

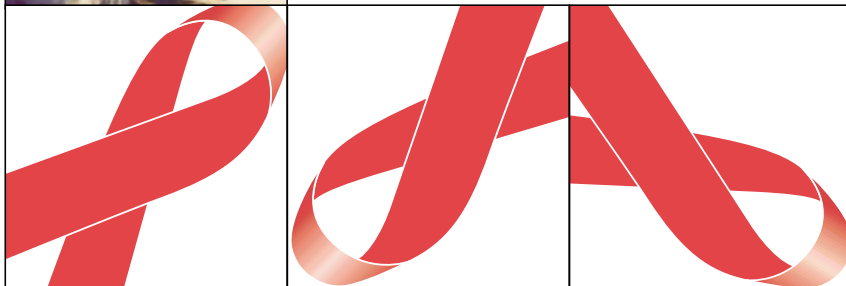


# Investing in Our Future



## Psychosocial Support for Children Affected by HIV/AIDS

*A Case Study in Zimbabwe and  
the United Republic of Tanzania*



Joint United Nations Programme on HIV/AIDS  
**UNAIDS**  
UNICEF • UNDP • UNFPA • UNDCP  
UNESCO • WHO • WORLD BANK



**UNAIDS  
Case Study**

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Photo:

*After his experience abseiling, Crosby demonstrated his new-found  
self-confidence in other situations: even blindfolded he could trust in the  
other children.*

Photographs: Gisele Wulfson and Susan Fox

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Gratitude and appreciation is expressed to the children for expressing themselves; the caregivers and organizations for sharing their time and resources; the offices of UNAIDS and UNICEF and the government agencies of Zimbabwe and the United Republic of Tanzania for their logistical support and cooperation in the undertaking of this study.

Acknowledgement is also provided to Maria Ndlovu, translator, guide and counsellor extraordinaire in Zimbabwe and William Rugaimukamu and James Kajuna in the United Republic of Tanzania.

### **In Zimbabwe:**

Farm Orphan Support Trust  
Island Hospice  
Masiye Camp  
ChildLine  
The Centre  
Mashambanzou

### **In the United Republic of Tanzania:**

HUMULIZA  
AIDS NGO Network of East Africa  
(ANNEA)  
African Women AIDS Working Group

## Dedication

This report is dedicated to all young AIDS Ambassadors,  
especially Nkosi Johnson of South Africa,  
who lived with the virus for 12 years  
and worked tirelessly and selflessly to improve  
the lives of millions of children and adults living with HIV/AIDS.



*Nkosi Johnson*

**“The future of any nation is directly linked to the future of its children – and by investing in children and in the families that sustain them, a nation is ultimately investing in its own development.”**

Carol Bellamy, Executive Director, UNICEF, speech at the release of *The State of the World's Children 2001*, New York, December 2000

## Foreword

The magnitude of the epidemic has highlighted in stark colours the needs of orphans and vulnerable children. By the end of 2000 36.1 million people were estimated to be living with HIV/AIDS, of whom 34.7 million were adults. Africa is home to 70% of these adults. Many of these adults, because of the ages of those most vulnerable to HIV infections, are also parents. In one year alone, 2000, 2.5 million adults died of AIDS.

Coping with the cumulative impact of over 17 million AIDS deaths on orphans and other survivors, on communities, and on national development is an enormous challenge, especially in African countries with social and health services already reeling from lack of human and financial resources. To date in the world, 13.2 million children younger than 15 years of age have lost either their mother or both parents to AIDS, with 95% of these children living in sub-Saharan Africa.

In spite of all hardships and stigma, these children also have a right to education, affection and cultural identity, as well as to services for the care of children. They have a right to be heard and to be protected from abuse, neglect, maltreatment and exploitation. They have the usual needs of children, including economic, social, educational, medical and psychosocial needs.

Of these, the latter has probably been documented least in Africa. The psychological effects are the least tangible and the most difficult for adults to address. And yet they impinge on all aspects of a growing child. "The devastation wrought by HIV is very real, whether the impact is measured in terms of children's future prospects or companies' bottom line."

Parents and organizations, religious leaders and counsellors are daily facing painful choices in relation to children: to disclose the parental HIV status; to involve children in home care of the sick; to talk about the dying and death of a parent or sibling; to find ways and means of postponing orphanhood; and to secure the best future possible for each child, even in the midst of massive constraints.

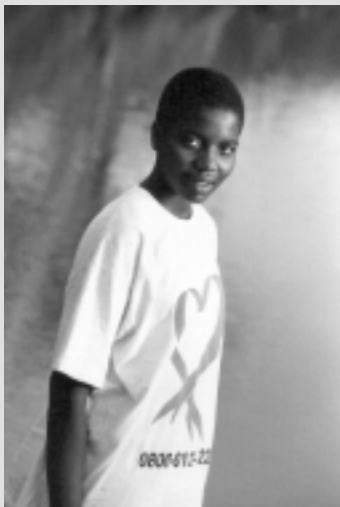
This case study, based on years of experiences in Zimbabwe and the United Republic of Tanzania where these situations are regularly confronted, describes efforts to address the tough questions related to the rights and needs of children affected by HIV/AIDS, with a focus on their psychosocial needs. We hope that the effect of listening and talking to these children affected by HIV/AIDS

will be to make their perspective much better known to adults who are working with millions of vulnerable children, not only in these countries, but also beyond.

Bunmi Makinwa and Sandra Anderson  
UNAIDS Intercountry Team for Eastern and Southern Africa  
Pretoria, South Africa



## “Living Positively with HIV: A Daughter’s Perspective”



### **Hard to Believe**

Usually the truth is hard to believe.  
It takes a century to believe the truth,  
But the lies are really easy to believe,  
They take only a fraction of a second to believe.  
I really don't know why the situation is like this.

When she told me,  
I thought I was dreaming.  
I thought there was something wrong with my ears.  
I could not ask questions because I thought it was a story about someone.  
Or just something that happened years ago to someone else.

It was hard to believe.  
It was as tough as counting all the stars in the sky.

It was hard to believe because it was a true story.  
I had to believe because it was true and real.  
It was a very long story filled with sorrowful words.  
It was filled with very painful words, which stay in your heart forever.  
It's a story to remember because it was the most painful and saddest story for me in my life.

It's a story you would hear while crying tears of blood,  
But I did not cry because it was a shock to me and too hard to believe.  
After listening, you would pray to the Lord to take you out of this wicked world the next hour.  
All because this is and shall be the most painful story to you and me.

--->

It's a story that happened to someone I'm really close to.  
Someone so special to me at good and bad times,  
Someone with a long lasting love for me.  
She is always by my side.  
She is the queen of my heart.  
She cares and loves me.  
She loves me, and I love her too.

I know you wish to know who she is.

It's hard to believe that something very bad like that can happen to someone who you never wanted to feel any pain.  
It's also hard for me to say who she is but I have to say it because you need to know.

It's.....my.....mother.

It is good to know that your parent or relative is HIV positive. It is even better if your parent tells you on his or her own rather than your asking after seeing a book or hearing it from other people. It's just as painful to find out on your own. AIDS is not something to hide; it's something natural. It is a disease like any other life threatening disease. Parents who are infected by HIV/AIDS and children who are affected need support, but most importantly, they need love.

I discovered my mother's status by error. I saw a tape that had my name and my brother's name written on it. I listened to it, only to discover that the voice on the tape was my mother's and she was talking to us. I was shattered when she said she had HIV and my first reaction was that she was going to die. Then she explained to me that the tape was three years old and I started to believe that there was hope of her survival for a long time. Then she explained everything to me about HIV/AIDS. I believe she told me of her HIV status because she loves us and she loves others by positively living with HIV/AIDS.

I get support from her immediate family, especially from her sister who is like a mum to me. Her friends are also a good source of support and so are other HIV/AIDS activists who are infected and affected. Some people talk of my mom

--->

as being very courageous but others point fingers at me or talk in low voices or in corners. I just brave it and say that they are the ones with the problem and not me because I know HIV can happen to anybody at any time.

As a person who has a mother living positively with HIV, I would like to thank all the children who have gone through thick and thin in supporting and taking care of their ailing parents. There is life after being HIV positive and we continue to live after our beloved ones are gone. To those who have parents who are infected, I leave you with this special message: never give up on life, pray for those who are infected and affected, but don't forget to pray for yourselves. As my mother says, "HIV for me means 'Hope Is Vital'."

**Eugenia Imagine Ndlovu, age 16, Zimbabwe**

## **“Living Positively with HIV: A Mother’s Perspective”**

Apart from the pain, anxiety and the feeling of death being so near during the time of my HIV diagnosis, another hurdle and indescribable pain was when I had to disclose to my eldest child. I had never cried in front of anyone to whom I had told my status. On this particular day, when I tried to explain everything about my HIV status to my daughter, the tears kept flowing down. It was not easy to tell her, yet it made my burden lighter when the truth was finally out. It was a form of therapy in a way.

Because of my experiences as a mother living with HIV, I believe I have the strength within me to support, empower and build the capacity and skills to help my children also deal with HIV/AIDS.

I think we need to cross the cultural norms and taboos that hinder the true understanding of the epidemic. Our children should learn how to deal with the truth and the reality of the virus. Instead of being in denial, we must face and accept HIV/AIDS and help our children to deal with the real issues.

I have a passion and compassion for this issue because I believe that we desperately need to revisit the basics in every country, community and as individuals. Although communities are diverse, disclosure requires us to take responsibility for ourselves, and to realise that our lifestyle needs to change. We need to renew the drive for HIV/AIDS education, awareness and prevention, pursue the reinstatement of societal respect and ultimately, account for our own actions.

I hope people working to psychosocially support children affected by the virus realise that involvement of people living openly and positively with HIV/AIDS is paramount to the success of these endeavours.

**Maria Ndlovu, South Africa**



# Introduction

“Dear Momma,

I’m writing this letter to tell you what has happened after you left. The baby is troublesome; our brother acts like our father and doesn’t respect our father. You left us alone. We remember you. We no longer go to school. You used to love us, you gave us things, life is no longer the same without you. I have to look after the kids myself. I won’t forget you Momma because you left us in a bad situation.”

**Elizabeth, Masiye Camp, Zimbabwe**

When considering the basic needs of a child one is inclined to think in terms of food, shelter, clothing, love, and security, a combination of the material and psychological needs. Children infected and affected by HIV/AIDS have similar needs, except the fulfilment of these needs is potentially in jeopardy when a parent or carer becomes ill and eventually dies.

Meeting these needs is important for the growth and ability of a child to succeed through life. According to the United Nations Convention on the Rights of the Child, meeting the psychosocial needs of children is not only a privilege, but also a right of the child.

Organizations in sub-Saharan Africa have begun to address the rights and needs of children affected by HIV/AIDS; however, many of them deal solely with material aid, such as school fees and food supplies. Monetary aid is also required,

as stated by a HIV positive mother from Tanga, United Republic of Tanzania, “There is nothing as bad as a spouse dying and then not being able to pay school fees.” Nevertheless, how a child feels cannot be overlooked.

“Although a family member’s death from AIDS may be a catalyst that propels children into escalating trouble, the psychosocial needs of children are too often perceived as somehow less important than their economic necessities. If children are to develop the resilience to deal with the challenges in their lives, their psychosocial needs must receive proper and prompt attention.”

**The White Oak Report,  
The Orphan Project,  
New York, 2000**

Experiencing the illness and death of a parent is different for everyone. Despite the resilience of children, the illness and death of a parent always affects them, even if they can not express it verbally. It can create a number of lasting problems for the child and alter the child’s interaction with family, school-mates, and peers. In order to help children through their grief, the possible ways in which they may express their grief must be identified.

“Since father died, I have had no clothing and food. Neighbours mistreat me. They chase me away at meal times. I go back home telling my mother that they have sent me away so I can’t eat.”

**Nelson, HUMULIZA counselling  
session in Itongo,  
United Republic of Tanzania**

When a parent has HIV and is ill for a protracted period of time, a number of changes occur in the family that affect the child both emotionally and physically. Out of necessity, children often assume adult roles, such as that of care provider for an ill or dying parent, and this can restrict their access to education. Frequently the disease process is not explained to children and they are left to draw their own conclusions. Group counselling and the empowerment of parents to discuss their status and situation with their children should commence early in order to prepare children psychologically for the eventual passing away of their parents.

Children whose parents have died of AIDS, whether they are infected themselves or not, are often referred to as “AIDS orphans”. The use of this terminology tends to label and stigmatize. In addition, it excludes children whose parent(s) are infected with HIV but are

## Introduction

still alive, a very important and substantial population of children.

This report refers to children as either orphans or children affected by HIV/AIDS. The term 'orphan' is used for children who have lost at least one parent to HIV/AIDS. A broader category of 'children affected by HIV/AIDS' is used to refer to all children, affected or infected.

This report is intended for people concerned about and working with families affected by HIV/AIDS, such as social welfare officers, medical and nursing practitioners, health care workers, government agencies, nongovernmental organizations (NGOs), churches, clubs and youth groups.



*Drawings can be used as a way of identifying problems that children have difficulty expressing verbally*

It highlights the experiences of children affected by HIV/AIDS, primarily those

under the age of 15, through the use of their stories, poems and drawings. The role that older teenagers are fulfilling as resources for the younger ones is also described.

Through providing examples of successful interventions being undertaken by organizations in Zimbabwe and the United Republic of Tanzania, the report shares experiences of essential psychosocial support to children who are infected and affected by HIV/AIDS in order to stimulate new awareness of needs and to open new doors for action.

It focuses on what can be done for the child of an infected parent before and after the parent dies, to enable the child to cope better with the situation. It advocates for parents living with HIV/AIDS to discuss their status and situation with their children and to live positively and stay healthy in order to postpone orphanhood.

The report illustrates how networking between organizations enables them to collaborate in addressing a variety of children's issues that they could not tackle alone. It identifies lessons learnt that can be drawn upon in triggering and strengthening comprehensive programmes to address the psychological and material needs of children infected and affected by HIV/AIDS.

## Child rights and HIV/AIDS

“What is needed now is to expand the relationship between current children’s rights initiatives and HIV/AIDS prevention and care efforts. Promoting the Convention on the Rights of the Child, as well as other human rights treaties, is one step in that direction.”

**Peter Piot, UNAIDS Executive Director**

Ensuring children’s rights is essential in order to limit the adverse affects of the HIV/AIDS on them. In 1990, the United Nations Convention on the Rights of the Child came into being.

The fundamental principle of the Convention is “in the best interests of the child”. This principle is based upon the understanding that children have full and equal worth, and that their vulnerability requires special support in order to enable them to enjoy full human dignity. There are 41 articles dealing with the rights of a child. The rights most relevant to HIV infected and affected children are summarized below.

### **The right of the child to:**

- Affection, love and understanding.
- Adequate nutrition and medical care.
- Free primary education and the opportunity for secondary, general and vocational education.
- Full opportunity for play and recreation.
- A name and a nationality.
- Special care if handicapped.
- Be first to receive relief in times of disaster.



- Learn to be a useful member of society and to develop individual abilities.
- Be brought up in a spirit of peace and universal brotherhood.
- Enjoy these rights regardless of race, sex, religion, nationality or social origin.

“Life became difficult for Sibongile after her parents died because she was treated like a slave. She woke up early to do the household chores while her aunt’s children were sleeping. She did not have time to study.”

**Pinkie, at the Masiye Camp,  
Zimbabwe**

Psychosocial support for children affected by HIV/AIDS is directly linked to the rights listed in the United Nations Convention on the Rights of the Child. Children are especially vulnerable to maltreatment or exploitation and a child cannot be physically healthy without also being psychologically secure.

Organizations, parents, carers, teachers and other people working with children, should therefore give priority to children’s rights and make decisions based on the “best interests of the child”. Therefore, in order to seriously respect, protect and fulfil children’s rights, it is vital that their psychosocial needs are met.

# HIV/AIDS and children in Africa

- FACT:** The number of people living with HIV/AIDS globally is 36.1 million, of whom 25.3 million reside in sub-Saharan Africa.
- FACT:** Current UNAIDS figures estimate that globally, 21.8 million adults have died of AIDS since the beginning of the epidemic, leaving an enormous number of children as orphans.
- FACT:** It is estimated that there are 1.4 million children living with HIV/AIDS globally.
- FACT:** 95% of the world's orphans live in Africa
- FACT:** Africa is home to 70% of the adults and 80% of the children living with HIV globally.
- FACT:** UNAIDS and WHO estimate that in the year 2000, 3.8 million adults and children became infected with HIV and 2.4 million people at advanced stages of infection died of AIDS-related illnesses.
- FACT:** Before the advent of AIDS, approximately 2% of all children in developing countries were orphans. It is estimated that by 1997, this proportion increased to 7% and has today reached 11% in some countries.
- FACT:** There are 13.2 million children under the age of 15 whose mothers have died of HIV/AIDS since the beginning of the epidemic.

*Source: AIDS Epidemic Update: December 2000, UNAIDS & WHO*

The HIV/AIDS epidemic has had an enormous impact on the world, especially in sub-Saharan Africa. The increasing rate of HIV infection affects African children in countless ways and in nearly every aspect of their lives. The number of children living with HIV/AIDS continues to grow daily, as children are born to HIV-infected mothers, contracting the virus from their mothers during pregnancy.

In addition, there are millions of orphans who have lost at least one parent to an AIDS-related illness. Although the number of orphans is staggering, its effects are only just beginning. HIV/AIDS has seriously

impacted upon children whose siblings, relatives or friends have HIV; children who are suffering from or have died of AIDS-related diseases, such as tuberculosis; and children whose homes are stressed with additional related orphans.

Girls are especially vulnerable to HIV/AIDS and the negative effects of the virus. They face the possibility of both physical abuse and the exploitation of their labour. When a family cannot pay school fees or there is sick parent who needs caring for, it is the girl child who is usually the first to drop out of school or to be given additional responsibilities.

## **The Effects of HIV/AIDS on Children's Lives: Adapted from HUMULIZA'S Manual for Psychosocial Support for Orphans**

### **Economic Effects:**

- Savings are used for medication/treatment and children must work to supplement the family's income.
- Illness reduces the economic performance of the household.
- Economic hardships make it necessary to look for alternative sources of income, for example through prostitution, street children, or early marriage.
- When both parents have died or are unable to care for their children, they are shifted into the homes of the extended family, often taxing the financial stability of those households.
- Inability to maintain or repair the home.
- Lower nutritional status in households with less income and many children.

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### **Educational Effects:**

- The presence of AIDS in the household, and the additional responsibilities and burden it brings on the family, may cause children to drop out of school.
- Due to unresolved psychological trauma, the school performance of children is negatively affected by HIV/AIDS.
- Traditional skills, passed through the generations, die with the parent before being taught to the children.
- Orphans face stigmatization by other children, including at school.

### **Social Effects:**

- In some communities it is taboo to take non-related children into one's home, especially if the children are sick.
- Dying is not talked about to children so they often do not understand what is happening in the household until the parent actually dies.
- Many times when a will is written it is disregarded by greedy relatives who leave nothing for the orphaned children.
- Medical concerns with opportunistic infections, such as tuberculosis, to other family members.
- Children and elderly people become the head of household.
- Poor families are more affected by losing a family member and may become impoverished forever, moving from poverty to destitution.

### **Psychological Effects:**

- This is the least visible effect because it is not tangibly seen.
- Emotional suffering appears in various forms for everyone (e.g. depression, aggression, drug abuse, insomnia, failure to thrive, malnutrition, etc).
- Children with sick parents worry about the future, where they will go and who will take care of them.
- Loss of consistent nurture, which can lead to serious development problems, and loss of guidance, which makes it more difficult for the child to reach maturity and to be integrated into society.
- Psychological damage can arise at any time after the event (months, days, and even years).
- Children may not understand the situation and therefore cannot express their grief effectively. Even if they want to express their feelings, there is often no one to listen.

**General Statistics:**

- Population: 12 million
- Size: 390,580 square kilometres
- Official languages: English, Shona, Ndebele
- Economy: Agricultural
- Ethnic groups: Shona (74%), Ndebele (18%), other (8%)

**AIDS in Zimbabwe, end of 1999:**

- HIV-positive adults: 1.4 million
- Percentage of adult population: 25.06%
- AIDS-related deaths: 160,000
- Children who have lost at least one parent to an AIDS-related illness: 900,000
- HIV-positive children: 56,000

*Source: AIDS in Africa: Country by Country, UNAIDS, 2000*

**HIV/AIDS and children: Zimbabwe**

A number of factors have contributed to the difficulties facing Zimbabwe today. These include the effects of the present political impasse, the declining value of the Zimbabwean dollar, rapid inflation, lack of investment, rising unemployment, escalating costs of living, the effects of frequent droughts and the emergence of HIV/AIDS.

The present political, economic and HIV/AIDS situation in Zimbabwe presents a number of challenges to individuals, families, communities, and especially children living with HIV/AIDS.

On an individual level, the income of HIV/AIDS-affected families dwindles, usually because the breadwinner is ill or the family’s savings are spent on medical treatment. Children in these situations are often forced to drop out of school and to work. The situation is exacerbated when the prices of food and household goods increase.

Inflation has severely impacted upon the country’s health care system, more specifically on the diagnosis of HIV infection and the care of HIV/AIDS patients. Even diagnosing opportunistic infections is too costly for the majority of the population. For example, while treatment for tuberculosis is free, it costs a minimum of Zim\$800 (US\$16) to reach a diagnosis before treatment can begin. This excludes the cost of transportation and other expenses.

The fuel crisis in Zimbabwe has impaired the ability of AIDS organizations to care for families

in need. In Harare, Mashambanzou is one nongovernmental organization (NGO) that provides food for HIV/AIDS-affected families. The scarcity of petrol inhibits volunteers for Mashambanzou and around the country from regularly reaching families with counselling, food, and blankets.

At the community level HIV/AIDS has placed an additional burden on the extended family system. This structure has provided security for children and families for generations. Traditionally in Zimbabwe, family elders would meet and assign a family member, usually the father's eldest brother, to care for an orphaned child and raise the child as part of his own family.

Recently the capacity of families to cope with additional children has become more and more strained. Relatives are starting to look at their familial responsibility towards related children as more of a financial burden. There are additional problems for orphaned children without relatives owing to the stigma attached to caring for non-related children. In this emergency, additional support from outside sources is required to assist these children to cope.

Early marriage is regarded as an option for households absorbing extra children. A man may marry to obtain assistance in taking care of his

dependants. A woman may marry to reduce the number of dependants in her family's household, as well as to obtain additional income through the bride price, i.e. money or goods given to the bride's family by that of the bridegroom.

The death of a mother or father can leave unsettled debts which impact negatively on the future care and resources left for the remaining children. In severe cases, the family of a deceased woman may refuse to allow her burial until the surviving husband and his family have settled the outstanding debts.

"We are four staying with our uncle. He is old. Our father died in 1998 and our mother died last year. I am the oldest girl. I am afraid what will happen to us if we all have to leave. Where will we go? Will we still be able to stay together? Will I have to care for my sisters and brother? I don't want to be a prostitute."

**H.F., age 15, quoted in a FOST survey, September 1999**

The majority of the population reside in the rural areas. It is estimated that there are presently two million people living on large-scale commercial farms in Zimbabwe, nearly 20% of the population. They help to produce major

items of the country's economy: tobacco, maize, cotton, sugar, groundnuts, horticultural produce and beef. One million children live on these farms.

A survey carried out in September 2000 by the Farm Orphans Support Trust (FOST) found that the average number of orphans at each farm was 12, as compared with 2 in 1994. The average age of orphans was 11 years and most

of the children were not infected with HIV/AIDS.

Children living on farms face some challenges that are unknown to children living in towns. The livelihood and accommodation of families living on commercial farms is tied to their fathers' employment, as workers do not own the land they reside on. Families affected by HIV/AIDS therefore face

Stanley, 22 years old, works on a farm outside of Harare. His mother died in 1995 and his father, who also worked on the farm, died in 1998. Stanley is part of FOST's programme.

After his parents died, Stanley became the head of his household, working on the farm to support his three younger brothers and sisters, aged 15, 11 and 9. He married a 15-year-old in May 1999, so someone would be at home to take care of his siblings while he is at work.

But the marriage that Stanley thought would solve his problems has only added to them. The children don't listen to his wife because they are nearly the same age. He still owes her parents a large amount of money for her bride price, for which he has had to borrow money to pay so far. A few months ago, they had a baby, so he must now support two additional people on his salary.

Stanley believes that if his parents had sent him to school his life today would be easier because he could get a better job. His father was a polygamist and couldn't afford to send all of his children from all of his wives to school.

Each month he gets Zim\$1,100 (US\$22) from the farmer to pay the younger children's school fees and uniform expenses. He says that the youngest boys are very smart, always ranking first and second in their classes, so he hopes that they can complete school.

Stanley keeps hearing about the possibility of retrenchment from other workers on his farm and he is worried because he was born on the farm and doesn't have a birth certificate or an identity document, thus making it difficult for him to find work legally elsewhere. If he had money he would buy a bike and sell goods from farm to farm, but he doesn't have any capital to plan anything for the future. He feels like things are crumbling down on him.

the prospect of losing their homes once their fathers or breadwinners pass away from HIV/AIDS, often resulting in young boys having to become the breadwinner to prevent this from occurring.

The recent farm invasions have also affected the lives of children living on the farms, endangering their physical and psychological security. For example, there has been a reported increase in the instances of rape among young girls living on the farms, thus making young girls in these areas more susceptible to HIV infection.



**General Statistics:**

- Population: 31 million
- Area: 943,000 square kilometres, including the island of Zanzibar
- Official language: Swahili
- Dominant tribes: Sukuma, Nyamwezi, Makonde, Haya and Chagga
- Economy: Agricultural (80%)

**AIDS in Tanzania, end of 1999:**

- HIV-positive adults: 1.3 million
- Percentage of adult population: 8.09%
- AIDS-related deaths: 140,000
- Children who have lost at least one parent to an AIDS-related illness: 1.1 million
- HIV-positive children: 59,000

*Source: AIDS in Africa: Country by Country, UNAIDS, 2000*

**Rural life and HIV/AIDS: United Republic of Tanzania**

There are many traditional cultural similarities between Zimbabwe and the United Republic of Tanzania, such as early marriage and the bride price. However, more than 70% of Tanzanians live in rural areas and depend on subsistence farming. Living with HIV/AIDS in the rural areas is especially demanding for many reasons. Subsistence farming fulfils only the family's immediate needs, so when the breadwinner becomes ill, there are no food or monetary resources on which to draw.

The epidemic is most severe in Dar es Salaam and in the north-western part of the country, where there are a large numbers of refugees from neighbouring Rwanda, Burundi and the Democratic Republic of Congo.

AIDS education is part of the national school curriculum; however, there is little general knowledge about the virus, especially in isolated rural areas. Access to health care can be difficult because of the distance, the road infrastructure and the lack of vehicles for transportation. There is also the problem of finding available HIV tests and confirming an HIV-positive diagnosis, even within health care facilities.

The United Republic of Tanzania is a traditional society where even in the language youth respect their elders. This can be illustrated by the

Swahili word for greeting an older person, “shikamoo,” which means, “I am beneath you”. This respect keeps order in society, but is a challenge to AIDS education. Breaking taboos, such as talking about sex or death with someone who is older and therefore more knowledgeable, is difficult. Writing a will also goes against tradition, and upon the death of a husband, his family generally takes as much of his property as possible, often leaving the widow and children with nothing.

Whenever a particular 15-year-old girl would attend a counselling session, she would cry and cry and say nothing else. When the counsellor asked her what was wrong, she would complain of headache and stomach problems. The counsellor went to her grandparents with whom she was living as both her parents had died when she was 6, but they said she cried every night and wouldn't say why.

In a discussion between the counsellor and the girl, she explained that she had been sick for a long time and was worried about her chest. Finally she admitted that she thought she was HIV-positive. When the counsellor asked her why she thought she was HIV-positive, the girl said that her mother and

her father had died of AIDS when she was young. Her grandparents had told her that her mother had chest problems and flu, and the girl also had chest problems and flu, so she just knew she was going to die. The counsellor explained to her how HIV is transmitted until she understood that she probably had not contracted the virus from her parents, but that she could go for a test. She had been expecting to die ever since her parents died, because she had thought that if someone's parent had died of AIDS, then no matter what, the child would also die of AIDS. A few months later, following an HIV/AIDS test that revealed she was negative, she had peace of mind again. Her pain was gone, both physically and psychologically. She stopped crying at night and was enjoying playing with the other children.

**Anonymous, her story was taken from a HUMULIZA counselling session**

It is projected that by the year 2010, there will be 4.2 million orphans in the United Republic of Tanzania. However, before this time, the country's support systems need to be strengthened to be

able to cope with the needs of these children and to promote HIV/AIDS awareness, especially in rural areas.

### **“My Parents”**

My parents are special,  
They gave and cared,  
They helped and also shared,  
They guide and they care.

My parents loved us,  
They gave us joy,  
They taught us good behaviour,  
They gave us happiness.

They were great to us,  
They gave us all we wanted,  
They told us interesting stories,  
But now we are lonely.

My parents enjoyed being with us,  
They showed us many places,  
We did not even lack anything,  
But now what remains is sadness.

Parents are special,  
All the nice things they did,  
Bringing us memories that last  
Our whole lives through.

**Princess  
Salvation Army's Masiye Camp,  
Zimbabwe**

# “Everyone’s child”: Educating the community on the child’s needs

“Children have their own world. For us it is small, for them it is everything.”

**Dennis Bamwenzaki, teacher trainer, HUMULIZA,  
Nshamba, United Republic of Tanzania**

There are many influences in a child’s life, such as family, community, peer group, school, culture—all of which are potentially contradictory and confusing for the child. As illness invades the household, children begin to have different concerns and problems, and their behaviour towards others can change.

When children are troubled they are not in a position to verbalize their concerns and may express them through actions and behaviour, such as crying, becoming withdrawn, shouting or playing. Adults need to remember that the way children act is in response to their situations and emotions, and that there are usually underlying reasons for their actions.

“My father died quickly, but my mother was ill for a long time so it was a different pain because I cared for her and washed her. It wasn't difficult though because I was the only one who could give her that care. My mother had relatives but they didn't help and refused to care for children that aren't theirs.

“We have to act like adults because no one else treats us like children and we have to do what adults do. Now I wake up at 4, do the housework, cook, bathe the younger ones, and then I walk about five kilometres to school. When we go to school it's our happiest time because we are away from our problems. I want to finish school and get a good job. I will care for my children and give them what I have missed.”

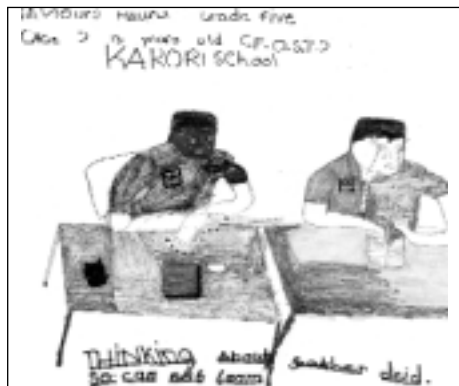
**Sarah is 16 years old. She is the oldest of 5 children and her parents died when she was 14. Today, all five siblings live with a foster father on a farm in Bindura, Zimbabwe.**



## **Educating teachers – HUMULIZA, United Republic of Tanzania**

A family provides a child's primary care so it is generally considered the most important influence on the child. With the rapid disappearance of family and parents due to HIV/AIDS in today's society, school and teachers become more important.

Teachers should be aware of what is happening in a child's life. Perhaps a child is truant from school for long periods of time, does not pay attention in class or becomes aggressive playing outside. From a teacher's point of view, this child could be considered a 'problem' child in need of reprimanding. However, it may not be a bad child, but a child who is having trouble coping with a difficult situation.



Children who are affected by HIV/AIDS often find it difficult to attend school for various reasons. These include the inability of the family to pay school fees or the child's responsibility to stay home to care for an ill parent. Some children even say they stay away from school for weeks at a time because they do not have soap to wash their dirty clothes and they do not want to be laughed at by other pupils. One Tanzanian child said that his biggest event from the previous week was that a sheep ate his piece of soap so he could not wash.

Some students say they cannot concentrate in class because they are worried about the condition of their parent or about what will happen once they pass away. In cases where children do express problems, adults may not take them seriously.

Children learn more from actions than from words. A teacher may reprimand a student in class without realizing the consequences. By reaching out to children and trying to communicate effectively, the teacher can have a stronger and more lasting effect on their lives. This can facilitate a bond of attachment that is missing from the children's lives. The teacher can serve as a confidant and a role model by providing love and guidance to the children, resulting in higher self-esteem, direction and good behaviour.

HUMULIZA is a pilot project based in Nshamba, and functions under the West Victoria Development Health Association. It is funded by Terre des Hommes, Switzerland. The project was launched in 1997 and has a staff of four. The target areas are the two wards of Nshamba and Biirabo of the Muleba District in the north-western part of the country.

At the early stage of the project, orphaned children identified needs such as support, guidance and school fees. The children wanted to share their problems and secrets with other children who had similar problems.

Activities were created to address these needs. HUMULIZA does provide school fees for orphans but concerns itself primarily with meeting the psychological needs of orphaned children through counselling sessions and educational seminars for teachers and other NGOs on the importance of communicating with orphans and other vulnerable children.

Ganyamukanda Primary School, in the Muleba District, has 16 teachers and 685 students, of whom 219 are orphans. At the beginning of the epidemic, these teachers, like most people, thought AIDS was a punishment from God and orphans were the family's responsibility.

Today, owing to the increasing numbers of orphans attending the school, they have come to realize that any child could become an orphan at any time. The situation is so widespread that it can no longer be hidden.

During the course of the seminars presented by HUMULIZA, the teachers were sensitized to identifying the problems and needs of students, as well as to the importance of attachment and how to improve the child's self-esteem. The teachers say the training sessions opened their eyes to the reasoning behind what they had identified as the misbehaviour of orphaned students.

It was discovered that a student was continuously absent from school because he felt uncomfortable sitting with the other well-dressed students. Another child who would not pay attention in class had no food at home, so he sat through the day with an empty stomach. Orphans who are care providers were found to spend much of their school time thinking about the situation at home and providing for the needs of their younger siblings.

After learning about problems that orphans confront, the teachers extended their commitment by visiting them after hours in their homes and making progress reports. They also followed up with caregivers and identified sever-

al problems such as inheritance mismanagement, poor distribution of property related to sex, and children born out of wedlock being denied rights of inheritance.

Since the first seminar, the teachers are able to identify the problems of orphaned pupils. The children are more open to expressing what they feel because there is a sympathetic ear. Class attendance has improved as the teachers encourage the orphans to realize that they have the same right to education as the other children.

The teachers said that they had always wanted to assist needy pupils but had been limited by the availability of resources. They have since created a fund for the orphans from their own salaries. Every month, each teacher contributes 200 TZ shillings (US\$0.26) to the "Help the Orphans" account, which is mainly used for buying school supplies.

Politicians implement policies that affect children and they carry weight in the community; therefore their support and understanding of the psychosocial needs of children is essential to providing sustainable programmes. Realizing the need to sensitize local and regional politicians, HUMULIZA invites them to educational seminars to make them aware of the experiences and needs of children affected by HIV/AIDS.

The HIV/AIDS epidemic poses another challenge to children affected by HIV/AIDS, which is the growing number of teachers who are infected with HIV. UNAIDS estimates that of the 2.4 million primary school students in Zimbabwe, 86,000 students had a teacher that died of an AIDS related illness in 1999. This means that while teachers may be interested and trained in issues related to children affected by HIV/AIDS, it would be difficult to continuously train the teaching population on these issues because of its high turnover rate. In addition, it may be yet another loss in the life of a child for which psychosocial support is required.

## **Educating peers – FOST, Zimbabwe**

Peers play an important role in the self-esteem of HIV/AIDS-affected children. Often the separation between orphaned children and children with parents is obvious in the classroom. One way of integrating the children is through school clubs, such as the FOST Clubs.

Farm Orphans Support Trust (FOST) is a national community-based programme that solicits and facilitates support for children in especially difficult circumstances, particularly

orphans, on the commercial farms of Zimbabwe.

The programme is based on the belief that orphaned children have the best opportunity for development within a family, without sibling separation, in an environment that is familiar and where they have the opportunity to learn their culture.

The overall aim is to increase the capacity of farming communities to respond to the orphan crisis and ensure that systems are in place to protect and care for the most vulnerable children. It also aims to give orphaned children at least the same opportunities as those of their non-affected peers and, where possible, to uplift the entire community.

FOST emphasizes community participation at every level of the programme. It is believed that if communities are not involved in the development of the solution, they do not feel a sense of ownership nor a need to continue to support the programme. Communities are encouraged not to expect problems to be solved from outside sources, but they should also be involved in the solution themselves.

On each farm FOST has recruited a Child Care Representative who undertakes domiciliary visits, motivates and supervises community childcare and



encourages interaction between orphans and non-orphans. The representatives report to the local "Farm Development Committee", which deals with farm social issues and forms a link between the farm workers and management.

The representative also works closely with the farm health workers in registering and monitoring all children. In addition, there are some 91 volunteers who help identify, befriend and support potential orphans and remain supportive of these children through their grief. Over 6,000 children are linked to the programme.

FOST established Community Project Clubs, which are an inexpensive means of equipping children with skills and creating awareness on HIV/AIDS, not only in schools but also in the community. Members of the club create dramas, which they perform for neighbouring farm communities. These plays focus on issues related to HIV/AIDS on farms, such as a foreman demanding sexual favours from women on the farm or a man having sex with other women after a night of drinking or problems faced by children stigmatized by orphanhood.

In some primary schools the FOST clubs normalize being an orphan by integrating both orphans and children with parents. Although HIV/AIDS is

part of the current primary school curriculum, club members learn more about the virus and other health issues. FOST has also trained teachers in psychosocial support for children affected by HIV/AIDS to give them a better understanding of the issues faced by these children.

At the Karori Farm School, the FOST club has been running for four years. The philosophy of Karori Farm School is that while it is the orphans who are in need of assistance today, HIV prevalence in the area is so high that it is possible that any child could become an orphan at any time. Participation of all the children in FOST club projects is emphasized because, as the principal of the school says, "Even children with parents don't like a child that just sits around and gets fat. Every child is a potential orphan, so they should work hard and make their relatives want to take them if the time comes." Including all students in the project also discourages the stigmatization of orphaned children.

To put into practice the philosophy adopted by the school a gardening project has been initiated. Each student has a responsibility to the garden, even if it is simply watering it with the rest of the class once a week. The students plant tomatoes and sell them, and the profit is used to meet the material needs of orphans at the school. Selling

the tomatoes and keeping a record of sales also encourages the development of mathematical skills.



*Student participation in the garden project at Karori Farm School has built ties between orphans and non-orphans, while at the same time teaching them life skills*

### **“A Poem about AIDS”**

You have probably heard a lot about AIDS,  
AIDS is a serious problem,  
Many people are dying from it,  
A lot of things have been said about AIDS.

People with AIDS need to eat plenty of nutritious food.  
Care for people with AIDS.

Melody Chipfiko, age 12, grade 6,  
member of the FOST Club, Karori Farm School, Zimbabwe

## **Learning life skills through adventure – the Salvation Army’s Masiye Camp and YOCIC**

Children learn through playing, as it fosters social growth, skills development and provides them with relief from stress. thereby enabling them to cope. However, owing to their responsibilities and pressures at home, orphans do not have time to play. The Masiye Camp in Zimbabwe is an example of life skills education through play and adventure-based learning for orphans.



*The trust fall at the Masiye Camp tests children's faith in others as well as in themselves*

The Salvation Army's Masiye Camp started in 1998. It offers a 10-day camp for orphans in the Bulawayo area. The idea of the camp is based on the principles of Outward Bound, which encourage trust and team building through adventure learning. This method of giving life skills through bush camps is an old African tradition still practised in some societies and has been revitalized to address this new stress on the community.

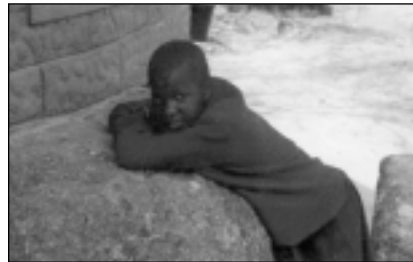
For many children, the camp is their first opportunity to relax and express themselves to someone who listens. Camps that focus on child-headed households and children living with ill parents are held during school holidays, August, December and May. Teenage parenting courses that focus on child-headed households and children living with ill parents are held in between. The children who attend the camp are identified by other organizations. The counsellors are volunteers, and most are orphans themselves, which enables the children to develop viable, personal solutions.

Recreational activities, such as abseiling, canoeing and hiking, are used to strengthen the children's interpersonal skills. The theory behind these adventure activities is that they represent life: they look almost impossible, they challenge the mind and body, but once the children overcome their fears they can

conquer the obstacle and face the challenge feeling confident and strong.

"At first I thought this place was boring and we were not going to have fun. Then I realised that it was fantastic, just like eating porridge. I was so glad that I forgot my name! Leaders, I thank you for taking care of me."

**Lorraine, 13, Masiye Camp, Zimbabwe**



An example of a dramatic transformation in behaviour was a slender young boy named Crosby who, like most children, came to the camp very quiet and sad. When it was time for abseiling, the instructor took the children to the top of a large boulder, gave them directions and then asked who wanted to start.

The group looked at how far away the ground was, then looked nervously at each other. Almost immediately, Crosby's hand was in the air to volun-

teer. The instructor quickly put the harness around his little body. His face tensed up as he took a breath and leaned back into the air until the rope tightened from above. Although starting out was difficult, he caught on quickly and climbed down without a problem. The moment he reached the bottom, he unhooked himself and sprinted around the corner to climb back up again.



*(Both pictures) After his experience abseiling, Crosby demonstrated his new-found self-confidence in other situations: even blindfolded he could trust in the other children*

When he reached the rest of the group, a smile had spread over his entire face and he told them, "That's as easy as eating sadza!" (a local staple food). From that point on, his whole demeanour changed. He was friendly with the other boys and girls, and always volunteered a joke or a story for the group. It was as if trusting the instructor suddenly allowed him to trust others enough to share of himself.

One afternoon, a group of 100 children went on a 30-kilometre hike in what was meant to be a lesson in endurance.

They climbed two large hills and finally reached the resting point where they waited for lunch to be delivered. After waiting for two hours, the group leaders decided that something had happened to the transport of the food and the group walked three hours back to camp without food or water. Surprisingly enough, not one child complained. At the camp meeting that night, the leaders asked the children what they had learned that day, and the children said they had learned the importance of patience and cooperation. Because they had approached the situation together, they could conquer it.

Each activity offered by Masiye Camp is facilitated and through debriefing afterwards the children are able to understand the themes that the activity addressed. Aerobics and running emphasizes fitness and discipline. Traditional dancing and drama in which each group is required to learn the steps and then perform at the nightly meeting promotes self-confidence in their ability in front of a group. Building a raft out of logs, ropes and barrels, inspires problem-solving skills. Craft making, such as bracelet making, provides the children with a skill they can take with them. Sessions on such topics as HIV/AIDS prevention and care, hygiene and alcohol and drug abuse are also integrated into the programme.

The Salvation Army is a Christian organization so the camp emphasizes spirituality. Through singing and praying, camp leaders share with the children the belief that they are never alone because God will always listen to them and love them. For many children this will become a defence mechanism against loneliness during tough times. It is interesting to note that when children cited what they remembered most about the camp, most children said it was the spiritual aspect.



Other children said the group leaders were their favourite part of the camp. These young adults created a fun and energetic environment that the children responded to. They took an interest in the campers, something that most of them had been missing at home. Because many of the leaders are orphans themselves, they can give advice and the children feel a sense of camaraderie with them. The leaders helped them in the activities as well as with their personal problems.

Nothing is actually achieved if the seed of independence and empowerment is planted but is left without regular nurturing. If children are counselled but return home and nothing has changed; if their families still mistreat them and other children still taunt them, the support will have achieved little. In order for a child to 'stay' empowered, the environment must be conducive to the child's growth and independence. Situations are often identified at camp or during counselling sessions that require follow-up.

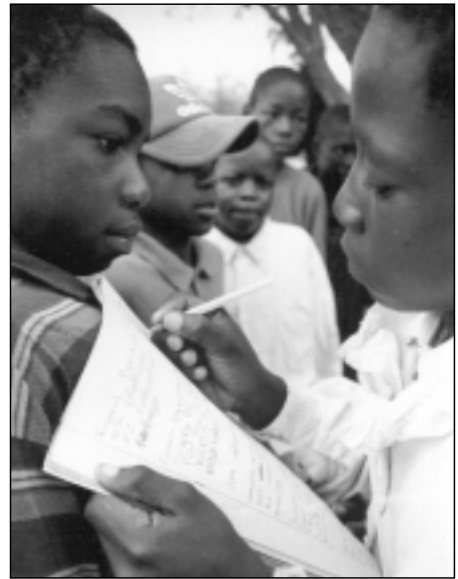
Youth for a Child in Christ (YOCIC) is an example of one organization that works with the Masiye Camp to provide ongoing support for children in their own communities. YOCIC is a youth initiative in support of children affected by AIDS and orphans in particular in urban high-density communities.

The organization started as an offspring of Hope for a Child in Christ (HOCIC), an interdenominational umbrella organization based in southern Zimbabwe working in support of programmes for children affected by AIDS. Seventeen different denominations are represented, with more than 45 local support programmes.

YOCIC was started and is entirely managed and run by youth for youth. It provides all the youth volunteers for

Masiye Camp as camp leaders and gives teenage orphans a platform to be actively involved in care and support of peers in the community. It was started in 1998 and has already over 250 members and is rapidly expanding. Over 1650 orphans are supported by YOCIC through various support clubs.

Orphans are referred to these counselling groups by support organizations in the area. These clubs offer activities, similar to those at the Masiye Camp, that encourage the children to build life skills and teamwork.



*As they leave camp, children know that the support from their new found friends and the community will continue*

## Involving youth in solutions – HUMULIZA and VSI

“There is something else which causes AIDS. That thing is Sugar Daddies. They may come to you with their cellular phones and cars and also nice clothes. Maybe at home you have a problem so when these old Sugar Daddies come to you and ask you to be their wives, you just say yes, especially young girls. THINK BEFORE YOU ACT! I tell you, when you are pregnant or you have AIDS, they are going to leave.”

**Loraine, Masiye Camp,  
Bulawayo, Zimbabwe**

The donation of food and money is not enough in order for children to survive on their own. They must also acquire certain skills, such as hygiene, interpersonal skills, self-esteem, and responsibility, in order to maintain a healthy and successful lifestyle. These skills often seem foreign to orphaned children, who tend to feel powerless to affect their situation and lack the strength and courage to make independent decisions.

HUMULIZA's Vijana Simama Imara Organization (VSI), Swahili for “adolescents stand firm”, is an

example of how orphans can utilize the skills they learn in order to grow and empower themselves for the future.

VSI receives financial support from HUMULIZA but is entirely youth-run. In VSI, orphaned youth learn skills to make empowered decisions and cooperation, and have the opportunity to put the skills to use. The members of this organization are older and the elder ones serve as a resource for the younger orphans in the area.

A belief that has been maintained at HUMULIZA is that if an adult introduces an idea a child's performance may be poor, but if the child introduces an idea, it is more likely to succeed. The leaders of VSI run the meetings while attendants from HUMULIZA sit in the back of the room, listening and waiting for their turn before they can contribute to the discussion. Below is the list of goals the youth themselves have set for the organization, as well as VSI's criteria for membership.

### Goals:

- To support each other during times of difficulty and pleasure
- To create, plan and promote income-generating projects
- To build unity and mutual cooperation
- To help the elderly
- To support each other by emulating good manners and behaviour

### Criteria for membership:

- 13-20 years old (i.e. must be old enough to walk long distances to meetings and to use a bicycle to help in the case of an emergency)
- Self-motivated (i.e. will clean the house without being told)
- Has lost at least one parent
- Trustworthy (i.e. if sent to wash clothes, will bring back the extra soap)
- Unmarried

Qualification for membership is strictly adhered to, as is the moral standard of the organization. The age restriction for joining was established because it was feared that the younger children would not be able to perform jobs as effectively and the older ones would not take VSI seriously. Although orphans under 13 years old do not participate in the work aspect, they are invited to the meetings and to participate in planning activities. VSI members bathe the younger ones, cut their hair, and assist them with reading and writing. They help to buy school supplies for the younger orphans when they cannot afford them.

Before VSI was launched, orphans in the area discussed with HUMULIZA what their needs were and how these needs could be met. The main characteristics of their parents that they missed were love and guidance, and the goals of VSI meet these needs. When a mem-

ber gets sick, the others take that person to the hospital. When a member is bereaved or has difficulties at home, they face the situation together.



*These youth leaders have found strength through unity and skills to build their future through VSI*

In one effort of cooperation, VSI members constructed a house for an 18-year-old member who was chased out of his home by an elder sibling after his parents died. He had inherited part of the family's homestead so the members of VSI collected poles, banana fibres, water, and prepared mud, and constructed the house for the member themselves. The construction of this house can be seen as a symbol of unity that VSI stands for as a whole. "Your problems are no longer for you alone," one VSI leader explained, "Building the house was hard, but because we were many, we managed."

Despite facing stigma from other children and difficulties at home, the orphans say that the best part of being



a member is the feeling of family. “We identify with each other as if we were brothers and sisters,” one member said.

The youth have undertaken many income-generating projects, including growing and selling tomatoes, selling small fish, and planting trees and coffee. Another major emphasis is on helping the elderly. Small tasks completed by members are rewarded with 150 TZ shillings (US\$0.20) each by HUMULIZA.

The funds generated are divided between individual day-to-day cash expenses and bank accounts. Personal and group savings accounts have been started. One account assists individuals in initiating a new project. Another savings account assists members in emergency situations. For example, the death of a Tanzanian family member requires a large-scale meal with relatives and friends, which is provided by the remaining immediate family. For orphans, such extravagance is nearly impossible. VSI decided that when a member has such a loss, the bereaved member receives a donation of 1,500 TZ shillings (US\$2) for expenses and members of the organization contribute food and assistance in preparing the meal.

As in any organization, there have been a few problems. For example, some members spent their time earning money by helping non-related elderly people, while neglecting their own

grandparent. For others, it was their first time to handle money so they spent their 150 TZ shillings (US\$0.20) on sweets. However, this first experience of handling and saving money is the basis for their ability to deal with money in the future.

The community has responded with interest to VSI. Sometimes visitors from the community observe their meetings to see what they are doing. Reported instances of abuse by caregivers are fewer, as they say they can see the positive results of belonging to the group and respond accordingly. The elderly are grateful for the help and said that VSI was bringing back the fading tradition of helping other people that are not related.

Members of VSI say that there are other youth with parents who wish to join the organization, but were turned down because it is intended for orphans only. This could be viewed as a positive result of the programme as the other young people have seen the cooperation and strength of the group.

However, it could also be seen as an example of one of the drawbacks of orphan organizations in general. Because being a member of VSI is dependent on the person's orphan status, it isolates others who are both financially and psychosocially in just as much need as the orphans.

The fairness of orphan programmes can also be questioned as they exclude children and youth with terminally ill parents. It is not until the actual death of the parent that the individual will qualify for assistance.

In addition it ignores the plight of other young people in households that have taken in additional orphaned, related children that are just as dramatically affected by HIV/AIDS.

The money and support given to communities from AIDS NGOs often excludes poor families with children who are not directly influenced by HIV/AIDS. For example, a Tanzanian donor who gave new school uniforms to orphans in one school the donor decided that the new uniform would not only include skirts, shirts and pants,

but also socks and shoes. Previously all pupils in the area went to school bare-foot because no one could afford shoes. When the orphans received shoes, the rest of the students were jealous and a counsellor from HUMULIZA remembers one student saying that if he could get new shoes if his father died, then maybe he would rather his father would die!

Members of VSI have been given the opportunity to organize themselves and make decisions. They have been exposed to invaluable lessons in decision making and life skills, such as handling money, work ethic and cooperation. Although there have been a few drawbacks, this combination of material and psychosocial support will benefit them long after their teenage years.

# Helping parents to disclose their HIV status

Talking to children about HIV/AIDS may seem like a desirable thing to do, but parents must overcome many barriers, both individually and within society, before disclosure becomes an option. Below are some of these obstacles.

## Overcoming traditional taboos

In both Zimbabwe and the United Republic of Tanzania, AIDS is such a taboo subject that people will refer to it as “the disease” or anything else besides “AIDS”. Most children whose parent or parents have died of an AIDS-related illness attribute death to such illnesses as tuberculosis, poisoning or diarrhoea.

It is not clear whether children really believe their parents died of these illnesses, or whether they simply say so to protect the family from the possible embarrassment and stigma that HIV/AIDS carries.

Traditional healers commonly credit AIDS-related illnesses to bewitchment, which can leave children with the fear that they too will be bewitched or that they caused it in some way. As traditional healers are often used as counsellors, they too need information on HIV/AIDS and on providing psychosocial support for children affected by the virus.

“My father explained to me that he had HIV. Other people also know and it hurts me when they talk about it. My mother doesn’t have problems with the community but I do because if something goes wrong, they tell me, ‘You’ll die like your father!’”

Gift, a 15-year-old boy from a farm near Bindura, Zimbabwe. His father died of tuberculosis, related to HIV earlier this year. He now lives with his mother, his younger sister and younger brothers.

In societies where there is little openness about HIV/AIDS, parents debate whether disclosing their HIV status would help or hurt their children.

## Telling the child

The views of parents differ on whether or not to disclose their HIV status. Disclosure is primarily dependent on how secure the parent is about the HIV-positive status. If the parent is not yet comfortable with being HIV-positive, HIV/AIDS education will not be shared positively with the child and may make the child feel uncomfortable with the information.

Disclosure can also depend on the age of the child. Dr Hores Isaac Msaky, a paediatrician in Dar es Salaam, United Republic of Tanzania and head of

ANNEA, says that children around the age of seven are mature enough to understand the finality of death and they have heard about HIV/AIDS in the community or at school. At that age children do not understand the stigma attached to the virus because they do not understand the implications of sexual transmission. The maturity of children and how curious they are about the virus can also affect disclosure.

When Chipo Mbanje told her 11-year-old son that she was HIV-positive, she was surprised to find out that the child suspected this already. Because he didn’t really know what that meant and didn’t feel he could ask her, he had spent lots of time with the fear that she would die any day. Every headache she had caused much stress for the child; he even saved up Zim\$10 (US\$0.20) and sent it to her from boarding school to help her out.

**Harare, Zimbabwe**

Some parents say disclosure is necessary because children with information can protect themselves from contracting the virus when caring for an infected parent. Because the carer has such intimate contact with the infected person, it is possible that opportunistic infections or even HIV itself can be passed to the carer if proper precautions are not taken. Others argue that

knowing about HIV in the family just makes the child's life harder. Eventually, it remains the decision of the individual.

Below are the experiences of two orphans. One was not told that her parents died of AIDS, while the other's mother told him that she was HIV-positive:

A young girl's parents died a few years ago. First, her mother had a baby who died soon after it was born. This girl saw on the baby's death certificate that she died of AIDS. Soon after, her mother died, but on the death certificate it said "pneumonia". Following her mother's death, her father also became sick and she cared for him day after day until he died. On his death certificate, it said he died of tuberculosis.

Today, years later, this teenager is concerned that her parents may have died of AIDS. She has learned about the virus in school and put two and two together. She is worried that because she cared for her father and came into contact with his blood, she may also be infected but she doesn't feel comfortable talking to anyone about it because she doesn't want to be stigmatized.

**16-year-old girl, Bulawayo, Zimbabwe**

"When my mother told me she has HIV I felt like crying and went to sleep. She explained that she's not dying but at first that's what I thought. Now I feel like I have to be there for her in everything, doing housework, cleaning, sweeping.

"Sometimes I wish she hadn't told me. I don't like talking about HIV. I'm tired of talking about it — I just don't want to keep spending time on it. I don't talk to others about my mother's HIV because it stigmatizes me, but I did talk to my teacher because I had to talk to someone."

**Marshall, age 13, is the eldest of his siblings. Harare, Zimbabwe**

Whatever is decided about disclosure, an HIV-infected parent must focus on living positively with the virus rather than on dying. There are many ways people with HIV can prolong their lives, including a better diet and a positive attitude. By facing the virus positively, parents can stay healthy longer and keep their children from becoming orphans for as long as possible.

## Reading Musa's Story

Even if an adult wants to talk to a child about HIV/AIDS, it is hard to know how or where to begin. In 1995, the National AIDS Control Programme told

Dr Anna Kisesa, a child psychologist in Dar es Salaam, of a group of older people who were having difficulty taking care of their grandchildren and asked her what she could do for them. Dr Kisesa went to stay with the women and children for a few weeks to assess the situation. The grandparents said they could not deal with such “prob-

lem” children. Dr Kisesa found that although the grandparents fulfilled the children’s basic needs, such as food and shelter, they felt awkward with the children because they could not communicate with them. *Musa’s Story* came out of the observations from working with these and other children. Below is a general description of the story.

### Musa’s Story by Dr Anna Kisesa, child psychologist

Musa lives with his mother, father, brother and sister. His father is in and out of the hospital, dying of AIDS. One day while he is getting ready for school, Musa suspects that his father has gone to the hospital again but his mother tells him he had gone to buy some wood. Throughout the day, Musa is preoccupied at school. He knew his father had gone to the hospital and was wondering why his mother had told him something different. The teacher catches him daydreaming, and he wants to explain why but he is quickly sent out of the classroom. When he gets home, his mother tells him she can not understand why he is always being sent out of class and sends him to do his homework. Then his sister asks him why he is always getting in trouble and he explains that he is worried about their father. His sister is not worried and tells him that if there were something to worry about, their mother would have told them.



Musa is sent on an errand to a neighbour’s house and on the way back into his house, he overhears his mother and aunt talking about taking Musa’s father back to the village because he is too ill to stay in town. They continue, saying that they should try a traditional healer because it seems like he could have AIDS—but they stop talking when they see

Musa. He tries to figure out why they are not telling him about his father. That night, he cannot sleep and his aunt asks what is wrong. Musa asks her if his father is going to die, and she says, “Poor Musa, I think we need to talk...”

This story is an example of how adults think they are protecting children by not disclosing to them. However, Musa did notice that things at home were not right. His situation became even worse when the adults lied to him about what was going on, which then led to other problems at school. Musa wanted to talk to someone about his fears, but when he was not given the chance, it came out through behavioural problems.

The story also shows Musa's attempt to communicate with two different adults who ignore him. The story ends when he finally mustered the courage to directly ask someone what is happening. This ending should trigger further discussion between parent and child.

*Musa's Story* can be read by parents or carers who can then read or tell the story to children. Either way, it is meant to open the lines of communication. It is also based on the principle that the

best person to prepare a child for illness and death of a parent is that parent. Dr Kisesa believes that it is the parent's right to choose when and how much information to tell children, which is why there is little in the story that deals directly with HIV/AIDS. *Musa's Story* simply makes it easier to start talking about the issue and leaves it up to the individual parent to decide what to discuss. The main obstacle to the effectiveness of *Musa's Story* is that it was published only once and locating a copy of it today is difficult.

Both traditionally and emotionally, HIV-positive parents face great difficulties in disclosing their status to their children. Each individual must decide whether talking about HIV/AIDS will help their children to deal with the future or contribute to their stigmatization and discrimination. Although there are a few resources that assist in disclosure, they are generally not easily accessible.

# Helping parents talk to their children about death and dying

Once children realize that a parent may die, the future becomes a major concern. “Where will I go?” and “Who will pay my school fees?” are common questions. When children are not given the opportunity to express their emotions about the situation, these feelings are left to fester and could have long term effects such as depression or nightmares.

“I dream a lot about my deceased father. He comes to me, this is the third time. Sometimes I see him as if he is walking in his sleep. It frightens me.”

**Daliusi, at a HUMULIZA counselling session for orphans in Itongo, United Republic of Tanzania**

## Fighting the conspiracy of silence

Traditionally, children are not encouraged to talk about themselves and how they feel; therefore when they are finally given the opportunity they often have trouble expressing emotions. However, just because they do not verbalize their emotions, does not mean they are not affected.

It is a common belief that because children are resilient, they are not in need of counselling about death. This can be demonstrated by the idea of comforting the widow at the funeral and sending the children out to play. Children are encouraged to keep their emotions inside and may hear such



warnings as, "If you cry, you will end up like your mother!"

On Saturday the 19th of February 2000, my father died. We had to go home and when they told me I cried and lost my appetite and I did not want to talk to anyone. When the people from our church came to make inkonzo, I wasn't concentrating. I always thought of my father and every time I think of him, I cry. On the burial day, my mother said I could not go, and I cried until they said they would let me go. Then they said, if I cry during the body viewing, then I would not be able to go, so I did not cry."

**Young girl's testimony, Masiye Camp, Zimbabwe**

In the Shona culture in Zimbabwe, children do not actively participate in rituals surrounding death, and they are usually kept away from the funeral and the grave, although changes have been noted in this custom. Traditionally, families who have moved away from the rural areas return to the village to bury a family member. Usually when this happens, the remaining children are left behind in town.

Adults also avoid talking about death to children because it is too painful for the adults. The child's grief can evoke memories and strong feelings in the adults

that they are not ready to deal with. Adults argue that by avoiding discussing death they are actually protecting the child. Many parents hope to minimize the impact of the loss by avoiding talking about it, a "conspiracy of silence".

"Children are fantastic observers, they miss nothing, however, they are poor interpreters of what they see and hear. They will often internalize the situation and feel a sense of personal responsibility for what they see around them."

**Sue Parry, FOST**

This "conspiracy of silence" does help parents control their emotions, but even though nothing is verbalized, the parent is still communicating with the child about sickness or death, only it is something negative.

According to Chipso Mbanje, head of Positive Women's Network in Harare, Zimbabwe, children are like a sponge; they absorb everything (emotions, tensions and actions) but adults do not realize there is so much water inside. Children's roles and lifestyles change dramatically when AIDS enters the household. The children often become the carers for a sick parent or they have to take on additional duties in the household, such as working to replace

the income of the sick breadwinner or to supplement the money needed for treatment.

Children can see these stressors and sense that there is something seriously wrong, but they may not understand what it is or its implications. This can make them feel anxious, guilty, depressed and misunderstood. Often they do not express these feelings because they do not want to upset the situation further or they may be afraid of being overwhelmed by their feelings and try to keep them under control by keeping them inside.

Sometimes they get the feeling that whatever the secret is, it is too horrible to be talked about. By discussing the situation, children's fears are alleviated and they will be able to cope better with the stress.

## **Saying good-bye**

Talking to children about death in advance gives them time to get used to the idea and gradually loosen the bond of attachment. Children who had the opportunity to say good-bye and were given last words of advice greatly appreciated it when the parent is gone. Having the chance to say actual thought-out good-byes to people, places or a familiar family structure is very healing for a child. Wishes and blessings can be exchanged, preventing the children from

blaming themselves and leaves less unfinished to complicate the grief process.

In 1998, research was conducted by HUMULIZA on talking to children about death in the Kagera region of the United Republic of Tanzania. The research consisted of talking to more than 200 families about how they had approached death and dying within the family.

The children whose parents had talked to them about dying appreciated being able to use the time to share information and advice. For instance, the children had the opportunity to learn how to do household tasks and could ask the parent, "When you die, how should I do this?"

## **Making a Memory Book**

Another tool for communication is the Memory Book, which was recently introduced in Zimbabwe. Originating in Uganda, the memory book is a journal of facts and memories for children who are facing loss or separation from a parent, including divorce, any terminal illness or adoption, and it is appropriate for any culture or background.

If children are separated from their parents, memories and identity tend to fade. The Memory Book is an attempt to keep

the memories alive and strengthens the child's sense of belonging. The parent or caregiver fills in information and personal stories under different headings, including "My favourite memories of you," "Your health," "Information about your father," "Family traditions and special events," and "The family tree."

As the introduction of the book states, it helps "children to understand the past and move on to a more secure future." It is a photocopyable resource, which makes it affordable and easy to distribute to parents and carers.

There are various ways of completing the memory book. The parent can complete it and then go through it with the child or the child can help in its completion. An important aspect of the book is that the child has the opportunity to ask questions about its history and future. If the parent wishes, the book can include input from other family members, photographs and other memories to remind the children of life before the separation from their family.

The Memory Book is a tool to help the parent and the child to deal with the past, present and future of the child. As it is common for orphaned children to be moved into a different area, the book serves as a reminder of their roots so they do not lose their sense of belonging. Disclosing the parents' HIV status is not the main goal of the book, but it does

allow the opportunity to talk about HIV and facilitates disclosure to other family members. The book is also beneficial with regard to HIV prevention, because the children witness and understand the ordeal the parent is going through and do not want to repeat it.

Mothers in Zimbabwe who have learned about the Memory Book from the Positive Women's Network say it made them aware of their children's fears about the future. By discussing the book, they were able to talk about who the child can turn to with questions and problems, and their children could be part of the decision on where they will live after the bereavement, both of which empower the children by giving them choices. Talking about death ahead of time affords the children the opportunity to test the decision of where to live over the holidays to see if it would actually work.

"By talking to your children about the future and teaching them how to take care of themselves, you create empowered orphans who can live on their own even if they're 8. It is important to teach children that life isn't always rosy, but that they are able to deal with the most difficult situations."

**Chipso Mbanje, Positive Women's Network, Zimbabwe**

Talking to children about death and dying is difficult for all parties involved. It brings out sensitive issues that the parent may not be ready to deal with. For example, one mother was filling out the Memory Book when she came to the page on the history of the father and said, “How do I tell my child about his father if I don’t even know who he is?” This and other similar problems indicate a need for additional counselling for parents while working on the book or of adapting the book format.

## Counselling in various situations

“Pain can be physical, emotional or spiritual – whichever aspect it starts with, it will always spread to others, so the earlier we start dealing with the pain of loss and death, the less likely it is to affect the other aspects.”

**Laura Mitchell, International Stress and Tension Control, Annual Conference, 1987**

During the period of illness, parents or other carers may be preoccupied with their own grief and would need the help of outside counselling. The aim of counselling for children at this time allows them to express grief and repressed feelings by allowing them to break down. Counsellors can encourage the child to deal with the reality of the loss and the adjustment to environment without the deceased. The child can then start adjusting and exploring the circumstances as an independent person.

Anticipating a parent’s death starts the process of grieving early, which makes it easier for the bonds of attachment to fade gradually over time. It prepares them for what lies ahead instead of taking them off guard, and can promote the awareness that although change is hard, the child can manage grief and loss – what has happened is not so awful that it cannot be talked about.

### **Family counselling through home-based care – Island Hospice**

Bereavement counselling usually refers to counselling for families after a loved one’s death. However, counselling can also begin during a

long period of illness, in anticipation of death.

Most frequently it is the parents who are counselled about death and because of the age-old idea that children are resilient and taboos on talking to the children, they are left out of the picture. It is important, however, that children are included in the family counselling, as is done at Island Hospice.

The Zimbabwe branch of Island Hospice was formed in 1979 to care for terminally ill cancer patients, their families and bereaved people. Today it has 8-9 active branches, with the largest located in Harare.

The majority of the patients presently visiting the Hospice are being treated for AIDS-related illnesses. It offers home-based care and bereavement counselling services free of charge. As part of the organization's home-based care, the nurses explore options with the family for the children after the parent's death, such as where the children will live and whether or not to write a will.

Island Hospice counsels children based on the belief that the death of a parent will have an effect on the mental health of the child if it is not adequately dealt with through the grieving process. The length of time that a grieving process will last depends on whether or not the child was prepared for the death.

If the parent is ill for a long period of time, the child can be involved in caring for the parent, thereby reducing the child's grief at the time of the actual death. Therefore, although bereavement counselling is commonly thought of as happening after the death of a loved one, patients with long terminal illnesses and their families can benefit from counselling ahead of time. Counselling continues after the parent dies and follow-up is done with the new family if necessary. Island Hospice holds regular group sessions for bereaved children.



*For the children, a strong relationship with a home-based care nurse from Island Hospice started during the course of their mother's illness and death, and then continued after her death*

The main branch of Island Hospice is in Harare and deals with the unique experiences of families affected by HIV/AIDS in an urban setting. While in rural areas the extended family system tends to be strong and can support orphans, it is taxed in an urban setting because there generally is not the same support network of family members. This strain on extended families is exaggerated by HIV/AIDS. Whereas there may be a “right” or choice family member to look after a child, often that person is already burdened with too many children, is sick, or does not have the money to care for an additional child. This child is then shifted between family members, creating an unstable and insecure environment.

The ethos of Island Hospice is to build on what is already in the family and the community, such as working within family and traditional rules. In Zimbabwe, wills are against tradition and often the remaining family will often resent the will or ignore it. Island Hospice encourages writing a will and explains to the client why it would be useful, but it is up to the individual to decide if it will help or disrupt the family further.

The same applies to the disclosure of parents to their children about HIV/AIDS. As Sam Mkwanzani of the Island Hospice says, the goal is to “put the child’s needs first without destroy-

ing the family relationship.” Telling the child about AIDS gives the child the choice whether or not to disclose to other people. Home-based carers have found that families are becoming more open about talking about AIDS. But children often face stigma from the community. For example, AIDS-affected children are sometimes chased away from playing at the neighbours’ houses. Children themselves are open to talk about AIDS, as long as it does not affect them directly.

“My name is Tsitsi. I am 12 years old. I live with my mother’s sister because my mother died in 1993 with AIDS. My mother’s sister looks after me like somebody who is (fit). She sells vegetables for money for school fees and food. I don’t mind (living) with somebody who has AIDS. We are looking at the future when we will be well-mannered children without HIV because we have already been taught about it.”

**A letter by Tsitsi, age 12, a client of Island Hospice, Harare, Zimbabwe**

Tsitsi, the niece of one of Island Hospice’s patients, is an example of how the combination of bereavement and HIV/AIDS counselling can positively impact a child and her future. In Tsitsi’s family, nearly all of the adults, including her mother, grandparents and

aunts, have died of AIDS-related illnesses. Today she lives with her aunt, who also has AIDS, and 10 younger cousins.

Through the home-based care team, she and the other children have been given an understanding about the virus that has affected their family so greatly. When she talks about the future, it is evident that she has come to terms with the virus and how it is affecting her family.

## **Counselling for groups of orphans / HUMULIZA**

Generally when children are in difficult circumstances, they feel worse about it when they feel alone in their experience. Another way to assist children's psychosocial needs is to establish a peer group where they can share similar experiences and support each other. In the United Republic of Tanzania, HUMULIZA has a unique programme to counsel and monitor the situation of orphans in the Kagera region.

In the rural Kagera region, one of the areas hardest hit by the AIDS epidemic, 20-70% of children in primary schools are orphans. In HUMULIZA's original survey on what orphans need,

a major concern expressed by the children was isolation from other children and the community. HUMULIZA's solution was to start counselling sessions for orphans at the primary school level in the district. The aim of the sessions is to help them to identify their feelings and to enhance their capacity to cope with their new and difficult situation.

Each counselling session follows a routine and provides a stable environment to comfort children whose lives are in chaos after losing a parent. The group atmosphere encourages the children to lose their sense of isolation by working and sharing experiences with other children in similar situations.

As the children arrive, the counsellor, or attendant, greets each one by name to emphasize that they are important. Before the counselling session begins, the children are given a meal. Dennis Bamwenzaki, one of the attendants, explains that providing food satisfies both the physical hunger as well as the psychological need to 'fill themselves up'. It shows the child that the attendants are interested in meeting their basic needs.

Once they have finished eating, the boys and girls joke with each other while they clean and sweep the room, which demonstrates the group's sense of cooperation and fun.





*This counselling session takes place in the local primary school*

The attendants start the actual counselling session by asking each child to say something important that had happened during that week and what problems they had encountered. It is interesting to note that at every school, the most common complaint was physical ailments, such as stomach problems or headaches, and the major event was usually the death of a relative or neighbour.

Other frequent occurrences were related to physical abuse from teachers or other students. A few expressed happiness that they had not been beaten that week, while others say they had been anxiously anticipating seeing the attendants. Most children were discouraged because they were not appreciated at home.

“I fetch the water and firewood, I cook and I wash clothes but they don’t honour my work.”

**A child’s description of his home life. HUMULIZA counselling session**

The rest of the session is filled with songs, games and esteem-building and self-awareness activities. Drama and hand puppets are used to address common situations for the children in a non-threatening way.

One drama is about Maria and Simon who find out that their father is dying. The children are asked what will change in Maria and Simon’s lives after their father dies, and they respond that there will be no food, clothes, shoes, soap, and they will be dirty and will not go to school. “Have you come into such a situation?” the attendants asked. Most children answer by crying and hiding their faces.

The children have the opportunity to vent their secrets to the group. Some said they were haunted by dreams of their deceased parents, others feel bad because they often cry but cannot express why. Others feel guilty because they are not successfully managing the responsibilities of both parents.

For Marcelina Biro, an attendant for HUMULIZA, one particularly memorable child from the counselling sessions was a very moody 12-year-old girl whose father had died of AIDS the year before. He was admitted to the hospital for a little while before his death and, because her mother was caring for him at the hospital, this young girl was in charge of taking food to him.

One day, after she had already started on her journey to the hospital, it started to rain. People saw her passing through the rain but she explained to them that her father was very sick and must be hungry, and if she did not get his food to him, he would surely die. She insisted that she keep moving. Finally she listened to the advice of others and rested until the rain stopped. When she reached the hospital, she found her mother outside crying. Her father had just died.

The girl did not say anything but became very depressed and sad. After that day she started to be very moody, very aggressive one minute and depressed the next. She stopped playing with her friends and her performance at school became very poor. She started saying she wanted to kill herself. When she was asked what was wrong, she said she wanted to follow her father.

Then she joined the counselling sessions with HUMULIZA. Towards the end of the second block of meetings, one of the activities was for the children to disclose a secret. This girl's secret was that she did not want to live because she killed her father. When the attendants asked how she had killed him, she explained that it was because she delayed in bringing him his food and he died. When she was seen in the community she was convinced that everyone else blamed her too. The attendants explained that death just happens, and all of the other children in the room had also lost their parents through no fault of their own.

Since that day, her behaviour began changing. She joined the drama group at school and played football with the other children. She just had not understood the cause of her father's death because it was never explained properly to her and by allowing her to speak to someone non-threatening, she was able to realize that it was not actually her fault and to release those emotions. Speaking to a counsellor gave her a chance to speak to someone about her fears and to learn.

**HUMULIZA peer counselling session, Nshamba, United Republic of Tanzania**

Issues addressed in other sessions include problem solving, dealing with sadness and helplessness, self-esteem and anger—skills to assist children with their grief today as well as to support them in the future.

During the first few meetings of the group, the children are shy and look down when they talk. Few children volunteer to tell their personal stories. But after a few sessions, the children generally feel comfortable enough to open up and share their stories. Once they have completed both blocks of seminars, the children can put these skills to use in HUMULIZA's orphan organization, which was discussed earlier in this report.



*These HUMULIZA attendants help the children feel comfortable about telling their stories*

Programmes such as HUMULIZA that are dedicated to meeting the needs of children may be a noble effort to help the children, but they also create dependency on the generosity of out-

side sources. For example, children who are provided with school fees through the organization are called, by both themselves and others, "HUMULIZA's children".

Another example of this idea is a mother whose child is provided with school fees through the African Women's AIDS Working Group (AFRI-WAG) in Tanga, United Republic of Tanzania. This mother believes that the NGO's involvement should not stop at the end of secondary school, and that it should find her child a job after he completes school.

Communities are faced with such a tremendous number of people dying of AIDS and the orphans left behind that outside help has become necessary. However, in the process of helping communities, AIDS organizations now dominate the situation, which has allowed others to relax in their responsibility to the situation and has created dependency on the continued support of the AIDS organizations.

This brings up questions of both the sustainability and the responsibility of NGOs and other organizations. What happens to the children when there is no funding? When do NGOs' responsibility for children end and does this alter parents' roles? One solution that NGOs have begun implementing is to involve the community in their projects

to a greater extent so they can retain some responsibility for the children.

Another way to increase the sustainability of a programme is income-generating activities. For example, the Masiye Camp has built a ropes course, which children at the camps use for team-building but will also be marketed to companies for similar workshops for use when the children's camps are not in session. Masiye's ropes course and its safari lodge camp, which has

been established nearby and will run parallel to the children's camp, will bring in revenue and help to ensure that the camp will continue.

Whether it is done individually or in groups, counselling for children is necessary to help them to cope with the death or impending death of a loved one. However, such assistance has to be constant, therefore supporting organizations must be sustainable.

# Networking for effective responses / ANNEA

It is realized that at present, the majority of programmes working with children affected by HIV/AIDS have not strategically integrated psychosocial support issues in their existing programmes. To bridge this gap, accelerated learning through sharing experiences and information is the easiest way for an organization to grow and meet the changing needs of people affected by HIV/AIDS, especially their psychosocial needs. One example of a network that has taken serious consideration of issues with children is the AIDS NGO Network of East Africa (ANNEA), which has as its slogan "Together we will achieve more".

ANNEA is a consortium of NGOs in Kenya, Uganda and the United Republic of Tanzania working in the HIV/AIDS field. In 1994 ANNEA was established with the idea that through networking, organizations could better support each other in order to conduct AIDS work more efficiently and effectively. At the end of 1999, ANNEA had more than 70 NGO member organizations from these three countries and is planning to expand to include other Eastern African countries. It focuses mainly on networking and experience sharing, organizing development and capacity building, and advocacy for human rights. Members are invited to participate in conferences on HIV/AIDS issues.

ANNEA works to build unity between NGOs in the three East African countries in order to strengthen and support their interventions in HIV/AIDS prevention and care. NGOs in one region frequently do not know what other NGOs in other regions are doing in the same

field. Networking opens up the lines of communication between organizations so that they can share their experiences and support each other. Through the exchange of ideas, programmes can be improved so that AIDS work can be done more efficiently. Workshops are held on various topics related to HIV/AIDS. The professions of participants from member NGOs vary and include doctors, home-based care nurses, people living with HIV/AIDS and project coordinators.

ANNEA gives priority to children's issues. For example, a recent workshop was held on psychosocial support for children affected by HIV/AIDS in Kampala, Uganda. As the majority of the 14 organizations present did not have programmes specifically working with children, the psychological impact

of the virus on children was something new. One theme of the conference was child participation in programmes aimed at them. Although most participants were proud of their programmes' material support, a survey of the group found that children had little say to affect these programmes.

As a result of these workshops, ANNEA advocates that children be listened to and actively participate in programmes, and that their talents be explored and used to improve programmes. NGOs are also encouraged to protect and advocate for children's rights and for the support of communities without discrimination against children who are infected and affected by HIV/AIDS, as they need holistic care, including physical and psychosocial support.

AIDS IS ALL AROUND US,  
EVERYWHERE WE SEE IT.  
SPREADING TO OUR FAMILY,  
SPREADING THROUGH OUR LAND.  
BUT THERE IS ONE HOPE FOR THE FUTURE,  
FOR THOSE WHO ARE STILL YOUNG,  
IF WE WORK TOGETHER WE CAN FIGHT AIDS,  
HAND IN HAND.

THANK YOU.

**Walter, age 12, Grade 6, Karori Farm School, Zimbabwe**

# Lessons learned about psychosocial support

## Listen!

Adults must listen to what children are saying. At first, children will generally identify material needs, such as food or clothing, as their greatest concern. However, when adults take the time to listen to their stories and poems and observe their drawings, children can disclose their personal experiences and feelings. This is the most effective way of identifying their needs to enable others to effectively assist them in having a better life. Through listening, the following lessons were learned from programmes in Zimbabwe and the United Republic of Tanzania on psychosocial support for children affected by HIV/AIDS.

### Ensure the child's rights

*"Life became difficult for Sibongile after her parents died because she was treated like a slave."*

- Respecting the rights of children, such as the right to protection against exploitation and discrimination, is essential for the well-being and growth of a child.
- Psychosocial support is an important aspect of children's rights and must be included by organizations concerned with children as part of their programming framework.
- Children play a vital role in the future, so they should be involved in decisions that affect them. Participation is a fundamental principle of the Convention on the Rights of the Child.

## **Acknowledge children's changing roles**

*"We have to act like adults because no one else treats us like children and we have to do what adults do."*

- Providing for the needs of children affected by HIV/AIDS requires not only material support for immediate needs but also skills from which they may benefit in the future.
- Children are aware of economic difficulties and changes within the household and these issues must be discussed with them in order to prepare them.

## **Create an enabling environment**

*"Children have their own world. For us it is small, for them it is everything."*

- Stigmatization of HIV/AIDS can be broken down through education and discussion.
- Educating family members, teachers, peers and other community members on the needs of children affected by HIV/AIDS increases their understanding of the situation and lets them respond positively.
- Teachers must not write off children with behavioural problems as "problem children", but should try

to understand the reasons behind their misbehaviour.

- When they are given the knowledge about the needs of children affected by HIV/AIDS and the opportunity to do something about it, teachers will generally respond sympathetically and generously to their students.
- By reaching out and trying to understand a child's situation, a teacher or caregiver can provide love and guidance that the child desperately needs.

## **Allow kids to be kids**

*"That's as easy as eating sadza!"*

- Playing and adventure-based learning provide an opportunity for children to strengthen their physical and psychological well-being.
- Giving children the opportunity to talk about their feelings and experiences with other children allows them to realize that they are not alone and helps to build their self-confidence.
- Listening to what a child has to say is a low-cost way of reinforcing the child's importance in an uncertain situation.



## Involve youth in solutions

*“Your problems are no longer for you alone.”*

- Orphans will work together to create the family that they are missing at home and deal with the stigmatization from other children.
- If they are given the opportunity, youth will make responsible choices to improve the situation of others, such as the members of VSI educating younger orphans and helping the elderly.
- Giving them the opportunity to handle money may not always be flawless, but will give them a starting point from which to work.

## Communicate with children about HIV/AIDS

*“AIDS is not something to hide; it’s something natural.”*

- HIV-positive parents must realize that living positively with the virus, such as providing proper nutrition and having a healthy attitude, greatly benefits their children because it prolongs their lives and postpones orphanhood.
- Disclosing an HIV status to a child can be based on many things, such as the child’s age or maturity, but

inevitably it is the choice of the individual parent.

- Providing food and shelter for children means little if it is not accompanied by psychological support, such as communication and tolerance.
- Traditional healers play a major role in various African societies, teachers circulate information on HIV/AIDS and religious leaders influence beliefs of their followers. Because all of these people can greatly influence the situation of a child affected by HIV/AIDS, they should be included in HIV/AIDS education.

## Talk about death and dying

*“When you die, how should I do this?”*

- Children may not be able to describe their thoughts and feelings easily, but this does not mean the illness or death of a parent does not affect them.
- Avoiding talking to children about illness in the household may make it easier for the parent to handle, but can make children feel anxious, guilty and depressed, and can even lead to long-term emotional problems.
- Talking about death and dying can be a positive experience for both

parents and children. It gives children the opportunity to say good-bye and start the process of healing and gives parents the satisfaction that the child will be prepared to live without them.

- Parents may also need counselling to assist them in talking to their children about dying.
- Using a supplement such as the Memory Book is a useful tool to facilitate discussion on the child's family history and preparing for the future.

### **Educate and counsel children individually, in families and in groups**

*"We are looking at the future when we will be well-mannered children without HIV because we have already been taught about it."*

- HIV/AIDS education as part of counselling can be an effective way of prevention.
- Counselling prepares children for what lies ahead and encourages them to believe that they can manage through grief and loss.
- Whether it is individual or within a group, counselling allows bereaved children to express their feelings and deal with their anxiety.

- An important part of counselling is working within family and cultural norms.

### **Final tips**

*"There is one hope for the future for those who are still young.*

*If we work hard together, we can fight AIDS, hand in hand."*

- Programmes dealing with children and HIV/AIDS should develop a holistic, multidisciplinary approach by balancing the supply of material and psychosocial support.
- There is no "right" way of addressing children's needs. Because their psychosocial needs are so broad and involve so many issues, organizations must work together to provide comprehensive, complementary services.
- Assisting only orphans isolates other children, such as children with terminally ill parents or from impoverished families, who are both as financially and psychosocially in need as the orphaned children.
- Include all children in orphan projects so as not to create or continue stigmatization.
- Giving the community a role in support programmes can make the programme stronger and more sustainable.

- Through networking, AIDS organizations can learn from each other how to deal more efficiently with children's issues.
- Following-up in children's own communities is vital to the continued growth and empowerment of the child.

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# Appendix A: The UN Convention on the Rights of the Child / Summary

- Article 3 includes the provision that the “best interests of the child” shall be a primary consideration in matters concerning children;
- Article 5 recognizes the responsibility of members of the extended family, community, or legal guardians to provide for the child in a manner consistent with his or her evolving capacities;
- Article 8 concerns the right of a child to preserve his or her identity, including name and family relations;
- Article 12 recognizes a child’s right to be heard in any proceedings that concern him or her;
- Article 18 recognizes the responsibility of the State to support parents and legal guardians in their child-rearing responsibilities and to develop services for the care of children;
- Article 19 concerns the protection of children from abuse, neglect, maltreatment, or exploitation;
- Article 20 concerns the responsibility of the State to provide special protection for a child deprived of his or her family environment;
- Article 21 addresses safeguards regarding adoption;
- Article 24 recognizes the right of children to the highest standard of health and access to health services;
- Article 25 concerns the periodic review of the situation of a child who has been placed in care;
- Article 27 recognizes the right of children to an adequate standard of living;
- Article 28 concerns the right of every child to education;
- Article 32 addresses the protection of children from economic exploitation, and
- Article 34 concerns the protection of children from sexual exploitation and abuse.



**Programming for orphans and other vulnerable children from a rights perspective is based on guiding human rights principles and the foundation principles of the Convention on the Rights of the Child.**

***Guiding human rights principles***

Accountability	<ul style="list-style-type: none"> <li>• Children are holders of rights and have special rights because of their developmental and vulnerable state.</li> <li>• Children are social actors.</li> <li>• States accept obligations and are accountable to respect, protect and fulfil the rights of children.</li> <li>• Families are the primary caregivers and the protectors of children's rights.</li> <li>• Governments, civil society, communities, families, parents and caregivers are duty bearers. All have obligations to children.</li> </ul>
Universality	<ul style="list-style-type: none"> <li>• Each and every child has equal and inalienable rights, all the time, no matter where he or she lives.</li> </ul>
Indivisibility	<ul style="list-style-type: none"> <li>• All rights are equally important and are mutually reinforcing.</li> </ul>

***Foundation Principles of the Convention on the Rights of the Child***

Best Interests of the Child	<ul style="list-style-type: none"> <li>• What the best solution for the child is must be the primary consideration in all actions regarding children.</li> </ul>
Non-discrimination	<ul style="list-style-type: none"> <li>• All children have the same right to develop to their potential: regardless of race, colour, gender, caste, language, opinion, origin, disability, birth, family status or any other characteristic.</li> </ul>
Right to Survival and Development	<ul style="list-style-type: none"> <li>• Child development is a holistic concept.</li> <li>• Access of children to basic social services is critical.</li> <li>• Actions must be taken to provide special assistance to the most vulnerable or most in need.</li> </ul>
Respect for the Views and Participation of the Child	<ul style="list-style-type: none"> <li>• The views of the child are to be heard, respected and taken into account.</li> <li>• Every child has the right to participate in decision-making processes that affect them.</li> </ul>

**Source: Principles to Guide Programming for Orphans and other Vulnerable Children, UNICEF, New York, draft 3, January 2001**

## Appendix B: Organizational resources and contacts

Organization	Contact	Documents / Training Material	Target Group
<b>HUMULIZA</b>	PO Box 158, Muleba-Kagera, U. R. Tanzania. k.madoerin@terredeshommes.ch	Psychosocial Support for Orphans. Manual <a href="http://www.terredeshommes.ch/humuliza/humuliza.html">www.terredeshommes.ch/humuliza/humuliza.html</a>	Child NGO staff, teachers, social workers
		Manual for Group Counselling with Orphans	Child NGO staff, teachers, social workers
		Training in psychosocial support for children affected by HIV/AIDS (1) handouts (2) instruction for facilitators <a href="http://www.terredeshommes.ch/humuliza/humuliza.html">www.terredeshommes.ch/humuliza/humuliza.html</a>	Youth leaders, programme staff, child NGO managers, social workers
		Modules for Adult Training	Trainers, child NGO managers
<b>Masiye Camp</b>	Ezekiel Mafusire, The Salvation Army, Box AC 800, Bulawayo, Zimbabwe. Tel: +263 /838 222 Fax: +263 /838 228  Info@masiye.com (Web: <a href="http://www.masiye.com">www.masiye.com</a> )	Training in psychosocial support for children affected by AIDS	Youth leaders, programme staff, child NGO managers, social workers
		Manual for Teenage Parenting and Household Maintenance	Heads of child-headed households and children caring for ill parents, NGO staff and youth leaders.
		Manual for Orphan Life Skills Education	NGO staff, youth leaders
		Masiye Camp Adventure Based Training	Youth leaders and NGO staff
		Psychosocial support for children affected by AIDS resource bag	NGO managers and staff, school psychological services, teachers

## Appendix B: (continued)

Organization	Contact	Documents / Training Material	Target Group
<b>Farm Orphans Support Trust</b>	CFU-FOST Box 390, Westgate, Harare, Zimbabwe. Tel: +263 /4 309 800 fost@cfu.co.zw	Farm Orphans: Who Cares?	NGO staff and managers
		Orphans on Farms: Who is Coping? An Exploratory Study into fostering orphaned children on commercial farms in Zimbabwe. March 1996.	NGO staff and managers
<b>Child Protection Society</b>	PO Box BE 220, Belvedere, Harare. Tel: +263 /4 708 829 or +263 /4 780 079 advocacy@mweb.co.zw	How Can We Help? Approaches to Community-based Care	Community-based care workers, NGO staff
<b>Island Hospice</b>	Sam Mkwanzani, PO Box CY 7, Causeway, Harare. Tel: +263 /4 335 888/6 Fax: +263 /4 335 953 island@africaonline.co.zw	Home Care of the Terminally ill	Carers for terminally ill patients at home
<b>AIDS NGO Network in East Africa (ANNEA)</b>	Secretariat, Rebman House, Old Moshi Road, PO Box 6187, Arusha, United Republic of Tanzania. Tel: +255 /27 75 21 annea@habari.co.tz		ANNEA Member NGOs working with children in East Africa

The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together seven UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its seven cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners – governmental and NGO, business, scientific and lay to share knowledge, skills and best practice across boundaries.

The magnitude of the HIV/AIDS epidemic has starkly highlighted the needs of orphans and vulnerable children.

Coping with the cumulative impact of over 17 million AIDS deaths on orphans and other survivors, on communities, and on national development is an enormous challenge, especially in African countries with social and health services already reeling from lack of human and financial resources.

In spite of all hardships and stigma, these children also have a right to education, affection and cultural identity. They have a right to be heard and to be protected from abuse, neglect, maltreatment and exploitation. They have the usual needs of children, including economic, social, educational, medical and psychosocial needs.

This case study describes efforts to address the tough questions related to the rights and needs of children affected by HIV/AIDS, with a focus on their psychosocial needs. We hope that the effect of listening and talking to these children affected by HIV/AIDS will be to make their perspective much better known to adults who are working with millions of vulnerable children worldwide.



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