



# Missing on Mother's Day

Millions of children across the world will be spending Mother's Day this year without their mothers – because they have lost them to AIDS. Many more will face it having to care for their sick mother, knowing that she will die soon. As their health declines – as it inevitably will without treatment – mothers are less and less able to care for their children. Gradually roles are reversed until it is older children who end up as the carers, tending to their ailing parents and caring for their siblings.<sup>1</sup>

With the rising numbers of children affected by AIDS, communities are struggling to provide support. Millions of dollars have been promised to fight HIV and AIDS, but funding bottlenecks and a lack of focus on children means the money is failing to reach the most vulnerable children.

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 orphaned children
- at least \$6.4 billion – 12 per cent of promised AIDS funding – to be targeted at children and families<sup>2</sup>
- support for 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 reach the most vulnerable children
- free healthcare and more testing and treatment facilities.

*"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 Simail, Chief Nurse,  
Megaza health post, Mozambique

**Right** In poor countries like Angola, children are increasingly born to mothers who either already have HIV or later contract it. As there are so few healthcare facilities, children often end up caring for their sick parents or orphaned at an early age.





## Mothers and children on the front line

The AIDS pandemic increasingly has a woman's face, as more and more women become infected. Among 15–24-year-olds in sub-Saharan Africa, young women are six times more likely to be infected than men.<sup>3</sup>

In all, around 19.2 million women are currently living with HIV – and most of them are already mothers. A study in Uganda found that death is four times greater among infants born to HIV-positive mothers, sometimes because the child is infected and sometimes because their mother is too sick to look after them.<sup>4</sup>

To date, any recognition of children's particular needs has focused on what happens after their parents have died. However, to truly make a difference we must also support children whose mothers are HIV-positive.

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. More than 80 per cent of new infections across the world now occur within marriages or long-term partnerships.

Many women living with HIV are ill, but others may have no symptoms. All of them, however, are at risk of transmitting the virus to their children during childbirth and postnatal care. Without treatment, one third of children born to HIV-positive mothers will contract the virus themselves. Only half of these will survive to their second birthday.<sup>5</sup>

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. Without proper nutrition and treatment for opportunistic infections, most will get weaker and weaker, until they are unable to fight off even the simplest infections.

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



Home-based care volunteer, Henrique Candeeiro, helping Graça with her homework. The friendship and support he gives her are as important as the practical help he gives to her ill mother.



*“After my chores I don’t do anything because there isn’t any food. I sometimes have an evening meal of chima [maize flour with cassava], and sometimes we have food at lunchtime, but never both in the same day.*

*“If I had a wish it would be for some food for today.”*

Josephina’s\* mother died two years ago and her father died last year, both from undiagnosed illnesses. She now lives with her grandfather, aunt and 11 other children in a tiny house. Many sleep outside. One sister is doing sex work to survive, but is now pregnant. HIV testing is available to very few people in Mozambique, but it is estimated that 273,000 children have been orphaned by AIDS in Zambezia province alone, which has the highest incidence rate in the country.

\*name changed to protect identity



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*Josephina, cooking a very basic meal of maize flour porridge – the only food available to her and her 11 orphaned siblings and cousins.*

## Keeping mothers alive

We have already lost millions of mothers to the pandemic, and at least 15 million children have already lost at least one parent. In sub-Saharan Africa alone, more than 12 million children under the age of 15 have lost one or both parents to AIDS. By 2010, at current rates of HIV infection, this number is likely to increase to more than 18 million. With HIV rates across Asia continuing to rise at a frightening rate, it will soon have a devastating impact on mothers and children there as well.

For a young child, losing a mother is the most tragic event that can happen. It can also have a disastrous impact on their future. 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. In other words, the AIDS pandemic robs millions of children of their childhoods as well as their mothers.

## Community matters

When a mother is sick, and after she dies, it is most often the extended family and the local community that help to support the family and care for her children. With the rising numbers of affected children, communities are struggling to provide support from their own resources. Even where national governments have funds, they rarely reach down to community level because governments do not have systems in place to channel money and other resources. Existing funding arrangements are not designed to reach communities, causing bottlenecks in the distribution of funds and making it difficult for community-based organisations to



access available funding. Also, communities often do not have the facilities to access and administer comparatively large amounts of money.

Community-based organisations often find conditions on funding inflexible and have identified many obstacles to applying for and obtaining funding:

- difficulties in identifying funders
- incompatibility of group activities with funders' requirements
- complexity of application forms, lack of feedback about progress of applications and delays in getting the funds.

## Global commitments

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. A major step forward was taken 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 means to provide such support to children orphaned and those living in families with HIV and AIDS comes from the 2005 UNAIDS Global Task Team (GTT). Their estimate is that \$6.4 billion, or 12 per cent of total AIDS resources needed over the next three years, should specifically address the needs of vulnerable

children. Yet to date, only the US, the UK and Ireland have committed funding specifically for children. 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 whose childhoods are being lost to HIV and AIDS.

Unless we act now, more women will die and many more children will be deprived of 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.

## What mothers and children need

The biggest problem most families face 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.

A few African countries have social welfare systems that entitle poor families to grants if a carer is sick. For many, this is their only means of survival. However, getting food or cash grants is

*One in three Angolan girls have at least one child by the time they are 18 years old. Yet studies show that 43 per cent of young Angolans start sexual activities at 15 years old, 70 per cent don't use protection and 90 per cent can't identify three ways of avoiding HIV infection."*<sup>6</sup>

Susan Grant, Save the Children Programme Director, Angola



*"I was identified by the Orphans and Vulnerable Children committee so I went along to the education fair. 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 meticais (£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."*

Both Manuel's parents are dead. He sleeps outside every night with his elder brother.



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*Manuel, 14, using the materials he received from Save the Children's education fair, without which he would be unable to attend school.*

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 enables them to receive grants.

Save the Children works with communities to help them identify vulnerable children, and to design appropriate responses that enable them to access benefits, healthcare and education. Such initiatives may also work with other members of the community to help children care for sick parents and obtain school uniforms and materials so that they can go to school.

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 also reduce healthcare costs and improve access to services.

It is important that children who have been orphaned or 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 parents die. Save the Children is supporting changes in laws to enable mothers and children to get their inheritances. We also work with parents and children to help them plan for the future after their mother's death.

To expand these initiatives, more funding must be targeted at children – not just those who have been orphaned, but also those whose parents are HIV-positive. In 2001, UNGASS made clear commitments for children. This June they will be meeting again at UNGASS +5 to review progress since 2001. Save the Children urges them to echo the commitments made by the G8, clearly endorse the resource needs outlined by the GTT, and to commit to providing the resources needed to provide more and better care and stop more children being orphaned by HIV and AIDS.



## Recommendations

**Focus on children in families as well as orphaned children.** As well as focusing on children who have been orphaned by AIDS, priority must be given to children living in families with a sick or dying parent.

**Insist on \$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 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 and local community organisations can work together 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 must ensure that community-based organisations or their representatives are involved in national planning and decisions about local service delivery.

**Make healthcare free and increase investment in health systems.** Mothers need more than access to antiretroviral therapies. Health systems should provide holistic 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.

## References

- <sup>1</sup> Gilborn LZ, Nyonyintono R, Kabumbuli R and Jagwe-Wadda G (2001) *Making a difference for children affected by AIDS: Baseline findings from operational research in Uganda*. Washington, DC; Yamano T and Jayne TS (2005) 'Working-age adult mortality and primary school attendance in rural Kenya', *Economic Development and Cultural Change*, 53(3):619–653
- <sup>2</sup> UNAIDS, *Resource Needs for an Expanded Response to AIDS in Low- and Middle-income Countries*, August 2005. 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.
- <sup>3</sup> UNAIDS/WHO, *AIDS Epidemic Update*, December 2004
- <sup>4</sup> Nakiyingi JS, Bracher M, Whitworth JA, Ruberantwani A, Busingye J, Mbulaiteye SM, Zaba B (2003) 'Child Survival in Relation to mother's HIV infection and survival: evidence from a Ugandan cohort study', *AIDS*, 17(12):1827–1834
- <sup>5</sup> UNICEF (2005) *A Call to Action: Children, the missing face of AID*
- <sup>6</sup> USAID/UNICEF/PSI, *Sexual Knowledge, Attitudes and Practices of Urban Youth in Angola*, Results of survey conducted September 2002

### IMPORTANT NOTE

Because there is little HIV testing in Mozambique, it is not known whether the parents of children quoted in this briefing have died or are ill because of AIDS. However, it is estimated that 20 per cent of the population in Zambezia province, where the children live, are HIV-positive.

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