

Focus

AIDS and orphans: a tragedy unfolding

“We wanted to stay together after our parents and grandparents died of AIDS. I want to go back to school, but there is no money... I must work hard to get a good life and look after myself not to get the disease my mother and father had.” – *Felix, 15 years old, the sole income earner in a household that includes his five younger siblings and an 80-year-old great uncle*

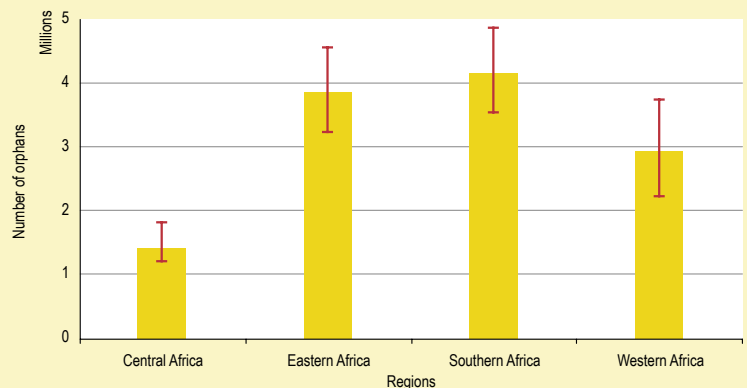
Children orphaned by AIDS are found in almost every country of the world. In some countries, there are only a few hundred or a few thousand. In Africa, there are millions. All have suffered the tragedy of losing one or both parents to AIDS, and many are growing up in deprived and traumatic circumstances without the support and care of their immediate family (see Figure 15).

Children orphaned by AIDS range in age from a few days or months old to 18 years of age. In countries with low-level and concentrated epidemics, it is impossible to reliably estimate the number of children orphaned by AIDS, or to determine what percentage they represent of all orphans.

The worst orphan crisis is in sub-Saharan Africa, where 12 million children have lost one or both parents to AIDS. By 2010, this number is expected to climb to more than 18 million. As staggering as these numbers are, the crisis will worsen if parents struck by HIV do not get access to life-prolonging treatment and effective prevention services.

Some countries have yet to experience the full impact of parental deaths. For example,

Orphans per region within sub-Saharan Africa, end 2003



Source: UNAIDS, 2004

Figure 15

in South Africa, the number of orphans is expected to increase from 2.2 million (12% of all children) in 2003 to 3.1 million (18% of all children) by 2010. Even in countries where HIV prevalence has stabilized or declined, the number of orphans continues to rise due to the time lag between when parents become infected and when they die.

Despite the daunting numbers, children orphaned by the epidemic can still have safe, healthy and productive childhoods, but only if all sectors of society respond with immediate, sustained and coordinated efforts that give high priority to protecting children and preserving the family unit.

Who is an ‘orphan’?

An orphan is defined as a child under the age of 18 who has had at least one parent die. A child whose mother has died is known as a maternal orphan; a child whose father has died is a paternal orphan. A child who has lost both parents is a double orphan.

Many agencies now avoid using the term ‘AIDS orphan’ as it is stigmatizing. Extensive research shows that stigma prevents governments and communities from effectively responding to the orphan problem, as well as hindering the emotional recovery of affected children themselves (Stein, 2003). Stigma and discrimination also intensify violations of these children’s rights—in particular, their access to education, social services, and community and familial support (see ‘Human Rights’ focus).

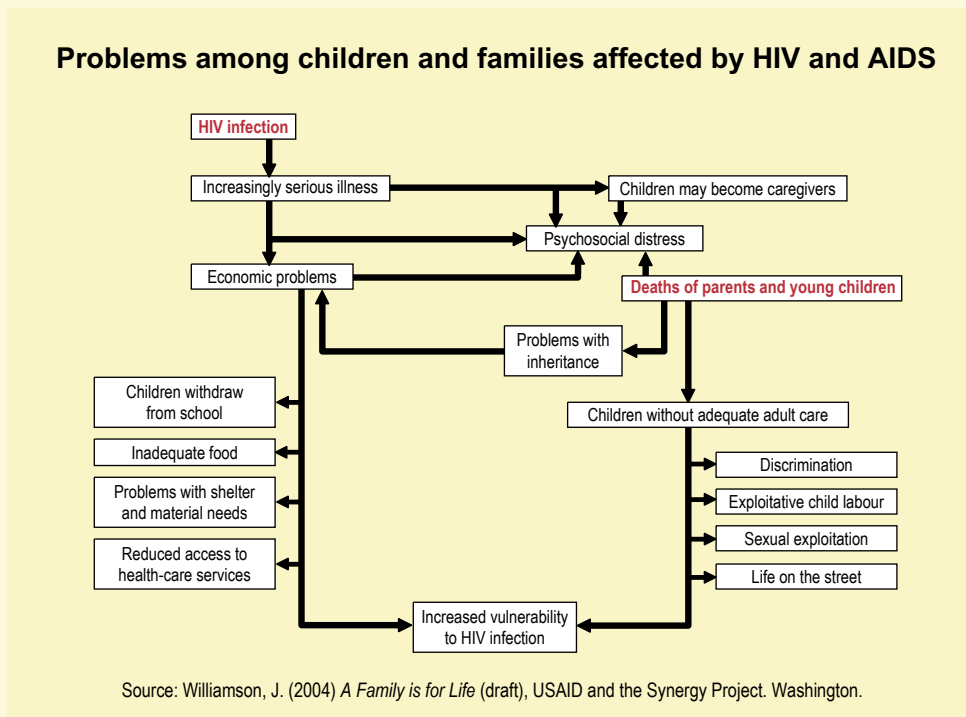
The impact on children

Even people who work with orphaned children struggle to understand the emotional anguish a child experiences as he or she watches one or both of his or her parents die. When one parent is HIV-infected, the probability is high that the other parent is as well. Therefore, children often lose both parents in quick succession. An orphan’s caregivers may also succumb to AIDS, with the result that children may suffer

multiple bereavements. The child’s suffering is often compounded by being separated from his or her siblings.

For example, in a report from Zambia, separated siblings said they see each other less than once a month (Family Health International, 2002). Many experience depression, anger, guilt and fear for their futures. This experience can lead to serious psychological problems such as post-traumatic stress syndrome,

Figure 15a



alcohol and drug abuse, aggression, and even suicide (Foster, 2002).

Poverty and social dislocation also add to an orphaned child's emotional distress. Factors such as loss of household incomes, the cost of treating HIV-related illnesses, and funeral expenses frequently leave orphaned children destitute. A parent's death also deprives them of the learning and values they need to become socially knowledgeable and economically productive adults. Recent research suggests that this breakdown in intergenerational knowledge may play a part in a country's economic decline (Bell et al., 2003).

Orphans at risk

Without the protective environment of their homes, orphaned children face increased risk of violence, exploitation and abuse. They may be ill-treated by their guardians, and dispossessed of their inheritance and property. Those living with foster families are more likely to be malnourished, underweight, or short for their age in comparison to non-orphans (Monasch and Snoad, 2003). In worst-case scenarios, orphaned children may be abducted and enrolled as child soldiers or driven to hard labour, sex work, or life on the streets.

In Cambodia, a recent study by the Khmer HIV/AIDS NGO Alliance and Family Health International found that about one in five children in AIDS-affected families reported that they had to start working in the previous six months to support their family. One in three had to provide care and take on major household work. Many had to leave school, forego necessities such as food and clothes, or be sent away from their home. All of the children surveyed had been exposed to high levels of stigma and psychosocial stress, with girls more vulnerable than boys.

However, there are many examples of successful help for orphans in these situations. In Zimbabwe, since 1998, the Salvation Army's Mayise Camp has provided psychosocial support to orphaned children. It recently expanded its care services to tackle violence, exploitation and abuse. Since children often have trouble obtaining medical, psychological and legal services, the Camp started a Mobile Law Clinic that brings essential services to the children. In Cambodia, the nongovernmental organization *Mith Samlanh* ('friends') runs 12 interlinked programmes for 1500 street children, ranging from HIV prevention and care, to reproductive health education and income-generating activities.

Ensuring access to education is critical in responding to the orphan crisis. Orphans often fall behind or drop out of school, compromising their psychosocial development and future prospects. This also affects a country's long-term recovery from the epidemic. For instance, research in the United Republic of Tanzania revealed that the school-attendance rate among orphans who had lost one parent was only 71%. Among double orphans it was even lower at 52% (Monasch and Snoad, 2003).

Staying in school offers orphaned children the best chance of escaping extreme poverty and its associated risks. Thus, everything possible needs to be done to keep them in school. For example, China's Henan Province recently announced that orphans living with their extended family would receive free primary and secondary schooling, and financial support for further studies. Similarly, Jamaica's National AIDS Committee helps some of the country's orphaned children with school-related expenses, including school fees, uniforms and books.

Grandmothers to the rescue: the ‘Go-Go Grannies’

The Go-Go Grannies are a group of grandmothers in South Africa’s Alexandra Township who help and encourage each other as they raise their orphaned grandchildren. They have lost their own children to AIDS and are now finding it difficult to cope, both emotionally and physically. The Grannies are part of the Alexandra AIDS Orphans Project, which runs support-group programmes for children and caregivers living with, and affected by, the epidemic. The project currently provides psychosocial, financial and material support to 30 grandmothers. This includes one-time building grants to ensure adequate shelter for their growing families, as well as seeds and fertilizers so the women can start their own gardens to bring in food and income for their families.

Strengthening the capacity of families to protect and care for children

Preserving some sort of family life is extremely important for children who have lost one or both parents to AIDS, whether the family is headed by the lone remaining parent, a grandparent, or another relative. Women and girls of all ages are shouldering much of the burden of the orphan crisis. Young girls may drop out of school to tend to ailing parents, look after household duties, or care for younger siblings. Mothers are more likely than fathers to continue to care for their children after the death of the spouse, and women are more willing to take in other orphans.

Then there are the grandmothers—older women who care for their own children when the latter fall ill, and eventually become surrogate parents to their bereaved grandchildren, often with few resources (see Figure 16). For example, studies in Thailand show that almost half of the country’s orphaned children live with their grandparents. Projects to support these elderly caregivers have been developed in response. In Chiang Mai, the Mother Child Concern Foundation helps to strengthen older people’s associations, develops volunteer schemes to assist older caregivers, and provides low-interest loans to set up small businesses.

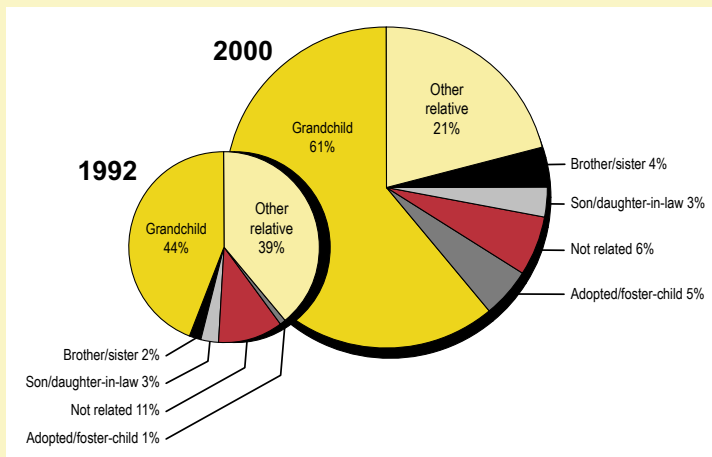
Formal institutions, such as orphanages, may provide a last resort for a limited number of orphaned or sick children. In the early days of the orphan crisis, countries such as Zimbabwe built a number of orphanages. But it quickly became apparent that the orphanage solution was unsustainable and conflicted with a child’s fundamental right to grow up in a family environment.

If preserving the family is the best option for orphaned children, then the family’s capacity to care for, and protect, these children must be urgently strengthened. This means adopting programmes that keep parents living with AIDS alive and healthy as long as possible, improve a household’s money-earning capacity, and provide children and their caregivers with psychosocial and other support.

Thailand is one country in which family capacity has been strengthened. There, the MTCT-Plus Programme (mother-to-child transmission plus antiretroviral treatment) provides antiretroviral treatment for HIV-positive mothers, their infected partners, and children (Beckerman, 2002). The programme was launched by UNICEF and Columbia University’s Mailman School of Public Health, and links preventing mother-to-child transmission with treatment and care options in antenatal-care clinics. The programme also operates in Côte d’Ivoire, Kenya, Mozambique, Rwanda, South Africa, Uganda and Zambia (UNICEF, 2003).

Growing role of grandparents

Relationships of double orphans and single orphans (not living with surviving parent) to head of household, Namibia, 1992 and 2000



Sources: UNICEF-MICS, Measure DHS, 1992 and 2000

Figure 16

Better nutrition and food security will improve a family's overall health and increase the time parents and children have together. For instance, in Haiti, the international NGO, Hunger Grow Away, is promoting a new micro-intensive gardening system that uses limited viable soil, water resources, tools and labour to offer orphaned children and their caregivers food security and incomes.

Mobilizing community-based responses

Communities are capable of responding effectively to the plight of orphans and children whose parents are dying of AIDS. A wide variety of relatively formal projects has sprung up from the concern of families, neighbours and religious groups. A case in point is Cambodia. The monks at Wat Kien Kes Temple provide some of the country's orphans and vulnerable children with vocational training and income-generating skills to improve their standard of living. They also mobilize local communities to donate food, land and material goods

to affected families. The monks have also stimulated HIV-oriented dialogue within the community, which raises AIDS awareness, engenders compassion and reduces discrimination (USAID, 2004). If properly recognized and supported, these initiatives can provide the backbone of national strategies (Foster, 2002).

National action plans needed

Until now, most orphan-support interventions have been piecemeal and have not matched the scale of the problem. In Uganda, officials recognized the orphan crisis early on. Yet government assistance fell short of the need, with only an estimated 5% of orphans receiving some sort of help between 1998 and 2000 (Deininger, et al., 2003). Clearly, urgent steps to scale up and replicate successful interventions are required and should include the following 'country commitments' to:

- conducting participatory situation analyses;
- implementing a national policy and legislation review to better protect children;
- establishing national coordination mechanisms for responding to the orphan challenge;
- developing and implementing national action plans addressing both orphan prevention and the needs of orphans; and
- implementing monitoring and evaluation activities based on indicators that specifically measure effects on the well-being of orphans and children made vulnerable by HIV and AIDS (UNICEF et al., 2004).

The 2003 report on progress in meeting the 2001 UN Declaration of Commitment on HIV/AIDS goals notes that 39% of countries with 'generalized epidemics' have no national policies to provide orphaned and vulnerable children with essential support (UNAIDS,

2003). Some 14% of these countries are developing policies, but 25% have no plans to do so.

The orphan challenge needs to be met through resolute political will before it reaches crisis proportions. In countries, a wide range of government and civil society stakeholders need to provide financial help to children, families and communities, along with HIV prevention, care and support.

National policies, such as those developed by Honduras, Jamaica, Malawi, Rwanda, Swaziland, Thailand and Uganda, are a good starting point. But policies are meaningless if there is no commitment to translate them into practical action. Families and communities often demonstrate strong commitments and resiliency, and are leading the responses to protect children affected by AIDS. Policy frameworks and national plans need to provide environments that foster these efforts so that orphans can survive and thrive in the future. 