avoid abuse by the stepfather or stepmother.

## HIV/AIDS and orphans in Calcutta

Due to lack of data, it is not possible to evaluate whether HIV/AIDS has yet increased the number of orphans in Calcutta. It is clear that the HIV/AIDS pandemic is in an early stage in Calcutta.

A project carried out by India's Ministry of Social Welfare from 1988-1992 profiled street children in ten cities in India. They estimated that out of 10.86 million people then residing in the city of Calcutta, there were 75,000 to 200,000 children living on the street. Eight years later, agencies working to assist orphans in Calcutta agree that this number is already much higher. The number of children on Calcutta's streets will rise even more rapidly in the years ahead, as HIV/AIDS takes the lives of many thousands of parents.

## CONCLUSION

The studies conducted in Rajasthan, Mizoram, and Calcutta indicate that children are not yet being orphaned by HIV/AIDS on a large scale. However, the Mizoram and Calcutta studies demonstrate that the problem of orphans in some areas of India is already severe.

A window of opportunity for action against AIDS and for orphans is open. It is the critical responsibility of the Indian government, Indian business, Indian civil society, and their allies in the global community to take advantage of this window, before the swelling tidal wave of AIDS crests and falls on the sub-continent. Effective joint action to prevent further spread of HIV/AIDS and to help families and communities to assist orphaned children is urgently required.

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# Transitioning from institutional care of orphans to community-based care:
## The experience of Ethiopia's Jerusalem Association Children's Homes

### Mulugeta Gebru and Rebecca Atnafou

Jerusalem Association Children's Homes was founded in 1985 as an indigenous NGO in response to the needs of Ethiopian children who were orphaned by civil war, drought, and the resulting famine of 1984. JACH established four residential institutions for children during the height of the orphan emergency in the 1980s.

In 1996, JACH made the decision to transition from institutionalized child care to community-based care. Guided by a six-year strategic plan for the transition, JACH has shifted its focus to promoting child-focused, sustainable development in communities near JACH children's homes.

## Why de-institutionalize orphan care?

A number of JACH's experiences during its first ten years of caring for orphans contributed to the 1996 decision to de-institutionalize. As the years passed and the children in JACH homes grew, JACH staff observed that the children had little knowledge about their society and the world at large due to their lack of exposure to community life. Many orphans felt alienated from their nonorphaned classmates. Some orphans exhibited aggressive behavior in school, partly because they were labeled as orphans and mocked by other students.

Children who had grown up in the institutions had little trust of others and limited knowledge of social norms and values. When they 'graduated' and left the institutions, many of the orphans had a difficult time sustaining themselves because they had no networks of family and community on which to rely and inadequate coping skills for 'real world' challenges.

In addition, the costs of residential care were high. JACH staff recognized that the organization could assist many more orphaned children if it employed alternatives to institutional care. In light of the huge number of children projected to be orphaned

by HIV/AIDS in the late 1990s and thereafter into the 21st century, JACH became convinced that it was imperative to shift to a community-based approach.

## The process of de-institutionalization

JACH's board and management consulted with local authorities and with JACH's partner organizations to develop a strategic plan for de-institutionalization. One of the earliest elements of the plan was enabling children to travel to their birthplaces during school holidays to trace their families and relatives. Older children accompanied the younger children on their trips. Children were encouraged to visit marketplaces, churches, and other sites where large numbers of people congregate to begin their search. The children documented their findings on a form provided by JACH.

This approach was remarkably successful in reuniting children with families. Of 1,000 orphans, some 285 children found families and relatives. Twenty-five children even found biological parents who had no idea that their children were alive. In some instances, foster parents, a new concept in Ethiopia, agreed to accept the children. All families were provided with a grant of 2,000 birr (equivalent to US$250) to cover resettlement costs for the reunified child. (In contrast, it cost over 5,500 birr per year to care for a child housed at JACH). Reunified children were assigned JACH social workers to monitor their adjustment in their new families.

While the younger children were receptive to the idea of reunification, most of the orphans aged 15 and over wanted something different: independent living as self-reliant citizens. An earlier attempt to enable the older children to become self-supporting by setting up small income generating projects for them was deemed a failure because the young people were not involved in formulating the projects. JACH used a new

approach instead: orphaned youth were given responsibility for developing their own ideas for becoming self-sufficient. They were encouraged to spend time at area markets, shops, and workshops, learning about business and trades and discovering opportunities. JACH assisted the youth in developing business plans and provided a startup grant for youth with viable proposals.

Another approach that JACH used to improve older orphans' abilities to support themselves was arranging apprenticeship training for orphans interested in metal works, auto mechanics, hair care, photography and other trades. Following their apprenticeship, the youth received a small grant from JACH to start their own business. In addition, agricultural training was provided at JACH homes for all interested children. Finally, JACH provided financial support to youth choosing to pursue higher education. Overall, this multi-pronged strategy was successful in guiding older orphans to independent living.

### Challenges of de-institutionalization

The proposed plan for de-institutionalization was met with resistance from staff, children, and donors. Middle management and support staff were concerned about job security. The children were uncomfortable with the prospect of venturing into the unknown world. An additional challenge was the lack of sufficient funds to operate the program as envisioned.

JACH's leadership faced the challenges head on. It was convinced that staff themselves had to be transformed into change agents who understood and supported the shift. Frequent discussions with staff were conducted, presenting strong arguments that reintegration of children into communities was in keeping with Ethiopian culture and religion and with Ethiopian traditions of raising children in an extended family setting. Over time, JACH was able to garner the support of staff.

The children living in JACH houses were apprehensive about the prospect of leaving the institution. They were uncertain what lay beyond the institution's walls and feared the unknown. JACH worked to help the children

understand that orphanages are artificial homes, far removed from mainstream life. Staff discussed with the children how residing in orphanages deprives them of the vital opportunities for socialization which enable them to survive and succeed in their adult lives. Children were encouraged to embrace the opportunity to learn about their roots and their identity. The children too eventually understood and accepted the de-institutionalization initiative.

Donors were initially not convinced that the concept of de-institutionalization was viable, and thus limited their contribution to this effort. However, after observing the positive outcomes of the early stages of the reunification and reintegration processes, donors made additional funds available to support de-institutionalization.

### Next steps

To date, JACH has reunified and reintegrated 810 children. The success of de-institutionalization has allowed JACH to close one home. Only 190 children reside in the three remaining homes. No additional children are accepted into these homes. In the near future, JACH plans to reintegrate all the children and close all the homes.

The need for orphan care has grown again in recent years because of the resurgence of conflict with Eritrea, drought, famine, and the HIV/AIDS crisis. JACH is working with communities in both rural and urban areas of the country to facilitate community development and to reinvigorate traditional mechanisms of caring for orphans.

JACH is sharing its experience of de-institutionalization through a national network of organizations working in support of orphans. A number of Ethiopian orphanages are beginning to follow JACH's example. The national effort to shift from institutionalized child care to community-based care is gathering momentum.

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# The potential of networks of child-focused organizations:
## *The experience of Zambia's Children in Need Network*

## Louis Mwewa

The HIV/AIDS pandemic has generated problems that are affecting everyone in Zambian society. Among those who are suffering most are the hundreds of thousands of children who have lost one or both of their parents to the disease. As the rates of dying and orphaning accelerated rapidly in the early 1990s, Zambian organizations working to assist vulnerable children found themselves facing unprecedented challenges.

In 1993, a small group of child-focused organizations began meeting informally to share ideas and to discuss ways of bringing the orphan crisis to the forefront of the nation's attention. This group called itself the Children in Need Network (CHIN) and established a secretariat with three full-time staff members in 1996.

The members of CHIN jointly defined the mission of the network: enhancing members' ability to strengthen communities' and families' capacity to promote and protect the welfare of children in need. Members decided that the network would focus on three groups of vulnerable children in Zambia: street children, abused children, and orphans, particularly those whose parents were killed by HIV/AIDS.

Today the membership of CHIN includes more than seventy community-based organizations and nongovernmental organizations, as well as two government departments. Membership remains open to any Zambian organization concerned with child affairs. Recently, CHIN has begun to facilitate development of provincial networks to complement the national network.

### The work of CHIN

CHIN employs several strategies to pursue its mission. First, the network gathers and disseminates information about the approaches and activities of its member organizations and other NGOs and CBOs working with children in need.

CHIN facilitates forums at which member organizations have the opportunity to share experiences and learn from one another. CHIN also arranges for exchange visits among organizations, seeking to enable organizations to learn from other groups' best practices of care and to replicate their successes. CHIN's newsletters allow members to exchange views and insights.

Second, the network provides training and educational materials to member organizations and other groups involved with children. Past trainings have built member organizations' knowledge of and skills in psychosocial counseling and mobilizing communities to assist children in need. The CHIN office in Lusaka includes a resource center with a wide range of materials discussing care for vulnerable children, from Zambia and beyond.

Third, CHIN strives to raise awareness of the needs and rights of vulnerable children, and to advocate on children's behalf with government and other stakeholders in society. CHIN works with its member NGOs and CBOs to develop a joint policy agenda and to advocate and negotiate collectively for that agenda.

### The benefits of networking

In our experience, the networking facilitated by CHIN has been very beneficial both to member organizations and to Zambian children. Before the network was created, most child-focused organizations worked in isolation. They knew little about one another, and they were little known at national level. Their individual voices were not strong enough to attract society's attention. CHIN provided a platform on which these organizations could unite and speak as one. The network's purposeful advocacy and lobbying campaigns have proved effective: today issues of vulnerable children feature prominently on the national agenda, and the work of many of CHIN's members is known countrywide. The

Zambian government is now actively involved with CHIN and seeks to draw on the experiences of CHIN's NGO and CBO members to refine policy and to improve service provision.

Through its information gathering and dissemination activities, CHIN has helped to ensure that consistent information is provided to Zambian organizations and communities. Joint research studies have provided valuable resources to members. Contacts among members have led to enhancement of referral systems for child and family support. Improved coordination among members through CHIN has reduced duplication of services. Membership in the network has also raised the profile of many CBOs and NGOs and broadened their exposure to potential supporters.

CHIN's efforts to promote exchange of experience among members have allowed members to learn from one another. Network members have used the lessons they have learned through exchange visits, discussion forums, and other measures to improve their assistance to children in need.

### Constraints on networking

As it has developed, CHIN has encountered a number of constraints on networking. In early years, some smaller CHIN members felt threatened by larger members and by the network itself. At times, some network members have been less committed than others. Other members seemed to become dependent on the network for direction.

CHIN has sought to overcome these constraints by continually emphasizing that CHIN exists to advance members' interests, and by reinforcing that CHIN's role is not to replace members but to serve them and to build their capacity. CHIN holds annual general meetings at which members make decisions about the priorities and directions of the network. CHIN's managing board is comprised of representatives of member organizations, elected by the members themselves. At CHIN's quarterly meetings, every member has the opportunity to speak. Also, CHIN has arranged for smaller members to visit larger members, in order to become familiar with one another's work and

to reduce the smaller organizations' discomfort.

The greatest constraint CHIN has faced is a shortage of funds. Funding initially came solely from UNICEF, and now is supplemented by two European organizations. However, resources mobilized to date have not been sufficient to enable CHIN to realize its full potential.

### The way ahead

The formation of CHIN was catalyzed by a recognition among child-focused organizations that the HIV/AIDS pandemic required a concerted response. The network has now united nearly every organization in the field of child welfare. The members of CHIN have found networking mutually beneficial and substantially useful in responding to the pandemic.

But all CHIN's members together are able to reach only a fraction of the children who are suffering because of HIV/AIDS crisis and the poverty that it aggravates. In the years ahead, the network hopes to help many more organizations in Zambia and abroad to become involved in supporting families and communities caring for the country's orphans and other children in need.

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# Qualities of effective community activists for orphans:
## *The experience of the COPE program in Malawi*

## Stanley Phiri

Common sense and pan-African experience tell us that the most affordable and sustainable strategies that outsiders can use to address the AIDS orphans crisis are strategies that help communities to help their neighbors in need. Recognizing this, the COPE (Community-based Options for Protection and Empowerment) program in Malawi and similar efforts in other heavily AIDS-affected areas have been working to develop ways of building community capacity to cope with the human consequences of the HIV/AIDS pandemic: the adults who fall ill and the children that they leave behind.

In essence, COPE and similar programs work to help community members to come together and help one another better. These programs build on efforts that are already underway in the community, seeking not to supplant but to support and strengthen the good work communities are already doing.

Our typical discussions of these programs are technocratic. We talk about structure and strategy, intervention and implementation, inputs and outputs and outcomes. Too often, we fail to acknowledge that, above all else, every program is powered by people. At the core of these programs are caring community members.

In my work, I have been continually impressed and inspired by the commitment of community members involved in care initiatives. These community activists share their time, their energy, and even their meager resources with those in the community who are suffering. The AIDS crisis, as it plunges communities into the worst of times, seems to bring out the best in people.

I have been fortunate to work with another group of activists dedicated to helping community members in their remarkable efforts. These 'other' activists are the community mobilization staff of the COPE program. It is their job to catalyze and strengthen community care initiatives. For most, it is also their vocation and passion. They come from many backgrounds – health workers, social workers, small enterprise specialists, even town administrators. The best of them share a number of traits with the community activists with whom they work. In this article, I have tried to identify the most important of these traits.

The following list attempts to describe the qualities that are vital for activists who promote the care of orphans and all those made vulnerable by the HIV/AIDS pandemic. These qualities characterize both activists in communities and activists in organizations working with communities.

➢ *A gift to lead with the heart.* An effective activist should possess a genuine love for human beings, deep empathy and respect for people, a sense of commitment, the strength and humility to admit s/he does not have all the answers, a willingness to learn, and an appreciation for the long-term view guided by optimism.

➢ *People skills.* An effective activist needs the abilities to communicate her/his vision effectively, to create an environment where members can interact openly and supportively with each other, and to identify and extract the natural abilities and strengths of others by accentuating their positive attributes while working with them on their weaknesses in a supportive manner.

➢ *Understanding of why communities resist change and how to overcome resistance.* An effective activist should work at the pace of the community, while seeking to maintain the momentum of the process. An activist must be patient, resourceful, creative,

confident, and persistent with the community, to build credibility and trust.

➢ *Recognition of the fact that an activist is a role model in the community.* An effective activist behaves appropriately and consistently with the messages s/he is trying to convey. For example, if an activist is advocating proper care of orphans and respect for children's rights, s/he should be demonstrating this with her/his own children.

➢ *A good sense of humor.* Building community capacity is a slow process and many times unexpected events will deter progress. An activist should be flexible, take situations as they come, and laugh often.

Two additional qualities should be sought and nurtured in activists working in communities other than their own:

➢ *Commitment to understanding and respecting the community and its culture.* To build the trust necessary for a positive working relationship with a community, an activist should both understand and respect the accepted cultural, religious, and other traditional values and practices of the community.

➢ *Commitment to playing a background role and ensuring that community members take the lead.* External involvement should not foster dependence or quash community motivation. Instead, an activist must ensure that all initiatives are fully owned and led by the community. At no point should an activist decide to 'take over' or push an agenda. The role of an external activist is not to direct action or make decisions. Rather, the role of an external activist is to facilitate a process through which the community starts and sustains the action prioritized by the community as necessary to assist orphans and other community members.

To supplement the set of characteristics above, I would like to offer a list of attributes of effective external activists developed by COPE's community mobilization staff.

### Personal Qualities

➢ Patience
➢ Commitment to work hard
➢ Sense of belonging to the community
➢ Trustworthiness
➢ Confidence
➢ Confidentiality
➢ Cheerfulness
➢ Genuine kindness and concern
➢ Respect for all people
➢ Empathy
➢ Love for human beings

### Professional Skills

➢ Motivation skills
➢ Planning skills
➢ Facilitation skills
➢ Skills in adult education techniques
➢ Knowledge of the community's language

The severity of the HIV/AIDS crisis challenges us all to become activists in support of communities that are hard hit by the pandemic. The millions of children in Malawi and across Africa who have been orphaned need our commitment and action. I hope that we can all learn from the courage, resourcefulness, and resilience of communities who are bearing the brunt of this crisis.

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