



Save the Children



Missing Mothers

Meeting the needs of children affected by AIDS

Missing Mothers

Meeting the needs of children affected by AIDS



Save the Children

Save the Children fights for children in the UK and around the world who suffer from poverty, disease, injustice and violence. We work with them to find lifelong answers to the problems they face.

Save the Children UK is a member of the International Save the Children Alliance, the world's leading independent children's rights organisation, with members in 27 countries and operational programmes in more than 100.

Published by
Save the Children UK
1 St John's Lane
London EC1M 4AR
UK

Tel +44 (0)20 7012 6400

First published 2006

© The Save the Children Fund 2006

Registered Company No. 178159

This publication is copyright, but may be reproduced by any method without fee or prior permission for teaching purposes, but not for resale. For copying in any other circumstances, prior written permission must be obtained from the publisher, and a fee may be payable.

Cover photo: Beatriz, seven, has lived with her grandmother in Huambo province, Angola, since her mother died of malaria. Save the Children has provided the family with clothes and other essential items, and has worked with the community to set up a Child Protection and Health Committee. (Photograph: Boris Heger)

Typeset by Grasshopper Design Company

Printed by Greenaways Ltd, London

Contents

Acknowledgements	iv
Abbreviations	v
<i>I Wish...</i>	vi
Foreword	vii
Executive summary	1
1 The crisis: missing mothers	3
2 What mothers and children need	7
3 Supporting communities to help mothers and children	11
Recommendations	15
Notes	16

Acknowledgements

This report was written by Christina D'Allesandro, with substantial input from Frances Ellery and Bill Bell.

It could not have been produced without the courage of the children and their families who have offered their stories. Thanks to the Save the Children staff and volunteers who have brought us the words of these families in their own voices.

Important note

Because there is little HIV testing in many countries, it is not known whether all the parents of children quoted in this report died or are ill because of AIDS. However, all the children live in areas with a high prevalence of HIV and AIDS.

Abbreviations

AIDS	acquired immuno-deficiency syndrome
ART	antiretroviral therapy
CBO	community-based organisation
GTT	Global Task Team
HIV	human immuno-deficiency virus
NGO	non-governmental organisation
TB	tuberculosis
UNGASS	United Nations General Assembly Special Session

I Wish...

I wish...

...that all my family members enjoy good health and live in harmony.

...for my family that they keep safe and sound.

...I can make my family members live happily.

...all my family members can have a long life.

...all my family members are happy and healthy.

...that every child could be happy every day.

...my parents are in good health forever.

...my father could soon be well.

...my father and grandma are in good health.

...my mother is healthy.

...that in ten years time we can still meet in this place.

...we can cure the disease in the future.

I worry...

...about my father's happiness, anger, grief, and joy.

...that my parents quarrel with each other.

...that I am misunderstood by my family members.

...about my parents' health.

...about my grandma and mother's health.

...that my mother's health is getting worse.

...others will look down on me because one of my family members has got HIV/AIDS.

From a poem by a child in Yunnan province, China, in *The Difficulties We Face*,
Save the Children, 2005

Foreword

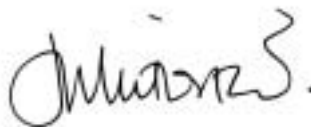
The most tragic thing that can happen to a young child is to lose his or her mother. It's not just an emotional tragedy. In many countries in the world, it has a dramatic impact on children's chances of surviving, getting an education and leading a healthy life.

In 2005, 2.3 million children were born to a mother living with HIV.¹ Throughout the world, there are nearly 20 million women living with HIV – most of them mothers. With proper support and care, they can live longer, and millions of children can have more years of their mother's care. The purpose of this report is to stress that, as well as supporting children who have already lost their mothers, we should be fighting to keep more mothers alive.

This has the scale and urgency of an emergency. Every day costs lives and has huge long-term implications. Women make up half of all those infected with HIV. In sub-Saharan Africa, young women between the ages of 15 and 24 are six times more likely than young men to be infected – just at the time when many of them are becoming mothers. This is not a problem for Africa alone; these trends are rapidly being mirrored across Asia, eastern Europe and Latin America.

Through our work on the ground, we know that the best care a mother and her children can get is at home. The extended family, neighbours and the local community are best placed to ensure that the right support reaches the right people. But, with few resources in the first place, and with the huge rise in the numbers of families affected, communities can't look after their own without support from outside.

This is why we're urging international donors to live up to the promises they've already made to provide 'proper support' for children. When UN member states meet in June to review what's been achieved in the last five years, they must commit resources to ensure that millions more mothers are not lost and that millions more children are not orphaned by AIDS.



Jasmine Whitbread
Chief Executive
Save the Children UK

Executive summary

Millions of children across the world have already lost their mothers to AIDS. Many more are currently caring for their sick mothers, knowing that they will die soon. As their mothers' health declines – as it inevitably will without treatment – it is the children who end up as the carers, tending to their ailing parents and caring for their siblings.

As well as the emotional cost, the loss of a mother can have a dramatic impact on children's lives. Children without mothers have less chance of getting enough food to eat, are more likely to miss out on school, and often end up having to care for themselves and the rest of their families. Over time the AIDS pandemic will rob millions more children of their childhoods, as well as robbing them of their mothers.

The AIDS pandemic increasingly has a woman's face, as more and more women become infected. In all, around 19.2 million women are currently living with HIV – half of all adults living with the virus. Most of these women are already mothers, and between them they are raising millions more children.

In the areas most highly affected by the pandemic, children make up nearly half the population. To date, any recognition of children's particular needs has focused on what happens after their parents have died. But children living with HIV-positive mothers have significant needs too, and can benefit enormously from any support to the family that can extend their mothers' lives and ability to care.

Communities are central to efforts to support mothers and children affected by HIV and AIDS. When a mother is sick, it is most often the extended family and the local community that help to support the mother and care for her children. But with the rising numbers of HIV-positive mothers and affected children, communities are struggling to provide support from their own resources and need external

help. Millions of dollars have been promised by donors to fight HIV and AIDS, but the failure to meet these commitments, funding bottlenecks, and a lack of focus on supporting children in their families and communities mean the money is not reaching those who are most in need.

Even where their own governments have funds available through social protection and other schemes, such funds rarely reach down to the family or community level. National social welfare schemes providing financial and other benefits rarely have extensive coverage, while existing funding arrangements make it difficult for community-based organisations to access funding. Communities often lack the knowledge and means to claim their share of the resources available.

A number of international commitments exist that indicate a growing awareness of the issue. In 2001, as part of the UN General Assembly Special Session (UNGASS) on HIV and AIDS, the member states of the UN made a commitment to meeting the needs of children affected by the pandemic – many of which arise from their mother's ill health. A major step forward was taken four years later in the communiqué from the G8 leaders at their 2005 Gleneagles meeting, where they committed to 'proper support' for children affected by AIDS.

The best estimate of what it will cost to provide such support to children living in families with HIV and AIDS or orphaned by the pandemic comes from the 2005 UNAIDS Global Task Team (GTT). Their estimate is that \$6.4 billion, or 12 per cent of the total resources needed over the next three years to address the AIDS pandemic, should specifically address the needs of vulnerable children.² Yet to date, only the US, the UK and Ireland have committed funding specifically for this purpose. Even if these three countries live up to their promises, this would amount

to just a quarter of what is needed. It is time for donors – in particular the G8 nations, the Global Fund to Fight AIDS, TB and Malaria, the World Bank and the European Commission – to come forward with the resources to support children who are losing their mothers and childhoods to HIV and AIDS.

In 2001, UNGASS made clear commitments for children. In June 2006, the member states of the UN will be meeting again at UNGASS +5 to review progress since 2001. Save the Children urges them to reaffirm the commitments made by the G8, clearly endorse the resource needs outlined by the GTT, and commit to providing the resources needed to provide more and better care for families, supporting mothers to provide continuing care for their children and reducing the numbers of children orphaned by AIDS.

That is why Save the Children is calling for:

- a focus on better care for mothers and children affected by HIV and AIDS, as well as support for orphaned children

- at least US \$6.4 billion – 12 per cent of promised AIDS funding over the next three years – to be targeted at children and families as recommended by the UNAIDS Global Task Team
- support for building national social welfare systems that provide direct financial and other benefits to families
- donors to remove funding bottlenecks and ensure that communities are involved in developing and implementing national AIDS plans, so that funds can reach the most vulnerable children
- free healthcare and more testing and treatment facilities.

Unless we act now, more women will die and many more children will be denied their mother's care. The sooner mothers can get support – and the better the quality of that support – the longer they will live and the better able they will be to care for their children.

I The crisis: missing mothers

The statistics are stark: 15 million children have already been orphaned, having lost at least one parent to AIDS. Many millions more are living in households with HIV-positive mothers at varying stages of the disease. The majority of these children are living in Africa. However, with India poised to pass South Africa as the country with the highest number of HIV-positive people, there is great concern that we have yet to feel the full effects of the pandemic in Asia. The pandemic shows little signs of being halted and, without an effective and co-ordinated response, more and more mothers will die.

To date, more than 60 million people have been infected and 20 million have died as a result of the pandemic.³ It is impossible to say precisely how many of those who have died are women because the statistics do not disaggregate deaths by gender, but we do know that, overall, around 19.2 million women are currently living with HIV – half of the total. Because women tend to seek treatment later, and generally have less access to antiretrovirals than men, women are likely to progress more quickly from illness to death. Given that most women with HIV are mothers, this has a drastic impact on their children.

There are many social and cultural factors that make women more vulnerable to HIV and AIDS. Young women are often not given the information they need regarding HIV and sexual activity as these subjects are considered taboo. Economic realities and social stigmas limit the options for women, and in particular younger women. They have less power in negotiating sexual relationships – and often none at all. Even when married, women are still vulnerable, as more than 80 per cent of new infections across the world now occur within marriages or long-term partnerships.⁴

As mothers grow sicker, they are less and less able to care for their children. Children – especially the eldest – often have to take on the role of carer,

tending to their ailing parents and caring for their siblings, often at the same time as working to earn a living for the family.

While mourning the mothers that have been lost, and ensuring support to their orphaned children, there is much we can and must do for the millions of mothers currently living with HIV. Resources must be channelled into improving the quality of their lives and protecting the welfare and development of their children. Children's needs cannot be addressed in isolation. The best response for children prioritises the needs of their family as a whole.

Mothers and children on the front line

The AIDS pandemic increasingly has a woman's face, as more and more women, especially young women, become infected. In Africa, women account for nearly 60 per cent of those infected.⁵ The increasing impact on African women is mirrored in other regions: the proportion of women becoming infected with HIV is rapidly increasing across Asia, eastern Europe and Latin America.⁶

Among 15–24-year-olds in sub-Saharan Africa, young women are six times more likely to be infected than men.⁷ These are the years when most will become mothers. After infection they will have many prime child-bearing years, often without visible symptoms.

“Children’s vulnerability starts when their parents become sick. When children stay with their sick parents or other relations, it usually results in their isolation from other people in the community. On top of that, children are forced to do hard work to support their sick parents and themselves. So there is a great need for us to work together with the home-based care

Pricilla

"I lost my mum six months ago, she was very sick. I did everything for her. Whenever she wanted water to drink I would get it for her. I would spoonfeed her and dress her. When I had to go to school I had to ask my neighbours to look after her, and particularly the carers from the clinic. She was really ill for five months and did not have a doctor.

"Before my mother was sick she did everything for me. She promised to take me to school to get a good education, which I'm worried about now. Whenever I look at the clothes my mum liked, they remind me of her.

"When I wake up I wash myself and sometimes I eat breakfast if there's pap (cornmeal porridge) or bread. Then I go to school, which is far to walk to. I like playing netball and I love school very much, especially politics and history, and learning about things that took place around the world and here.

"Every day I come home and wash my uniform. I wash my little sister and, if there is homework, I do this too. I cook pap for everyone, which takes a long time on the [Primus] stove. When my older sister comes, she eats in her bedroom with her children, and me and my younger sister eat together.

"I want to finish school and raise my little sister in my mum's house. The house is registered in my name now."

Pricilla,* 14, lives in Free State, South Africa, one of the country's poorest provinces and with the third highest prevalence of HIV and AIDS. Save the Children is training and supporting community volunteers to identify orphans and vulnerable children and refer them to social workers and the home affairs department, ensuring that they have birth certificates and helping them to get child support grants and go to school.

*not her real name



PAUL WEINBERG/PANOS

programme, which trains community volunteers to make home visits to families with sick parents, and the Orphans and Vulnerable Children Committee.”

Joaquim N’chumali, Save the Children Programme Officer, Morrumbala, Mozambique

Most women currently living with HIV are already mothers, and between them they are raising millions of children. Children born to HIV-positive mothers face many risks. Many women living with HIV experience ill health, but others may have no symptoms. Because of the lack of testing facilities in many countries, many mothers – especially the poorest living in the poorest countries – are not aware of their HIV status until they get ill and, in some cases, not even then. All of them, however, are at risk of transmitting the virus to their children during childbirth and postnatal care.

Without ante- and postnatal care, one third of children born to HIV-positive mothers will contract the virus themselves. Only half of these will survive to their second birthday.⁸ Even those children born before their mother is infected, and those who remain HIV-negative despite being born to a mother with the virus, are at risk as their mother’s health

declines. Without proper nutrition and treatment for opportunistic infections, most mothers will get weaker and weaker, until they are unable to fight off even the simplest infections. A study in Uganda found that death is four times greater among infants born to HIV-positive mothers, either because the child is infected or because their mother is too sick to look after them.⁹

To date, attention to children’s needs has focused on what happens after their parents have died. Clearly, orphaned children need care and support. However, to truly make a difference for the millions of children affected by HIV and AIDS, we must also support those whose mothers are HIV-positive but alive and still trying to care for their children.

“We have no testing facilities for HIV. We diagnose it ourselves by looking at the physical state of the person and give treatment, but we don’t have specific treatment for HIV. When we suspect a patient has HIV we can send them to Morrumbala for a test. We don’t have any idea of the percentage of people who are HIV-positive here.”

Adelino Simali, Chief Nurse,
Megaza health post, Mozambique



BORIS HEGGER

Graça

"I look after my mum every day. I go and fetch water, I clean the house and wash the plates. I prepare food for her when she's sick. My mum can walk, but if she does, for two days afterwards she can't walk or go to the fields. Henrique comes to visit my mum every week and helps her."

Graça, nine, lives with her mother who has been ill for three years. Her father is dead. Henrique Candeeiro, President of the local Orphans and Vulnerable Children Volunteers Committee, visits twice a week to help out – bringing them something to eat, cleaning the house or fetching medicine for Graça's mother. He says:

"Graça's mother became sick three years ago. We found out about her and included her in our programme. I visit her twice a week. She has diarrhoea, dysentery and chronic fevers, and stays sick even after going to hospital."

"On a normal visit I would come and find out how she is. If she's in a critical condition, I'll try and help her. I sometimes clean the house and bring something to eat. Sometimes I take her to the clinic or go and fetch medicine for her."

"The children benefit not just from the moral support, but also practically because they are too young to take care of their mother."

Save the Children trains community volunteers in first aid and counselling, and provides them with basic medicines so that they can care for chronically sick people, like Graça's mother, in their homes.

2 What mothers and children need

For a young child, losing their mother is the most tragic event that can happen. It is also likely to have a disastrous impact on their future. Mothers are crucial to a child's survival and development. Children who lose their mothers have less chance of getting enough food to eat, are more likely to miss out on school, and often end up having to care for themselves and the rest of their families. Maternal death from any cause results in higher mortality in children.¹⁰

Families living with HIV and AIDS have a range of needs. Mothers need proper nutrition, access to various forms of treatment and increased financial resources. Children need to be supported emotionally and given access to basic healthcare and education. Most mothers desperately want to continue to care for their children. There are many support systems that can enable this to happen, prolonging a mother's life and enabling families to cope better with the financial, social and emotional impact of the illness.

Currently, most people living with HIV die from preventable and treatable opportunistic infections. Regular medical attention and treatment of common opportunistic infections delay the need for complex antiretroviral therapy (ART). ART is indeed necessary for those with a highly compromised immune system. However, proper nutrition and access to well-known, proven treatments can delay the need for ART.

It is important, therefore, that access to medications to combat other illnesses is considered as well as antiretroviral treatment. This is particularly true with tuberculosis (TB) co-infection. The World Health Organization estimates that more than one-third of all HIV-positive people die from TB.¹¹ If co-infected mothers are treated and cured of TB, their lives can be extended by an average of three years.¹² Treatment of more minor infections and good nutrition from the early stages of diagnosis can prevent deterioration in the immune system. Many symptoms, such as cough,

nausea and fatigue can be treated simply and inexpensively in the home, preventing unnecessary visits to hospitals and clinics, and maximising resources for the family.

Many aspects of palliative care can be provided in the community through trained volunteer health workers, local non-governmental organisations (NGOs) and government services. The more support that can be provided at home, the longer HIV-positive mothers can stay with, and care for, their children. In the early stages of disease, healthcare workers with limited training can treat most HIV-positive people. Home-based care systems reduce healthcare costs, improve access to services and reduce community misconceptions regarding transmission of HIV between carers and patients. It also means that the systems are in place to support the family following bereavement.

User fees and other charges block poor families' access to vitally important treatment and care. To make a significant difference, treatment for basic infections and ART must be delivered free as part of an essential healthcare package. Community health workers and clinic staff need training in the management and treatment of HIV and AIDS to support this. However, treatment is only one answer.

More than just treatment

The biggest problem most families face in the developing world is poverty. HIV and AIDS drives them into even deeper poverty as carers become sicker and are unable to work. This means going without food, and being unable to get basic healthcare or pay for their children to go school. Families need financial support so that they can afford nutritious food and so that children do not have to drop out of school to support the family.



BORIS HEGGER

Maria Varista

"There was a survey by the government asking people, 'How do you live?' and I almost cried. They came to me on the Monday and on the Wednesday they came back with a bag of rice, sugar and cooking oil for me, my sister, and five others. We shared it. The others took theirs and sold it, but I couldn't because I had to feed my children.

"Then Save the Children encouraged us to set up a group and each member paid a fee of 1 kwanza [less than half a British penny]. Three of us bought rice and we shared the sack for food and for sales. Save the Children said they would help us carry it on, and we started to have more members joining. We were relieved because at the beginning we just bought one sack of rice. Now, we buy three or five sacks and we make more profit.

"With the profits, if one member of the group is sick, she can get money from the treasurer and go to the clinic. It is helpful."

Maria Varista, above right, is a member of the Ajuda Mutua co-operative in Luanda, Angola. Save the Children supports seven consumer co-operatives, most of which are made up of women, many of whom are widows. They buy basic foods together at cheaper prices and then sell them. As well as increasing the number of meals their families can have each day, they are able to support their children to go to school.

A few African countries have social welfare systems that entitle poor families to small grants or other benefits if a carer is sick. For many, this is their only means of survival. However, getting food or cash grants is often a complicated, expensive and bureaucratic process. Many mothers and children do not have, and cannot afford to get, birth certificates and other documentation that would enable them to receive such grants. Governments must be held to account to provide the basic services and support – including healthcare, education and cash transfers – that those who are most vulnerable are entitled to. National governments should be supported to develop and deliver formal safety net mechanisms that can assist families living in chronic poverty and those who are least able to support themselves.

In response to the current gaps in support, Save the Children works directly with communities to help them identify vulnerable households with children, and to design appropriate responses that enable them to access benefits, healthcare and education. Such initiatives work with members of the community to help children care for sick parents and obtain birth certificates, school uniforms and materials so that they can go to school. By involving children in designing and implementing such programmes, it is possible to ensure that their needs are met in the present, as well as increasing their ability to cope in the future.

Emotional support for HIV-positive parents throughout their illness is critical. Mothers face particular issues regarding pregnancy, disclosure of status to their children, and concerns over the fate of their children after their death. Community support

groups for people living with HIV and AIDS can provide a forum for sharing strategies for prolonging health, overcoming stigma, and coping with illness. Hope for the future can help mothers stay healthy longer, and increase their confidence to get access, and encourage better adherence, to treatment.¹³

In addition to the millions of children living in families already affected by HIV and AIDS, many millions more are living with asymptomatic HIV-positive parents. The more HIV-aware communities are, and the less stigma is attached to the disease, the more likely mothers are to learn their HIV status and prevent transmission to their children. It is widely known how to prevent transmission from mother to child. Offering mothers information and access to all options is crucial to preventing the spread of the pandemic.

It is important that children whose parents are sick do not have to drop out of school, and that legal services are provided to prevent them losing their homes and other property when their parents die. Save the Children is supporting changes in laws to enable mothers and children to get their inheritances. Working with families, communities, traditional leaders and law enforcement bodies can reassure mothers that their children will not lose their entitlement to family land, property and other assets when they are no longer there to defend them. Memory work, such as creating memory books telling the history and stories of their families, increases communication within families, and enables them to make plans about what will happen after the mother dies.



BORIS HEGGER

Manuel

"I was very young when my parents died and I only remember my father. I used to have two more brothers, but they died as well. Now I live with my brother Costordio, who is 18, but we don't have a house. Before, when we lived with other family members in another community, we used to sleep inside. But it was a long walk to get to school, so we came here [to this village]. I hope to get a house one day, but I have no idea how.

"In the morning I get up and have a little bit of chima (made from cassava flour) and my brother usually sends me to the market. I buy salt and sometimes maize, which we make into flour. Then I sweep the floor and go looking for firewood. My brother and I work on the farms in the community. We earn about 10–15,000 meticaïs [about 20–30p] in a day, and we get work about three days a week. We don't have anything to eat in the middle of the day, but have a little bit of chima again in the evening. I only get about an hour a day to play because I have to work. But I love playing football.

"Before the education fair, I could only afford one exercise book and one pen for both subjects, and my trousers were falling apart. But I was identified by the Orphans and Vulnerable Children Committee so I went along to the education fair set up by Save the Children. Afterwards someone from Save the Children came to visit me to see how I was doing. At the fair, I got a voucher for 130,000 meticaïs (£2.80) which I exchanged for a shirt, a pair of trousers, a coat and also four exercise books and two pens.

"It's not enough though. We're still facing problems because we don't have enough food and clothes."

Manuel, 14, and his older brother have no home. Both their parents are dead. Manuel benefited from an education fair organised by Save the Children with his local Orphans and Vulnerable Children Committee in Morrumbala, Mozambique. At the fairs, children are given vouchers to exchange for school materials and clothes, which means they are then able to go to school.

3 Supporting communities to help mothers and children

Most children live in families and, in difficult times, families rely on each other and on the support of their communities. Any response acknowledging the impact of the AIDS pandemic on children, therefore, must place families and communities at its centre.

There is a strong history of neighbours and informal community groups helping each other. However, with the huge rise in the numbers of affected children, poor communities are struggling to provide support from their own resources. Families and communities provide more than 90 per cent of the economic support currently received by AIDS-affected households.¹⁴ Throughout sub-Saharan Africa, lack of essential services is nothing new. When families face crises such as illness or death, other households and communities provide monetary gifts, loans, food, clothing and school fees, enable access to medical care, donate labour and provide employment.

Communities are best placed to offer a holistic, organised and sustainable response to vulnerable families and children. They are a natural choice for many reasons.

- Community child-focused initiatives can involve a blend of material, social and emotional support.
- Community-based organisations (CBOs) are usually acutely aware of the importance of promoting self-help, providing handouts only where absolutely necessary.
- CBOs are often best placed to know who is in most need, and what support is required.
- Activities implemented by communities frequently benefit entire households.
- Community support is flexible and can be mobilised rapidly in response to crises.
- Administrative costs for community responses are generally very low.¹⁵

However, children's rights within their families and, for example, to inheritance may not be recognised or respected by the community. Children whose parents are ill or who have died may be vulnerable to other forms of exploitation or discrimination. Also, most children will remain in their communities after their parents have died. It is therefore important that CBOs themselves are supported and trained to identify needs, provide appropriate support and ensure that all children are protected.

The vast majority of funds to support families in need come from the pockets of the poorest families – those least likely to be able to cope. In spite of the recognised benefits of community-based responses, even where their own governments have funds, they rarely reach down to community level. National welfare systems are not in place to channel money and other resources to such local levels. Existing funding arrangements are not designed to reach communities, causing bottlenecks in the distribution of funds and making it difficult for CBOs to access available funding. Many have difficulty in identifying funders, find that their group's activities are incompatible with funders' strict requirements, or that application forms are too complex. There is also often a lack of feedback about the progress of applications, and delays in getting the funds. Also, communities often do not have the facilities or support to administer comparatively large amounts of money.¹⁶

To ensure that money is reaching those who need it most, donors must ensure that CBOs or their representatives are involved in national planning and decisions about local service delivery. National governments must create the channels that enable money to reach communities, and donors must ensure that their funding requirements do not prevent communities accessing funds.

Angelo

"We have 16 people in the committee (M'bobo Orphans and Vulnerable Children children's committee), aged ten to 16. We started in January 2004 when we collected data to find out the total number of children in the area. We did a study and found that many children had lots of problems.

"Children of all ages come to the meetings. We teach them how to protect themselves against HIV and how it's transmitted. We're also teaching the communities about the need to protect children generally. Sometimes if there is an orphan child living in a household, they don't get the same food as the other children.

"HIV is a big problem here. We don't know who has HIV because we don't have any testing facilities and we don't point out that anyone has HIV because that is discrimination. Discrimination has definitely decreased in our community because of the work of our committee. Every week we do these games and talk to the children and the parents. We're having a meeting this weekend to discuss the rising number of orphans here.

"The most worrying problem children have in our community is hunger. Another is lack of clothes and blankets. Some don't even have houses. Children also have problems with having to buy school materials at the beginning of the year. Children can't go to school because they haven't got registration papers. Save the Children approved a project we proposed to help register children, and we helped 297 children get their papers. But we didn't just stop there. Now we teach, educate and sensitise children and adults about all sorts of problems."

Angelo, 16, above right, is the only child who is president of an Orphans and Vulnerable Children's Committee in his area in Zambezia province, Mozambique. Last year, over 20 per cent of the population in the province were estimated to have HIV. There are many families in which children are caring for parents and many others are orphans. It is one of the poorest regions in Zambezia and is suffering from drought. Save the Children trains Orphan and Vulnerable Children's Committees to do surveys in the community to work out who are orphans or vulnerable children and what support they need. They can then apply for small grants for livelihood and social protection projects.



BORIS HEGGER

Global to local: donors' support to families and communities

Recent global commitments have belatedly started to acknowledge the needs of children and families arising from the pandemic and sought to raise their profile in the response. One key global policy document, the inter-agency *Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV/AIDS*, sets out the key principles and strategies for any global response, including strengthening families and communities.¹⁷

This Framework (produced by the UN, government, faith-based, community, private sector, academic and non-governmental organisations) is intended to act as a guide to policy-makers and planners for the formulation of scaled-up, effective national responses for children made vulnerable by HIV and AIDS. This key document can and must form the backbone of a collective response.

In 2001, as part of the UN General Assembly Special Session (UNGASS) on HIV and AIDS, the member states of the UN made a commitment to meeting the needs of children affected by the pandemic. The

declaration coming from this meeting recognised the importance of care, support and treatment for an effective AIDS response, with articles 65, 66 and 67 referencing children affected by AIDS specifically.¹⁸

2005 brought renewed commitment. At the G8 summit in Gleneagles, leaders of the world's richest nations made strong statements on HIV and AIDS. In addition to increased access for children to health services and education, support for vulnerable children was mentioned explicitly, and 'proper support' guaranteed. Furthermore, the G8 committed to expanding the delivery of treatment beyond the existing targets to ensure 'as close as possible to universal access for all' by 2010.

The best estimate of what is needed to meet the needs of children affected by HIV and AIDS comes from the 2005 UNAIDS Global Task Team (GTT). This team estimated that \$6.4 billion, or 12 per cent of total AIDS resources, is needed over the next three years specifically to address the needs of vulnerable children living with HIV-infected parents or who have been orphaned.¹⁹ To date, only three donors have committed funding specifically for children: the

Key strategies to support children

- Strengthening the capacity of families to protect and care for orphans and vulnerable children by prolonging the lives of parents and providing economic, psychosocial and other support
- Mobilising and supporting community-based responses
- Ensuring access to essential services
- Ensuring governments protect vulnerable children through improved policy and legislation
- Raising awareness through social mobilisation to create a supportive environment for children and families

Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV/AIDS

Children orphaned and affected by HIV/AIDS need special assistance

UNGASS *Declaration of Commitment on HIV/AIDS*, Articles 65, 66 and 67

65. By 2003, develop and by 2005 implement national policies and strategies to build and strengthen governmental, family and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS, including by providing appropriate counselling and psychosocial support, ensuring their enrolment in school and access to shelter, good nutrition and health and social services on an equal basis with other children; and protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance;

66. Ensure non-discrimination and full and equal enjoyment of all human rights through the promotion of an active and visible policy of de-stigmatization of children orphaned and made vulnerable by HIV/AIDS;

67. Urge the international community, particularly donor countries, civil society, as well as the private sector; to complement effectively national programmes to support programmes for children orphaned or made vulnerable by HIV/AIDS in affected regions and in countries at high risk and to direct special assistance to sub-Saharan Africa.

US, the UK and Ireland, and only Ireland exceeds the 12 per cent. Even if these countries live up to their promises, this will amount to just a quarter of what is needed.

This year, delivery on the commitments to the response to HIV and AIDS will be evaluated when the UNGASS on HIV and AIDS meets again in June.

Although there have been some developments, donors have clearly not delivered on their promises, and support is not reaching those who most need it. 2006 is the year for donors to fulfil their commitments to children whose mothers and childhoods are being lost to HIV and AIDS. Save the Children is making the following recommendations.

Recommendations

To preserve families and to keep mothers and children together for as long as possible, more funding must be targeted at children living with HIV-positive parents – as well as orphans. In 2001, the member states of the UN made clear commitments for *all* children affected by HIV/AIDS. This June they will be meeting again – at the so-called UNGASS+5 – to review progress since 2001. Save the Children urges them to reaffirm the commitments made by the G8; to clearly endorse the resource needs identified by the UNAIDS Global Task Team; and to commit to providing the necessary resources to provide more and better care for families and to stop more children losing their mothers prematurely to HIV and AIDS.

Focus on better care for mothers and children affected by HIV and AIDS, as well as support for orphaned children. As well as focusing on children who have already been orphaned by AIDS, priority must be given to the situation of millions of children living in families with a sick or dying parent.

Deliver US \$6.4 billion for children at UNGASS+5. Donors have committed to ‘proper support’ for children. To meet this commitment, donors (in particular the G8 nations, the Global Fund to Fight AIDS, TB and Malaria, the World Bank and the European Commission) must spend 12 per cent of their AIDS funding over the next three years on proper support for children.

Support national governments to provide national social welfare systems. Poverty is the stark reality for many families affected by AIDS. National social welfare systems providing cash grants and other benefits can work with local community organisations to deliver directly to families in need. The design and delivery of such support will vary from country to country and must be linked to national planning processes.

Increase community involvement at national and local level. Local communities are best placed to identify and meet the needs of vulnerable children and their mothers, and should be at the forefront of the response. To ensure that money is reaching those who need it most, donors and national governments should involve community-based organisations or their representatives in national planning and in decisions about local service delivery.

Make healthcare free and increase investment in health systems. Mothers need more than access to antiretroviral therapies and other medication. Health systems should provide a range of care, including emotional support and access to home-based care that enables mothers to stay in their homes and care for their children. Save the Children supports the removal of all fees at point of service for essential healthcare.

Notes

¹ UNICEF presentation, Chew Luo, 9 February 2006, Global Partners Forum Technical Consultation, London, UK.

² UNAIDS (2005) *Resource Needs for an Expanded Response to AIDS in Low- and Middle-income Countries*. The \$6.4 billion figure is calculated on the basis of 12 per cent of the \$55.1 billion estimated by the UNAIDS Global Task Team as total AIDS funding needed over the next three years.

³ UNAIDS (2004) *Report on the Global AIDS Epidemic*, UNAIDS, Geneva.

⁴ Communications Consortium Media Center (2003) 'Fight HIV/AIDS' in *A Mother's Promise the World Must Keep: The 10th anniversary of the Cairo Consensus*.

⁵ UNAIDS/WHO (2004) *AIDS Epidemic Update*, December 2004, UNAIDS, Geneva.

⁶ UNAIDS (2004) *op cit*.

⁷ UNAIDS/WHO (2004) *op cit*.

⁸ UNICEF (2005) *A Call to Action: Children, the missing face of AIDS*, UNICEF, New York.

⁹ Nakiyingi JS, Bracher M, Whitworth JA, Ruberantwani A, Busingye J, Mbulaiteye SM, Zaba B (2003) 'Child survival in relation to mothers' HIV infection and survival: evidence from a Ugandan cohort study', *AIDS*, 17(12):1827–1834.

¹⁰ Barnett T, Whiteside A (2002) *AIDS in the 21st Century: Disease and globalisation*, Palgrave, Macmillan.

¹¹ World Health Organization, February (2006) www.who.int/hiv/topics/tb/tuberculosis/en.

¹² Creese A, Floyd K, Alban A, Guinness L (2002) 'Cost-effectiveness of HIV/AIDS interventions in Africa: a systematic review of the evidence', *Lancet* Volume 359 165–1642.

¹³ UNAIDS (2002) *Report on the Global AIDS Epidemic*, UNAIDS, Geneva.

¹⁴ Save the Children UK (2005) *Bottlenecks and Drip Feeds: Channelling resources to communities responding to orphans and vulnerable children in southern Africa*.

¹⁵ Save the Children (2005) *ibid*.

¹⁶ Save the Children (2005) *ibid*.

¹⁷ UNICEF (2004) *A Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*, UNICEF, New York.

¹⁸ UN General Assembly Special Session (UNGASS) on HIV and AIDS (2001) *Declaration of Commitment on HIV/AIDS*, A/Res/S-26/2.

¹⁹ UNAIDS (2005) *op cit*.



Save the Children

06 0243a

Missing Mothers

Meeting the needs of children affected by AIDS

Millions of children across the world have already lost their mothers to AIDS. Millions more are caring for their sick mothers, knowing they will die soon. With proper support within their communities, mothers can be cared for in their homes, and continue to care for their children.

Until now, support for children affected by AIDS has focused on orphans. In *Missing Mothers: Meeting the needs of children affected by AIDS*, Save the Children argues that we should also be targeting mothers. The more care a mother gets, and the longer she can be supported at home, the better her children's chances of survival.

Save the Children UK
1 St John's Lane
London EC1M 4AR
UK

Tel +44 (0)20 7012 6400

www.savethechildren.org.uk