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Innocenti Research Centre

Innocenti Insight

A photograph of two young girls in school uniforms. The girl on the left is wearing a red dress with a floral pattern and is writing in a book with a white pen. The girl on the right is wearing a blue school uniform and is looking at the book. They are standing in front of a dark doorway with a window in the background.

CARING FOR CHILDREN AFFECTED BY HIV AND AIDS

For every child
Health, Education, Equality, Protection
ADVANCE HUMANITY

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November 2006

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The UNICEF Innocenti Research Centre

The UNICEF Innocenti Research Centre in Florence, Italy, was established in 1988 to strengthen the research capability of the United Nations Children's Fund and support its advocacy for children worldwide. The Centre (formally known as the International Child Development Centre) generates knowledge and analysis to support policy formulation and advocacy in favour of children; acts as a convener and catalyst for knowledge exchange and strategic reflections on children's concerns, and supports programme development and capacity-building.

Innocenti studies present new knowledge and perspectives on critical issues affecting children. For that reason, they may include opinions which do not necessarily reflect UNICEF policies or approaches on some topics.

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FOREWORD

Around the world, millions of children have lost one or both parents to AIDS, and millions more live with sick and dying family members. The profound trauma of losing one or both parents has devastating long-term implications, not only for a child's well-being and development, but for the stability of some communities.

AIDS is killing not only parents, but also brothers and sisters, aunts and uncles, neighbours, teachers and other members of the community. It is emptying schools, wiping out families and extinguishing hope. If it takes a village to raise a child, what happens to that child when the village is besieged by the dying and the dead?

HIV and AIDS cut childhood short. Children are pulled out of school to care for dying parents or to earn money. Many become destitute when their parents die. The powerful combination of shame and fear surrounding HIV and AIDS feeds a culture of silence that fuels stigma and inflicts further damage. Hungry and lonely, these children grieve silently in constant fear that they might be next or that their secret might be told. HIV and AIDS compromise children's rights to survival, education and health care. They jeopardize children's right to protection from discrimination and abuse and sexual exploitation, including through trafficking and child labour. They rob children of their rights to grow up in a family environment and to develop to their fullest potential.

With the Convention on the Rights of the Child, the international community has reiterated States' accountability for the safeguarding of children's rights, including by providing assistance and support to families and communities, and by ensuring priority

attention to the most vulnerable groups. But just as HIV and AIDS exacerbate the risks faced by children, they reveal the weaknesses of existing infrastructure and government systems to support children, including orphans, made vulnerable by AIDS. The chain of shared responsibility for the survival and development of children and for the realization of their rights has too many broken or missing links.

In October 2005, UNICEF, UNAIDS and many other partners launched a Global Campaign: Unite for Children, Unite against AIDS. The campaign provides a platform for joint support to national and local programmes to prevent infection among adolescents and young people and mother-to-child HIV transmission, provide paediatric treatment, and protect children affected by HIV and AIDS.

The global Campaign is a five-year drive to achieve significant, measurable progress for children based on set key objectives 'Four Ps', urgent imperatives that can make a real difference for children affected by HIV/AIDS:

1. Prevent mother-to-child HIV transmission (PMTCT). By 2010, offer appropriate services to 80 per cent of women in need.
2. Provide paediatric treatment. By 2010, provide either antiretroviral treatment or cotrimoxazole, or both, to 80 per cent of children in need.
3. Prevent infection among adolescents and young people. By 2010, reduce the percentage of young people living with HIV by 25 per cent globally.
4. Protect and support children affected by HIV/AIDS. By 2010, reach 80 per cent of children most in need."

In communities around the world, people are rising to the challenge to care for the children affected by HIV and AIDS. Amidst the horror and despair are enormous acts of courage, solidarity and commitment. This *Innocenti Insight* draws on many of these efforts.

This *Insight* is intended to advance the discussion on the impact of HIV and AIDS on children in three key ways: by drawing attention to the situation of children orphaned by AIDS and the limitations of current responses for the realization of their rights; by reviewing the options for the care of these children, highlighting effective experiences and lessons learned from family and local approaches; and by identifying ways in which local, national and international actors can effectively fulfil their responsibilities to safeguard the human rights of children, with particular focus on children orphaned by AIDS.

Recognizing the inextricable linkages between HIV, AIDS and poverty, this *Insight* supports a growing movement among the international community to develop social welfare strategies as a vital safety net to reach the growing numbers of vulnerable children. In a number of communities, social protection measures, including direct cash transfers to families, health insurance and initiatives to ensure access to school, are providing crucial support to families in need. The impacts of HIV and AIDS are a direct consequence of inequality and social exclusion, and access to social welfare assistance must not be seen as charity, but rather as a fundamental human right. Yet key challenges remain: How can existing mechanisms in low-income countries be transformed into effective social welfare policies and systems? How can these systems be financed to ensure sustainability?

The tsunami disaster of December 2004 showed that the world is capable of providing coordinated and comprehensive support on a large scale, responding to immediate relief needs as well as addressing longer-term rehabilitation. The extraordinary solidarity and response in the aftermath of the tsunami disaster demonstrated a collective capacity of people to work together to care for and protect children and safeguard their rights in the context of a dramatic emergency situation.

The same determination and compassion must be harnessed to care for those children whose lives and families have been devastated by HIV and AIDS. Children who have lost their parents to the pandemic need sustained assistance to recover their physical and emotional well-being and to realize their full potential. Children cannot wait; they cannot postpone their future. They require immediate assistance, health care, education and protection, as well as opportunities to play and participate in family life.

When the village that raises a child is ravaged by AIDS, it must be supported and sustained by the global community. That is the call that we all must answer, to collectively safeguard the rights of the children who are facing the terrible realities of a world under siege by HIV and AIDS.

Marta Santos Pais
Director
UNICEF Innocenti Research Centre

1. MAGNITUDE OF THE CRISIS

“Concerted action is what is required. Every moment spent in deliberation that does not lead to action is a moment tragically wasted.”

Nelson Mandela, Johannesburg, 2002¹⁴⁴



Today, an estimated 15.2 million children globally under the age of 18 have lost one or both parents to AIDS. The numbers, already vast, continue to grow. It is expected that in sub-Saharan Africa alone, the number of children orphaned by AIDS will swell to 16 million by 2010.¹

Millions more children are living with parents or other adults who are chronically ill or with families that must stretch scarce resources to care for them. Children in these situations may be expected to care for their parents and also to take on financial and household responsibilities. They may drop out of school or be forced into exploitative work. Some children have been abandoned and are living on their own.

Many children are infected themselves. Every day:

- There are nearly 1,500 new infections among children under 15 years of age, most of them from mother-to-child transmission.
- More than 4,500 adolescents and young people between 15 and 24 years of age are newly infected.
- Some 1,000 children under 15 die of AIDS-related illness.²

Children orphaned by AIDS account for a relatively small proportion of the total number of children orphaned around the world – about 11 per cent in 93 countries for which there are estimates. Although orphaning rates in general are declining, that is not the case in areas most affected by HIV and AIDS.

1.1 MULTIPLE EPIDEMICS

There is not a single epidemic of HIV and AIDS, but rather there are multiple epidemics that evolve over time, with differing origins, transmission patterns and impacts on regions and population groups. The extent and prevalence of these multiple epidemics may vary considerably, even within geographical regions and countries.

In **sub-Saharan Africa**, home of 24 of the 25 countries with the world's highest levels of HIV prevalence, the number of orphans – 48 million in 2005 – has increased by 60 per cent since 1990. Today, 8 out of 10 of all children orphaned by AIDS are living in the African region. Even where HIV rates stabilize or decline, the number of orphans will continue to grow or at least remain high for years to come, reflecting the long lag time between HIV infection and death. The sharp-

est increase in the number of orphans is expected in countries with the highest rates of infection, such as Botswana, Lesotho and Swaziland.

Within Africa, there is tremendous diversity in trends and rates of infection, with HIV prevalence among adults ranging from under 2 per cent to over 30 per cent in some countries. Infection rates tend to be higher in urban areas than in rural areas, although this ratio varies considerably from one country to another.

In **Latin America and the Caribbean**, the overall number of orphans has dropped by almost 10 per cent since 1990, although in countries with the most serious HIV epidemics, such as Haiti and Guyana, orphaning rates are much higher. Haiti has an adult HIV prevalence of about 3.8 per cent and an overall orphaning rate of 12 per cent – more than double the regional average. Similarly, Guyana, with an HIV prevalence of 2.4 per cent, also has an orphaning rate of 12 per cent.³

In **Asia**, concentrated and smaller scale epidemics mean that HIV prevalence is much lower than in sub-Saharan Africa – and so is the share of children orphaned by AIDS. But Asia (with 1.2 billion children) has almost four times the child population of sub-Saharan Africa (350 million), so even a small increase in prevalence could result in greater absolute numbers of children orphaned by AIDS.

In **Eastern Europe and Central Asia**, the number of people living with HIV reached an estimated 1.6 million in 2005, an increase of almost 20-fold in less than 10 years. AIDS-related illnesses claimed the lives of an estimated 62,000 adults and children in 2005, almost twice as many as in 2003. The great majority of people living with HIV in this region are young: 75 per cent of the reported infections between 2000 and 2004 were in people under 30 years of age. The majority of the people infected with HIV in the region live in two countries: the Russian Federation and Ukraine, with the Russian Federation having the largest AIDS epidemic in all of Europe.⁴ As AIDS-related deaths rise, the number of orphaned children is also expected to increase.

The differences in prevalence, patterns and trends across the globe require that responses be country-specific and based on accurate local data and trends. Responses must also acknowledge the varying capacities of governments and communities to respond as part of their commitment to safeguard children's rights.

'Double orphans'

When one parent is infected, there is a higher probability that the other parent is also HIV-positive and that both will eventually die. 'Double orphans' – children who have lost both mother and father – are especially vulnerable to poverty, exploitation and abuse. The number of double orphans due to any cause is expected to reach 14.1 million by 2010.

Yet even when one parent dies, cultural factors influence who will care for the children, affecting their vulnerability. In Malawi, nearly three quarters of the children who have lost their fathers continue to live with their mothers, whereas only one quarter of the children who have lost their mothers continue to live with their fathers.⁵ Additional research is needed to understand the specific risks and needs of maternal, paternal and double orphans in AIDS-affected communities.

1.2 THE MULTIFACETED IMPACT OF HIV AND AIDS ON CHILDREN

HIV and AIDS affect virtually every aspect of child development and jeopardize the enjoyment of children's rights. They undermine health and schooling, reinforce marginalization and deprivation, and place the burdens of loss, fear and adult responsibility onto the shoulders of children.⁶ The effects of HIV and AIDS on children reach in expanding circles, also affecting the children within extended families and in the kinship or friendship circles that help to care for orphaned children. Key impacts of HIV and AIDS include:

Endangering nutrition and health

Globally, about 800 million people are under-nourished and thousands die of hunger every day, with the numbers rising as the food crisis in southern Africa escalates. The illness and death of an adult due to AIDS often results in less food for a family.¹¹ This problem is especially acute for extended and foster families who have more children to feed with the same – or often lower – income.¹² In fact, children affected by HIV and AIDS may endure a double nutritional penalty. Many AIDS-affected households not only reduce the area of land they cultivate, they also grow crops that are less labour intensive and often less nutritious.

Deepening gender inequality

Increasingly, the HIV epidemic affects girls and women, especially in the more advanced epidem-

ics of eastern and southern Africa. In several southern African countries, more than three quarters of young people living with HIV are women, while in sub-Saharan Africa overall, young women between ages 15 and 24 are almost three times more likely to be infected than men.¹³ Sexual violence, early and forced marriage, female genital mutilation/cutting, and lack of access to education and employment opportunities all reflect a legacy of gender inequality that hampers and often eliminates girls' and women's ability to negotiate safer sex practices. The danger of infection is highest among the poorest and least powerful.

Box 1. Poverty, HIV and AIDS: A vicious and unrelenting cycle

Poorer countries face the most severe impacts of the epidemic, with the vast majority of all AIDS cases occurring in the developing world. Inadequate nutrition, health care, education and economic opportunities all contribute to the spread of HIV and shorten the life span of those infected. At the same time, the staggering burden that HIV and AIDS imposes on populations and resources worsens poverty in communities most affected. The inability of communities and families to develop the human and social capital required to overcome poverty generates a vicious cycle that leaves children even more vulnerable.⁷

In wealthy countries, the rate of new infection of babies due to mother-to-child transmission has been reduced to nearly zero.⁸ But in low- and middle-income countries, less than 10 per cent of pregnant women are being offered services to prevent transmission of HIV to their infants.⁹ In some countries, the lack of access to services has been catastrophic: In Botswana, Zimbabwe, Namibia, Swaziland and Zambia, mortality rates for children under the age of five due to HIV infection have exceeded 30 per 1,000 live births.¹⁰ The high cost of and lack of access to antiretroviral drugs (ARVs) in developing countries have resulted in the deaths of millions of children and parents – deaths that might have been prevented if ARVs had been affordable and available.

Strategies to provide care and support for children living in communities affected by HIV and AIDS must tackle hunger and malnutrition, increase employment opportunities and income for families, and improve access to quality health care and education. They must reach the very poor and address high levels of inequality to ensure that the rights of all children are protected.

Patterns of gender disparity related to HIV and AIDS are not limited to sub-Saharan Africa. Rising infection rates among females are also emerging in other regions. In the Commonwealth of Independent States and Baltic states, one in five new cases of HIV in 1998 were among girls and women aged 13 to 29. By the first half of 2002, that figure had risen to one in four.¹⁴

In many households affected by HIV and AIDS, girls tend to be the first to be taken out of school and the first to take on increased family responsibilities. There is evidence to suggest that girls who are suspected of being HIV-positive are more likely than boys to be denied access to education and health care.¹⁵ Girls who are orphaned by AIDS are particularly vulnerable to loss of property and inheritance rights. They may also face discrimination in extended families and in other care arrangements. They may be sexually abused or exploited, forced into domestic service or early marriage, or taken advantage of in other ways.

Damaging psychosocial development

The illness and death of one and often both parents as a result of AIDS is a significant trauma for any child.¹⁶ The lack of a parental bond, especially for infants and very young children, can severely affect a child's physical and emotional development. When one or both parents die, siblings may be separated, and life with members of the extended family may fail to provide adequate emotional support and security. Extended families in communities affected by AIDS are frequently poor and under stress. They may themselves include close family members who are living with HIV or may be grieving over the loss of loved ones. In communities severely affected, children suffer the serial loss of adult figures and carers such as teachers, mentors, aunts and uncles, leaving them with a crippling sense of abandonment and insecurity that can affect their decisions later in life and ability to act in their own best interests.

Isolating and excluding

Efforts to stop the spread of HIV and AIDS and provide care for affected children and families are complicated by the stigma, shame and fear that are typically associated with the disease. Stigma is fuelled by misconceptions about how HIV is transmitted, by lack of access to treatment, and by association with social taboos surrounding sexuality, disease, death and drug use.¹⁷ All of these factors are reinforced by wider patterns of inequality and social exclusion within societies.¹⁸

Stigma may have serious consequences and can lead to loss of status or job and social ostracism. The fear of rejection by family, friends and community can prevent persons living with HIV from seeking treatment and other assistance. Silence and denial are the most common reactions to perceived stigma. In many cases, persons at risk have refused HIV testing because they fear that their results will not be kept confidential or simply because they prefer not to know their status, especially when treatment is not likely to be available.¹⁹

For children who have lost their parents to AIDS, the risk of stigma can expose them to even greater risks, limiting access to health care and schooling, and possible rejection by family, friends and community members. In a number of countries in Central and Eastern Europe, as well as in other regions, children identified as HIV-positive are at increased risk of abandonment.

Eroding social and cultural heritage

The loss associated with AIDS extends beyond individuals, affecting both communities and cultures. In many of the worst-affected countries, children miss out on learning important life skills, including how to farm, cook and participate in community life – skills usually transmitted by parents, relatives, neighbours and other adult role models in the community. In some AIDS-affected communities, the high death rates have altered the culture surrounding death, mourning and burial. Both the emotional and material resources of society may be depleted by the number of deaths and, as a result, traditionally long periods of mourning and the expense of burial may not be manageable. The long-term effects on children's sense of cultural and social identity can be devastating.

Cultural heritage acts to build up a sense of identity and community. Without this legacy, tradition and oral history may fade and customs and rituals dissipate. In communities eroded by HIV and AIDS, the adults of tomorrow may lose not only economic and social stability, but also a sense of family memory, community heritage and social responsibility. Community elders provide leadership and guidance for the next generation of young people. If that leadership is lacking, children are more exposed to unstable social, economic or political forces.²⁰

2. PRINCIPLES AND COMMITMENTS

“All our policies and programmes should promote the shared responsibility of parents, families, legal guardians and other caregivers and society as a whole, in this regard.”

A World Fit for Children Plan of Action, 2002



2.1 GLOBAL COMMITMENTS

The Convention on the Rights of the Child, approved in 1989, provides a guiding framework for policies and practices to ensure the realization of children's rights. It is the first binding instrument in international law to deal comprehensively with the rights of children, and the most widely and rapidly ratified human rights treaty to date. This is evidence of the global political will to improve the lives of children and safeguard their human rights.²²

The Convention recognizes the critical role of the family in the development, care and protection of the child. Guided by the best interests of the child, "parents or, where applicable, the members of the extended family or community, ... legal guardians or other persons legally responsible for the child" have a responsibility to provide "appropriate direction and guidance in the exercise by the child" of his or her rights, as well as to ensure the upbringing and development of the child. The State is required to "render appropriate assistance to parents and legal guardians ... in the performance of their child rearing responsibilities." The State, parents and society at large have responsibilities for safeguarding the rights of children. These responsibilities require not only the will, but also the means.

The Convention reaffirms the responsibility of the State in the protection of children's rights, without discrimination of any kind, and through the adoption of all appropriate legislative, administrative, budgetary and other measures.

The Committee on the Rights of the Child, the body set up by the Convention to promote and monitor its implementation, paid special attention to children and families affected by HIV and AIDS, particularly to safeguarding children's care and protection. In a General Comment devoted to this reality, it has stressed that States should ensure that laws and practices support the inheritance and property rights of children without parents – especially where gender-based discrimination is concerned.²³ The Committee has also addressed HIV prevention for children, as well as prevention among parents, in an effort to stem the numbers of children living with HIV and those orphaned by AIDS. The Committee noted that, "It is now widely recognized that comprehensive treatment and care includes antiretroviral and other drugs, diagnostics and related technologies for the care of HIV/AIDS, related opportunistic infections and other conditions, good nutrition, and

social, spiritual and psychosocial support, as well as family, community and home-based care".²⁴

A series of global commitments, all informed by the Convention on the Rights of the Child, have highlighted the importance of safeguarding the rights of children orphaned and made more vulnerable by HIV and AIDS.

- The *UN Millennium Declaration* (2000) recognized that "the continuing spread of HIV/AIDS will constitute a serious obstacle to realizing the global development goals set at the Millennium Summit". Among the eight Millennium Development Goals (MDGs), goal number six reflects the commitment "to halt and reverse the spread of HIV/AIDS". Current planning for MDG achievement in many countries takes into account the effect of HIV and AIDS on other MDGs, such as poverty reduction, education, maternal health and child mortality.
- The *UN Declaration of Commitment on HIV/AIDS* (2001) adopted by the General Assembly Special Session on HIV/AIDS recognizes that women and children, and especially young girls, are most vulnerable to the disease. It calls for a 20 per cent reduction in the number of infants infected by HIV by 2005, and a 50 per cent reduction by 2010. It also calls on nations to develop comprehensive care strategies by 2005 and to make significant progress in implementing them. Three articles (65, 66 and 67) are specific to children orphaned and made vulnerable by HIV and AIDS.
- The UN's *A World Fit for Children Declaration and Plan of Action* (2002)²⁵ recognizes that a considerable number of children live without parents. It calls for special measures to support the facilities, services and institutions that look after these children and to build and strengthen the ability of children to protect themselves. It also calls inter alia for 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 and AIDS.
- The *UN 2005 World Summit* addressed a range of relevant actions for children orphaned and otherwise affected by HIV and AIDS in the context of the review made of progress towards achievement of the MDGs. The outcome document includes the

important commitment to “developing and implementing a package for HIV prevention, treatment and care with the aim of coming as close as possible to the goal of universal access to treatment by 2010 for all those who need it, including through increased resources, and working towards the elimination of stigma and discrimination, enhanced access to affordable medicines and the reduction of vulnerability of persons affected by HIV/AIDS and other health issues, in particular orphaned and vulnerable children and older persons”.²⁶

In October 2005, a major initiative was launched by UNICEF, UNAIDS and other partners to draw worldwide attention to and consolidate the response to children affected by HIV and AIDS. The Unite for Children, Unite against AIDS campaign calls for concerted action in four key areas:

- Preventing new infections among young people.
- Preventing mother-to-child transmission (PMTCT) of HIV.
- Providing paediatric treatment for children living with HIV.
- Protecting, caring for and supporting orphans and other children affected by HIV and AIDS.

The campaign reinforces the message that to make a real difference in the lives of children affected by HIV and AIDS, all four of the above areas must be addressed. To provide effective care and support for children orphaned by AIDS, treatment must be provided to children living with HIV and to their parents to delay orphaning, efforts must be made to prevent mother-to-child transmission, and new infections must be prevented. Meeting the challenge will require strengthening and coordinating partnerships at all levels.

The above commitments were reaffirmed by the UN General Assembly in the 2006 High-Level Meeting on AIDS held from 31 May to 2 June 2006, which adopted the *Political Declaration on HIV/AIDS* (see Box 2).

2.2 FACING THE CRISIS TOGETHER: SHARED RESPONSIBILITY

Families and local communities carry the main burden of care and support for children orphaned by AIDS. In sub-Saharan Africa, 90 per cent of children orphaned by AIDS are cared for by extended families, with little or no outside support.²⁷ The impact on family members – single parents, grandparents and relatives, and espe-

Box 2. Renewed commitment to support affected children and families

The UN General Assembly reviewed progress in implementing the 2001 Declaration of Commitment on HIV/AIDS during its High-Level Meeting on AIDS, held from 31 May to 2 June 2006. The Political Declaration adopted at the meeting reaffirmed the urgency of response to HIV and AIDS as a cause and consequence of poverty, and reiterated the importance of this response for the achievement of internationally agreed development goals and objectives, including the MDGs.

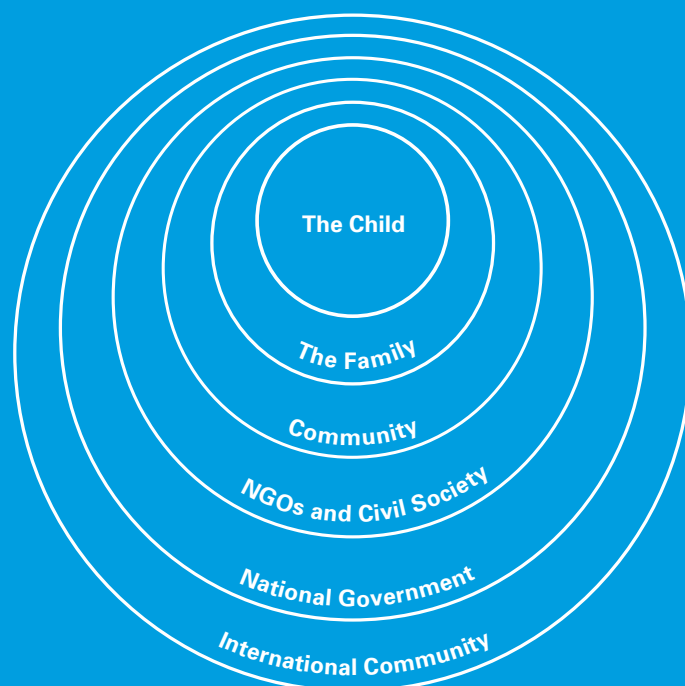
The Declaration pays particular attention to the needs of children and women. It recognizes the need to promote gender equality and the empowerment of women, and promote and protect the rights of the girl child. It commits world leaders to increasing the availability of and access to effective treatment for women living with HIV and for infants in order to reduce mother-to-child transmission. It includes a commitment to “addressing as a priority the vulnerabilities faced by children affected by and living with HIV; providing support and rehabilitation to these children and their families, women and the elderly, particularly in their role as caregivers; promoting child-oriented HIV/AIDS policies and programmes and increased protection for children orphaned and affected by HIV/AIDS and ensuring access to treatment and intensifying efforts to develop new treatments for children; and building where needed and supporting the social security systems that protect them” (paragraph 32). A wide range of measures were endorsed in order to ensure the full implementation of the UN Declaration.

cially on children – is severe, and in many cases, the burden has become too great to bear.

A study in Côte d’Ivoire found that when a family member had AIDS, family income fell by proportions ranging from one half to two thirds; food consumption dropped by over 40 per cent, while spending on health care quadrupled.²⁸ Since local custom gives priority to men and boys when it comes to the distribution of food, girls and women are particularly affected.

Families and communities urgently require assistance and resources to strengthen their resilience and provide the psychosocial, emotional and material support that is essential to children’s growth and development. Although non-governmental, community-based and faith-based

Figure 1. The levels of care and protection



Source: Adapted from framework developed by the UNICEF Eastern and Southern African Regional Office

organizations have played a leading role in assisting with the care of children affected by HIV and AIDS, they are only reaching a fraction of the children hardest hit by the disease. Governments and the international community must assume their responsibilities in the face of the epidemic and create the conditions for children to develop to their fullest potential and to be protected from discrimination, exploitation and abuse.

Figure 1 illustrates that the best interests of the child are served when a girl or boy is at the centre of the concerns of a caring family, within a supportive community, surrounded by a protective state and the solidarity of the international community. Parents and the extended family represent the primary duty-bearers with respect to children's rights and the first 'ring of security' for children facing challenging circumstances.²⁹ The local community can be seen as the second ring of protection. Other national actors, including all levels of government, NGOs and other civil society organizations, constitute a third and fourth ring providing support and services to children, families and communities. The international community can be seen as the fifth ring, cooperating

with and supporting national and local actors for children's care and protection.

HIV and AIDS increase demands on all the rings of care and protection. The innermost and most important circles of care – the family and community – are the first to respond but, as is widely evidenced, they are increasingly overwhelmed by the demands of the epidemic. As these inner circles weaken and even collapse, the children left behind stand alone, without protection.

The 'rings' of protection for children also reflect more complex relationships than the figure suggests. Rather than being neatly nested, the rings are in reality interconnected and overlapping in terms of responsibilities and actions for children. Therefore, when support is provided in one area, the benefits are realized in other areas. For example, national governments may eliminate school fees, thus promoting children's access to school and making it possible, or at least easier, for children to enjoy their right to education. Meanwhile, parents may decide to make it a priority for their children, especially their daughters, to stay in school. These actions may not be directly related,

but they play a mutual and complementary role in promoting a child's right to education, critical to halting the spread of HIV and AIDS.

Everyone has a role and responsibility to ensure that children's rights are protected in communities affected by HIV and AIDS. Government can fulfil its responsibilities towards children by building capacity and enabling families and communities to fulfil theirs. For example, government can train and support teachers to keep schools staffed and provide quality education. Government can also establish a supportive legal environment and flexible funding mechanisms to encourage the emergence of civil society and community-based organizations, committed to the protection of children's rights. An NGO or other national actor can help with succession planning by building capacity and promoting training of parents who have HIV. An international agency can provide food and supplies to community volunteers who support child-headed households. These kinds of support help those closest to the children to care for them.

The challenges are enormous in all communities affected by HIV and AIDS, yet they are particularly complex in countries with very large populations, enormous geographic distances, dispersed populations and with significant decentralized responsibility over finances and administration. In such countries, action at state, provincial and district

levels is crucially important to support national policies and direction.

In China, a national policy for comprehensive prevention, care and treatment of HIV and AIDS has not only focused attention on the disease but it has also helped to generate and strengthen local actions. The 'Four Frees and One Care' policy aims to provide: 1) free schooling for children orphaned by AIDS who have lost both parents; 2) subsidy provisions to affected low-income families; 3) free antiretroviral drugs to people living with HIV who have financial difficulties; and 4) free treatment for prevention of mother-to-child transmission.³⁰

The international community can support such national commitments and frameworks by providing technical resources and policy suggestions to address the epidemic on a multilateral and bilateral basis. In addition to and building upon the global commitments noted above, a variety of vehicles for funding, policy support and national capacity building have been established, most significantly the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). In addition, efforts are supported directly by many donor governments as well as the private sector. Collectively, these mechanisms mobilize attention and support, including for orphans and other children and their families affected by HIV and AIDS.



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3. KEEPING CHILDREN IN FAMILIES AND COMMUNITIES



In countries most severely affected by the epidemic, HIV and AIDS are eroding the efforts and hard-won achievements in human development. In some cases, the economic and social fabric of communities and institutions has been so badly damaged that it is not a question of repair but rather of rebuilding the very foundation of social and community life. The epidemic exposes the weaknesses and gaps in care and protection for all children. It is highlighting the urgent need to provide a more comprehensive response that raises standards of care and safeguards children's rights.

Child care solutions need to keep children in a nurturing and supportive family environment and as close to a child's primary family as possible. This means keeping both parents alive and capable longer; keeping siblings together, or as close as possible; supporting good care in the extended family; and enabling children to stay in the community that they identify as home. It requires considering the availability of family networks, the capacity for care and support in the community, together with the needs and wishes voiced by the child.

Responses to HIV and AIDS must also reflect local circumstances. In countries of sub-Saharan Africa, for example, where the extended family has been the main provider of care and support for children orphaned by AIDS, resources and responses should be targeted to support and develop the capacity of the extended family within AIDS-affected communities. But in other regions of the world, alternative strategies may be needed. In Central and Eastern European countries and some nations of the Commonwealth of Independent States, the emphasis may need to be on supporting the child's family environment and considering alternatives to institutionalization, a common practice in that region. In all countries, responses must be directed at households in immediate need and towards individual children who are most vulnerable, using locally defined criteria established by the communities themselves. They must also be sustainable over the long term.

3.1 PROTECTING THE IMMEDIATE FAMILY AND HOUSEHOLD

Four key strategies have been identified for keeping the child in the immediate family and household for as long as possible. (For the purpose of this report, the 'family' includes parents and siblings in the immediate family as well as other family members such as grandparents who live in

the household. It may also include non-custodial parents, step-parents or others whom the child identifies as immediate family.)

Keeping parents alive longer and keeping families together

The most effective way to minimize the devastating effects of HIV and AIDS on children is to improve the health of parents and other caregivers and keep them alive as long as possible.³¹ This is crucial both in delaying and preventing orphaning and in improving parents' capacity to care for their children.

In recent years, there has been a dramatic increase in commitment and action at both the national and international levels towards increasing access to antiretroviral (ARV) therapy in every region of the world. ARV therapy significantly improves quality of life and enables people to live longer. Ensuring that children and pregnant women have access to ARV therapy and other measures to prevent mother-to-child transmission (PMTCT) of HIV is a dimension of many international initiatives and forms a cornerstone of the Unite for Children, Unite Against AIDS campaign promoted by UNICEF, UNAIDS and other partners.

Yet in low- and middle-income countries, especially in sub-Saharan Africa, only a fraction of individuals living with HIV have access to the drugs. In places where resources are scarce, ARVs are still too expensive and inaccessible for most people. Even when ARVs are free, weak health care systems and critical shortages of skilled health care workers make providing treatment complex and challenging.

Increased access to treatment and more effective prevention strategies will make a difference in the longer term, but it is likely that families and communities will continue to suffer high rates of infection in the foreseeable future, and that access to AIDS treatment and to other essential health services will remain unequal.³²

Much can be done to keep parents healthy and delay the need for ARVs. When a parent is diagnosed with HIV, regular treatment of common infections and proper nutrition can keep the parent healthier longer. This reduces trips to hospital and maximizes resources for the family.

When individuals become too sick to care for themselves, home-based care by formal and in-

formal caregivers can provide crucial support and help keep families together. Home-based care, which includes medical, psychosocial, palliative and spiritual care,³³ allows HIV-infected people to stay with their families and communities – promoting community awareness of HIV and AIDS in the process. It also shortens hospital stays for the chronically ill, thereby reducing overall health care costs. Many governments are recognizing the benefits of home-based care programmes. The Kenyan Government has drawn up national guidelines and provides training materials for NGOs and other organizations that support home-based care programmes.³⁴ Other governments – including those of South Africa, Malawi, Botswana, Rwanda and India – either support home-based care programmes or are planning to implement similar national strategies.

In Thailand, home-based care has traditionally

been provided by external health care service providers, but not by other members of the community. To provide more comprehensive support to children and families living with HIV and AIDS, practical partnerships have been developed among regional hospitals, district health centres, local NGOs (including organizations of people living with or affected by HIV and AIDS) and the Buddhist clergy to actively promote solidarity with and support for children and families affected.³⁵

Ensuring that families living with AIDS stay together requires that all members of the family are supported. Particular efforts must be made to ensure adequate household resources when ill family members are unable to work or obtain food, and to meet the costs of medical care (see Box 1). Interventions are required to promote family livelihoods, and to provide income

Box 3. Schools provide crucial support to families affected by HIV and AIDS

Schools can provide day-to-day support and protection for children living in households affected by HIV and AIDS, while offering a sense of normality, of belonging and the opportunity to play and form friendships. Schools can also set an example to the community by promoting understanding, solidarity and positive attitudes towards children and teachers infected with or affected by HIV.

School meals and take-home rations supported by the World Food Programme (WFP), which provides food assistance in 21 of the 25 nations with the highest HIV prevalence, encourage children from households where food is scarce to stay in school while providing them and their sick parents or carers with vital nutrition.³⁶

Schools can also ensure students receive critical information, knowledge and skills to avoid high-risk sexual behaviour and protect themselves from HIV. In Namibia, the Window of Hope programme, begun in 2004, provides 10- to 14-year-olds with the skills to cope with HIV and AIDS in their personal lives, in school and in the wider community.³⁷ The programme, implemented by the Ministry of Education with support from UNICEF and bilateral donors, recognizes that early adolescence provides a critical window of opportunity to deliver prevention messages and prepare young people to take on the challenges posed by HIV and AIDS. Children are able to build on their skills in

secondary school when they are introduced to My Future is My Choice, Namibia's school-based life skills intervention for 15- to 18-year-olds. The two programmes reinforce critical messages, enabling young people to improve and develop their skills and confidence.

Other effective educational initiatives include:

- making the school experience relevant and useful to children's daily lives and circumstances to provide greater motivation to attend and stay in school;
- eliminating formal as well as informal school fees so that financial barriers are reduced for all vulnerable children;
- providing community-based child care as an option to increase the opportunities for older siblings to attend school, as well as offering respite for older caregivers;
- ensuring children's safety in school, including protection from infection and sexual assault;
- offering flexible, non-formal approaches that accommodate children who work.

The right to education remains critical to children affected by HIV and AIDS. Strategies to support families and communities must emphasize the importance of education, especially for girls, and make it possible for all families to send their children to school.

support through such means as cash transfers (see Box 11). Families must have access to health services, proper nutrition, education and psychosocial support, provided through an integrated approach. As described in Box 3, schools have a particularly important role to play in keeping families together.

Preventing child abandonment

Evidence from many countries, including Jamaica,³⁸ Russia, Swaziland³⁹ and Viet Nam,⁴⁰ points to a significant increase in the rate of child abandonment in AIDS-affected communities.

Abandonment may be motivated by poverty, fear that the child is infected by HIV, or the inability of parents to shoulder the responsibility of raising a child. Many abandoned children spend their crucial early years in a hospital or institution, where the lack of personal care and family environment are likely to have a serious, long-term impact on their development.

Government social welfare services and NGOs can provide crucial information, guidance and counselling to enable HIV-affected families to provide better care for children and make informed decisions about alternatives available, including fostering or adoption.

To prevent child abandonment and support women with HIV in the Dominican Republic, the Adoritrices, an order of the Catholic Church, together with the Centro de Orientación e Investigación Integral (COIN), a local NGO, established a day-care centre for the children of sex workers and HIV-positive women.⁴¹ Children under five years of age received meals, played, and participated in organized activities run by psychologists and secondary school students and in hygiene education. The staff also met with mothers and held training sessions, mainly focused on child health and education. Many of the mothers who originally participated in the programme have died of AIDS-related illness. Their children have been absorbed into the extended family and, in some cases, the Adoritrices have provided material aid to these families, including support for school costs.

In the Mekong subregion countries of Cambodia, Myanmar, Thailand and Viet Nam, Buddhist temples which operate 'temple schools' are increasingly active in supporting orphans and children living with HIV, helping them to stay in families and to participate in school and in the community. In northern Thailand, the Community Preservation Network and Rung Rueng Tham Christ Church

in Chiang Rai instruct elderly caregivers on how to care for orphans and children living with HIV. They are also building and strengthening youth networks to help children orphaned and affected by HIV and AIDS. Youth volunteers, trained in counselling techniques, conduct home visits to affected children, primarily those who are in the care of grandparents. Home visits, shelter, food and clothing, where needed, access to health care services and psychosocial counselling are provided to children and caregivers. Foster placements are made for orphans who lack caregivers.⁴²

Also In Thailand, ACCESS, a local NGO working to promote a better quality of life for those living with AIDS, is helping HIV-affected families to take better care of their children. A central goal of the project has been to encourage community awareness and participation through the development of local groups of people living with AIDS. ACCESS sponsors skills training that teaches how to understand and work with children affected by HIV and AIDS; holds seminars to encourage the participation of local governments; runs workshops that bring together care providers/parents, groups of people living with AIDS and community organizations; and performs assessments of the situation and needs of orphaned and affected children.

Recognizing and supporting child-headed households

Many children orphaned by AIDS live in households without direct adult care. Households headed by children are often difficult to identify, due to their inherently shifting nature as well as to a lack of appropriate census and survey mechanisms. Although they may be relatively few in absolute number, households in which children are living without direct adult care appear to be on the rise in some communities weakened by HIV and AIDS.⁴⁴ Survey evidence from Kenya, Uganda and Malawi suggests that up to one half of 1 per cent of households in high-prevalence countries are child-headed at any given time. While such households remain a minority among all households with children who have been orphaned, they represent an extreme circumstance that requires urgent attention.⁴⁵

The appropriateness of child-headed households as a legitimate form of care for children without parents is a matter of current debate. Still, while reflecting on options for care, it is important to more fully understand the context and situation

of child-headed households and to consider the views and perceptions of the children themselves. In many cultures, children learn to take responsibility for domestic and child care tasks from an early age. When parents become ill with AIDS-related diseases, it is likely that older children will already have taken on the task of caring for their parents, as well as their younger siblings. When parents die, some young people may prefer to continue to live as a family, which has the advantage of enabling siblings to stay together and allowing them to maintain a relationship

Box 4. HIV-infected children: A special challenge for care

Nearly 1,500 children under the age of 15 are infected every day with HIV. An overwhelming majority – 9 out of 10 of these children – contract the disease from their mothers.

Without access to ARV therapy and proper nutrition, up to 50 per cent of HIV-positive babies die before reaching their second birthday.⁴³ Infants who are born HIV-positive often do not receive early treatment because the most easily available HIV tests cannot properly measure antibodies in children under 18 months of age. As their HIV progresses, infected children are less able to fight off common childhood diseases – a situation that is made worse by malnutrition.

Even when an infant is HIV-negative, the child may be mistakenly assumed to have the disease. A child who is infected, or who is assumed to be infected, may be abandoned by parents or primary caregivers or placed in a hospital or residential institution. However, some institutions refuse to accept children who are HIV-positive or who are born to HIV-infected mothers.

It is crucial that parents and other caregivers understand and supportively address HIV in children. When a child's HIV status is determined at an early point, appropriate treatment, care and nutrition can dramatically enhance that child's quality of life and chances of survival. Children and their families will benefit most from an integrated approach – one that takes into account the psychosocial needs of all those involved, and the medical, nutritional and palliative needs of the HIV-infected child. All efforts must promote the child's development to his or her fullest potential and protect the child from discrimination, abuse and exploitation.

with their home community – with the associated benefits of support networks, cultural guidance and helping to ensure maintenance of property. Decisions about living arrangements must also take into account the costs of time spent by older children in caregiving, which may hamper their development and lead to school drop-out, and the costs of the struggle for subsistence, limited mentoring and lack of protection that such arrangements frequently entail.⁴⁶

When children make an informed choice to remain together without direct adult care – care that in many cases is simply not available – this choice should generally be respected and supported. It is crucially important to bolster the capacity of societies and communities to provide social and material support for child-headed households and to protect the children from abuse, discrimination and exploitation.

In some settings, both informal and formal efforts have been made to support, rather than separate, child-headed households. In South Africa, for example, the Law Reform Commission has proposed the legal recognition of child-headed households “as a placement option for orphaned children in need of care” and consequently for provision to be made to ensure adequate supervision and support by persons or entities selected or approved by an official body and directly or indirectly accountable to that body.⁴⁷ This would enable child-headed households to access financial support from the government in the form of social grants, currently available only to families where children are living with an adult primary caregiver or in formal foster care.

Responding to psychosocial impacts on children

Children who have lost a parent or close family member experience profound grief and loss. The grief begins when a child, sibling or parent living with HIV falls ill. It is compounded by misconceptions about AIDS that fuel stigma and discrimination and lead to isolation, even at times from extended family and community. Income is reduced, bringing new fears and worries. Children may be forced to leave school due to lack of funds or increased responsibilities, including caring for an ailing parent. Adult care and protection gradually disintegrates. All of these factors contribute to children's distress, a sense of hopelessness and, at times, emotions of resentment and anger. This may in turn contribute to failure to benefit from professional attention and care

Box 5. Breaking the silence

The deep stigma and prejudice surrounding HIV and AIDS create a deadly veil of silence around the disease. Stigma keeps people from getting tested and seeking treatment. It keeps those who do get tested too ashamed and fearful to share the results. It forces children living in AIDS-affected households to maintain secrecy and to suffer in silence.

Increasing knowledge and awareness about HIV and AIDS and dispelling misconceptions about the disease have proved effective to help reduce stigma and its impacts at the family and community levels. Faith-based organizations have actively promoted community support for children and others affected by HIV and AIDS through public dialogue and advocacy campaigns.⁴⁹ The mass media is also helping to reduce stigma through public education campaigns that disseminate information and promote a culture of compassion and understanding.

Home-care programmes and organizations of people living with HIV are also playing an important role in breaking the silence surrounding the disease. In Cambodia, a home-care programme for people living with HIV, supported by the government and NGOs, actively seeks to correct misconceptions and to prevent stigmatization through home visits, counselling and care and treatment that focuses on altering public perceptions about contact with persons affected by HIV and AIDS.⁵⁰ In Mozambique, Kindlimuka ('wake up'), an association of people living with HIV, provides support to families affected by HIV and AIDS. Many of the members, who refer to themselves as activists, speak out at public events and in schools about being infected by HIV in order to break the silence that still stalks the disease and thrives on ignorance and fear.⁵¹

and, in the case of children who are themselves living with HIV, difficulty in adhering to treatment and medication regimens.

When a parent dies, it is usually adults who make vital decisions about where a child should live. Children themselves are often not consulted, even though they may have strong views about who would best care for them.⁴⁸ In some cases, children are simply left on their own, neglected in their development and deprived of the ability to enjoy their human rights.

It is critical to increase understanding about the psychological trauma experienced by children living in households affected by HIV, including among family members, neighbours and other local community members with whom the child and family interact. Key service providers, including health care workers and teachers, clergy and local media, must also be sensitized and, when relevant, trained to meet the psychosocial needs of children affected by HIV and AIDS. A major constraint, however, lies in the limited number of trained psychologists and social workers who can provide services and build local capacity.

Local organizations and associations, as well as children affected by HIV and their caregivers, have played a central role in addressing

the psychosocial challenges resulting from HIV and AIDS in many countries. A number of strategies help to alleviate the psychological and social problems experienced by children affected by HIV and AIDS, including reconnecting children with family members, friends and neighbours; restoring a sense of normalcy to children's daily lives; promoting a sense of competence and feeling of control; and building on and encouraging the innate resilience of children and communities. Increasing evidence underscores the importance of closely linking psychosocial support to other services for children and support for them, responding to the multidimensional needs of the child.

All initiatives must be guided by child development theory, address the needs of children at different ages and plan for the long term. The best interests of a child orphaned at age 2, for example, are different from those of a child orphaned at age 12. Respecting a child's need and ability to express opinions and make informed choices is crucial at every stage. To avoid stigmatization and discrimination, children affected by HIV and AIDS must not be singled out and provided with separate services, but rather have access to services available to all children.

3.2 SUPPORTING THE EXTENDED FAMILY

When parents die or are unable to care for their children, the children are most likely to be taken in by close family members: grandparents, aunts and uncles, even adult siblings. This is the best solution to keep family ties strong and ensure continuity in the child's upbringing. If closer relatives are also HIV-affected, it is also common for children to be taken in by more distant relatives. In sub-Saharan Africa, as well as in some other regions, the great majority of all orphans are cared for by the immediate or extended family.

But in communities severely affected by AIDS, extended families find it increasingly difficult to shoulder the burden of care. An additional child or children stretches existing resources far beyond the capacity of families that are already poor and stressed. In many cases, families are simply unable to cope.

Very often, it is grandparents, particularly grandmothers, who come forward to provide care for the next generation of children. The strains imposed on elderly people are especially difficult as they often need care themselves and have an expectation that their families will look after them. With the spread of HIV and AIDS, grandparents face the serial traumas of losing several of their children to AIDS-related diseases and are then left to take care of their orphaned grandchildren, alone. In Ethiopia, 68 per cent of adults who died of AIDS-related illnesses left their children in the care of their parents. In such situations, the elders take on total social and economic responsibility for their many grandchildren.⁵² Research in Thailand found that two thirds of adults who died from AIDS-related diseases lived with or near a parent in the last stage of their illness. A study in northern Thailand revealed that grandparents were the main carers of children who had lost one or both parents to AIDS, caring, on average, for more than four grandchildren each.⁵³

Being looked after by family members is not sufficient to guarantee a child's welfare, protection and ability to cope. Moving into the extended family may mean that a child is separated from siblings and has to leave the family home and, in some cases, the child's community – compounding the already traumatic loss of parents. In addition, without succession planning, family disputes may arise over care arrangements. As noted above, children are often given no say in deciding with whom they will live.

Children who have been taken in by family members out of a sense of duty rather than genuine affection may be denied emotional support and treated differently from biological children in the home. Some children are pushed into domestic service, or otherwise exploited. They may, for example, be deprived of land or assets belonging to their parents. Gender bias can also affect the readiness of families to take in children who have lost their parents. In India, for example, the dowry system may discourage families from taking in additional girls.⁵⁴ In these circumstances, children may end up with caregivers who are not relatives. Some children may search for their own solutions, such as living on their own, or seek support from a range of households.⁵⁵ This may place them at even greater risk if they end up living on the streets, where they become vulnerable to violence and exploitation.

Families and extended families need assistance in bearing the responsibility of care for children orphaned by AIDS. Stakeholders outside the family must become involved, to guarantee that the rights of the child are realized. In some cases, cultural and community customs must be set aside to ensure that identified solutions are genuinely in the child's best interests.⁵⁶

To be effective, responses need to take into account the different customs relating to kinship care across communities and cultures. In Nepal, for example, orphanhood carries a negative connotation and is widely stigmatized. Orphans may be blamed for their parents' deaths, and orphans of all economic and social groups suffer significant hardships and isolation.⁵⁷ In Malawi, a child can be considered an orphan even if he or she is living with a disabled or chronically ill parent. In contrast, in Rwanda, a child whose parents have died, but who is living comfortably within the extended family, is not considered an orphan.⁵⁸ Culture influences how orphaned children are identified, how they are perceived by others, what their needs are and how their needs are understood and met.

3.3 CARE IN THE COMMUNITY

In some cases, the immediate and extended family is simply unable to take on the responsibility of caring for children who have lost their parents to AIDS. Communities, typically with the support of an NGO or external agency, are now developing strategies and responses to keep orphaned children in family-like settings and in their home communities.

Box 6. Succession planning⁵⁹

Parents with HIV or AIDS can look after their children's best interests by planning for their future. Succession planning can help parents ensure that their children stay together and are cared for by immediate or extended family. By appointing a guardian who can meet regularly with the children, parents can also provide their children with a sense of security, belonging and continuity once they're gone.

Succession planning helps to ensure that continuity of care is not broken, family history and cultural identity are preserved and family property is secured. It may even mitigate the sense of helplessness and hopelessness that often accompanies the disease. But the process can be difficult, in part because of social taboos and the belief that preparing for death and the writing of wills will hasten death's arrival.

Children should be encouraged to be involved in succession planning, yet too often they are not consulted – even in cases where children are already caring for an ill parent. A recent study in Malawi found that although children themselves had clear and informed preferences about who should become their caretakers within the extended family, they were never asked for their opinion.

It can be important for the ill parents to talk with their children about their condition and prepare for their deaths. This process can be aided by

compiling memory books and baskets or, as is done in Andhra Pradesh (India), by making family trees. A study in Uganda showed that parents responded positively when encouraged to talk about their condition with their children, to write wills and plan for the care of their children. All of the parents interviewed also said that disclosing their HIV status could strengthen family bonds and encourage children to take precautions against HIV and AIDS. In Tanzania, research shows that children appreciate receiving advice from their parents on what to do after their parents die.

Gathering important documentation, such as birth certificates and other important papers, before a parent dies can also facilitate access to small grants and other support that might be available to orphaned children.

Any succession plan drawn up by the family must be in accordance with and supported by appropriate policies and laws, both traditional and in the formal justice system. Legal measures are particularly required to recognize and safeguard the inheritance rights of children and women. At the same time, it is important to recognize that inheritance is not only about land and money: informal as well as formal measures are needed to ensure the protection of a child's name, nationality, cultural heritage and sense of belonging and purpose.

Fostering

Fostering is usually understood to refer to the situation where children are cared for in a household outside their family. It is generally regarded as temporary, with the birth parents retaining their parental rights and responsibilities.⁶⁰ This differs from legal adoption, where the adopters assume full parental responsibilities.

Traditions of fostering children within extended families have existed in many cultures. However, foster care in a formal or legal sense – i.e. recognized in national laws and policies – is not common in the areas most affected by HIV and AIDS, including sub-Saharan Africa. Nor is formal fostering a strong practice in countries in Central and Eastern Europe and the Commonwealth of Independent States, where state institutions have

been the main response to orphans and children with disabilities for much of the 20th century.

HIV epidemics, however, create environments where formal fostering may be an effective and desirable response; for example, when extended families are not available or as an alternative to institutional care. A recent analysis of children separated from family in emergency situations concluded that a lack of cultural familiarity with fostering is not necessarily a barrier to its successful introduction.⁶¹

In Rwanda, for example, the government, in partnership with NGOs, promoted fostering on a large scale when more than 100,000 children were left orphaned or separated from family following the 1994 genocide and civil war. The available evidence suggests that the idea of

fostering took root successfully, despite its being an unfamiliar concept.⁶² Other successful fostering programmes have been introduced in Kenya, Tanzania and Liberia.

Several factors have contributed to the successful introduction of fostering in a variety of settings:

- well-publicized government support – for example, through radio campaigns;
- working with and through community structures to select, support and monitor foster families in their child-rearing responsibilities;
- foster caregiver training: one evaluation suggests that training was significant in improving the quality of care and protection for fostered children;⁶³ and
- using existing foster caregivers and sometimes older children to identify new foster homes.

In foster care programmes in the West, the fostering agency normally oversees the arrangements, while delegating day-to-day responsibility to the caregivers. While caregivers receive material support in some fostering programmes, many do not.

Where fostering is not a common practice, the absence of legislative provisions for fostering leaves foster families in an ambiguous position. A

number of issues arise regarding the child's status within the foster family, such as whether the child is entitled to dowry payments or inheritance and to what extent the foster parent is responsible for the behaviour of the foster child. For example, if the child commits a misdemeanour requiring compensation to be paid, is the foster caregiver responsible?

When foster care is formalized into law, however, the State's accountability for children and the child's entitlement to protection is clarified. Legal recognition provides safeguards for the child as well as for the foster family by clarifying how responsibilities vis-à-vis the child are shared between the foster family, the child's own family, external agencies (governmental and non-governmental) and community representatives. Above all, clarifying the legal status of fostering lays the foundation for safeguarding children's rights throughout the fostering arrangements, guided by the child's best interests.

Where foster care agencies do not exist or may not have the means to support and monitor children and their families, different models of fostering have been adopted to address the needs of large numbers of children. Experience suggests that, even in the most adverse circumstances, it is possible to identify and build on existing community structures, such as faith-based congregations, women's groups, cooperatives and other associations, to support orphaned children. In conflict and refugee situations, for example, the local community often assumes increased responsibility for monitoring and supporting children and foster families. Moreover, a review of programmes in emergency situations showed that the absence of material support from agencies did not prevent the recruitment of caregivers.

Unlike conventional fostering, in which caregivers receive one or more children into their home, 'group fostering' brings together a group of children, who may not belong to the same family, under the responsibility of a single caregiver or couple in a home. Siblings are kept together when possible to secure family ties. In some cases, the caregivers are paid a modest wage, allowing the caregivers to focus full-time on caring for the 'family'. An agency may also provide material support or start-up costs, such as a house, domestic equipment, land and tools, and other means to enable the new family to be self-sufficient.⁶⁴ Although this model requires a sustained contribution, it has the advantage of providing



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children with a high level of personal care, while keeping them in the community, so that they can enjoy as normal a life as possible. Several organizations in Sudan have promoted a similar model for children with special needs.⁶⁵ This involved providing a house and employing a couple (with or without their own children) to provide care. Particular attention was paid to integrating the children living in these homes into the local community.

Under 'collective foster care', a group of people – from the same church, for example – work together to look after children who do not have adult care.⁶⁶ There is also evidence of foster caregivers themselves rallying networks of social support – for example, from within a particular church community – resulting in 'clusters' of both children and adults within mutually supportive networks.⁶⁷ A variety of experiences demonstrate how a shared responsibility towards orphaned children can be created and sustained among different actors within communities (see Box 7).

Community support for child-headed households

Community support is crucial to enable the small but noteworthy number of households headed by children to function effectively. Community-based programmes often use volunteers to visit children living on their own and offer a range of support. In Rwanda, providing opportunities for such children to get together has enabled them to support one another and helped to reduce their sense of isolation. The establishment of Associations of Child-Headed Households, whose main aim is to develop cooperative economic activity,⁶⁹ is also helping these children fight isolation. Regular meetings encourage mutual problem solving and provide an important opportunity for social support.

Evidence suggests that child-headed households are more likely to be a viable care option if they are linked to NGO support.⁷⁰ It is less clear whether, without targeted assistance, these children would be satisfactorily absorbed into the extended family or would end up in a more vulnerable situation, perhaps living on the street. In some cases, NGOs offer a high level of material and social support to households headed by children.⁷¹ For example, in AIDS-affected communities where children living without adult care are unable to locate family members, methods used for helping war-separated children trace their relatives can be adapted to help reunite families.⁷²

Box 7. The Farm Orphan Support Trust (FOST) in Zimbabwe⁶⁸

FOST was established in 1997 as a community response to meet the needs of the growing numbers of orphans living on their own in commercial farming areas. Many of these orphans were children of migrant farm workers who had become detached from their extended families and communities of origin. FOST was officially registered as a Private Voluntary Organisation.

The first priority for FOST has been to support orphans within their extended families. Where that is not possible, foster relationships are established with volunteers from the community. Cultural barriers, such as a belief in the presence of *ngozi* (avenging ancestral spirits), have been addressed by reframing fostering as a form of extended hospitality.

Supported by the Ministry of Public Service Labour and Social Welfare and farming organizations in the country, the FOST model emphasizes community participation at every level of the programme. A Child Care Representative, recruited by FOST on each farm, registers and monitors all children to identify the levels of support necessary and to assist with family tracing, when possible. The representatives report to the local Farm Development Committee, which deals with farm social issues. Foster caregivers are trained in various aspects of psychosocial care and attend regular meetings to discuss problems and issues. Households are monitored and supported through regular visits by the FOST Child Care Representative and the farm health worker. Where necessary, material support is provided; for example, for school fees and uniforms. FOST works closely with farmers to ensure that foster caregivers are given permanent work to continue supporting the household. In some cases, the farmer supplies additional food and other forms of support for a family in particular need.

In 2004 FOST facilitated access to education for over 6,000 orphans and vulnerable children, supported over 50 orphan-headed households, trained 145 youth volunteers and 200 teachers in psychosocial support and worked with 234 community-based volunteers.

4. BUILDING COMMUNITY CAPACITY



In communities affected by HIV and AIDS, the forms of care that seem to be most realistic, and therefore most widespread, are those where the care of children is shared among various actors. In these arrangements, volunteers, other families or alternative families take responsibility for the well-being of the child. Many of these arrangements combine local initiatives with external support.

External support can come from a range of actors, including national or international NGOs, community-based organizations and groups, faith-based organizations, as well as government. In Thailand, for example, there are more than 500 self-help groups and organizations of people living with and affected by HIV and AIDS that have differing degrees of legal formality. An increasingly important role of these self-help groups is to advocate greater access to care and treatment for their members – parents, young people and children.

In countries that do not have a history of social mobilization in the form of civil society organizations, such as NGOs and CBOs, support can come from other partners. In China, Lao PDR and Viet Nam, mass organizations for women and young people, which were originally formed to support national solidarity in the context of economic and political reforms, have become increasingly important partners in social and other forms of development, including in efforts against HIV and AIDS.

Expanding networks and partnerships that are committed to sustaining community safety nets is crucial to providing care for the rising number of orphaned children in urban and rural areas. The challenge is to better understand the way that links and partnerships between families, communities, institutions and government agencies work, so that successful initiatives can be replicated and expanded.

Building community capacity requires:

1. Assessing the situation and identifying those in need of support and the resources available in the community.
2. Strengthening the organization of communities to build the necessary infrastructure that will ensure adequate and continuous care and protection for children.
3. Developing networks and partnerships to serve as mutual support mechanisms.

4.1 COMMUNITY-BASED ASSESSMENT

Assessments carried out at the local level play a vital role in bringing to light the situation of children orphaned by AIDS. They help people become more aware of the impact of HIV and AIDS on children, and of the extent to which children's rights are compromised. They enable the community to identify the children in need of assistance, to devise appropriate means of responding to their needs and safeguarding their human rights, while monitoring their development and well-being.

When communities partner with external institutions, situation analyses can be a powerful mobilizing force for ongoing analysis and active learning. External institutions can raise awareness of the psychosocial needs of children and draw attention to protection challenges, which can often be overlooked by communities that are principally concerned with issues of immediate survival.⁷³ For example, a child's right to inheritance may not be recognized in a community. For external support to be effective and sustainable over the long term, it must be informed by an assessment of local needs and be dedicated to building the capacity of communities.

Community assessments should focus on all vulnerable children, relying on locally developed definitions of vulnerability.⁷⁴ Focusing only on children orphaned by AIDS can exacerbate the stigma and discrimination against them, and it is therefore crucial to address the situation of all vulnerable children – including children orphaned due to other or unknown causes, those with sick parents, those in households headed by women or elderly people, and those living alone or without adult care. The assessment process should determine the range of different needs of these groups.

Community assessments are important to develop strategies to care for vulnerable children. An assessment in Lao PDR of children affected by HIV and AIDS and other vulnerable children, including children with disabilities, children living and working on the streets and children affected by substance use,⁷⁵ revealed that there were few institutional systems of care and protection for these children. The majority of these children remained in their community of origin in extended family care. The assessment, supported by UNICEF in collaboration with the Ministry of Labour and Social Welfare, the Ministry of Public Health and the National Committee for the

Control of AIDS, concluded that, as the overwhelming majority of vulnerable children in Lao PDR already live in family-based care within their community of origin, the country is well positioned to develop family- and community-based strategies for care and protection of these children.

By highlighting the plight of children, assessments can stimulate and inform local and national action. In Swaziland in 2002, the Office of the Deputy Prime Minister conducted an assessment to determine the circumstances of orphaned children, especially those heading households. Communities were actively engaged in the process and prepared lists of local children living on their own. As many as 10,664 such children were identified living in 2,600 homesteads. A lack of community 'safety nets' had left them to fend for themselves. They did not have enough food to eat and lived in poor-quality housing. Many did not attend school. The assessment also revealed that there were few places where orphans and vulnerable children could go for a meal and benefit from educational and recreational activities.

The assessment drew attention to the situation of child-headed households and inspired the Neighbourhood Care Point strategy – a national initiative designed to make orphaned and vulnerable children visible, while improving their access to health, nutrition, care and psychosocial support. Neighbourhood Care Points are places within communities – a house, church, school or even the shade of a tree – where neighbours come together to provide care for local children. Preschool children are cared for by adults in the community, enabling older children, who are often responsible for their younger siblings, to attend school. The spaces also serve as a refuge for out-of-school children. Most importantly, Neighbourhood Care Points provide children with a sense of hope, love, care and support in their own neighbourhood – a place where they can mix and play with other children.⁷⁶

Other assessments, such as in Viet Nam⁷⁷ and Nepal,⁷⁸ have analysed the situation and needs of children affected by HIV and AIDS at family, community, district and national levels. They have identified ways to support families and communities as a first line of response, supported by policy reform and strengthened government coordination and monitoring. The Viet Nam assessment found that 12 per cent of the country's most vulnerable children were affected by HIV and AIDS, and that there were many enabling

conditions to support existing and expanded community-based care. Like other assessments, it noted that support groups of people living with or affected by HIV and AIDS were being formed and needed training and financial assistance to strengthen their support to affected and vulnerable children and families.

4.2 STRENGTHENING THE ORGANIZATION OF COMMUNITIES

When communities are organized around HIV and AIDS in general, and around children in particular, they are more likely to make better use of existing resources and to attract external support to provide care for orphans and other vulnerable children.

One way communities organize themselves is through various forms of mutual support. For example, families faced with the loss or illness of a parent, or with an increased number of children to care for, can support one another. Individual children orphaned by AIDS, whether they are cared for by their own family or in some form of alternative care, can draw support and encouragement from their peers. Even when they must rely solely on the resources of the group, mutual support structures increase the capacity of the community as a whole to care for children.

A number of programmes build on children's peer relationships by setting up clubs or providing other opportunities for children to share their experiences and support one another. The most effective interventions build upon what children themselves can contribute and take into account the particular needs of children of different ages, and the different situations and needs of boys and girls. A recent study in AIDS-affected communities in Malawi, for example, revealed that while boys tended to seek out companionship through sport and other activities, girls tended to sit down to talk and 'share secrets' with friends. Such knowledge is vital for programme design.

In Sri Lanka, children's clubs, supported by Save the Children UK, provide children with safe spaces to develop knowledge and awareness of HIV and AIDS issues. These clubs also provide opportunities for children to receive psychosocial support, share experiences and address problems they may otherwise have to face on their own, such as sexual abuse, exploitation or alcoholism in the family. Also in Sri Lanka, Save the Children Norway and the Eastern Self-Reliant Community-Awakening Organization (ESCO), a local NGO, have

developed residential workshops to provide war-separated children, living with their extended family or in foster care, with opportunities to share their experiences. The workshops bolster children's confidence and self-esteem, enabling them to deal better with their problems.⁷⁹

In Tanzania, the youth-led Vijana Simama Imara Organization (VSI) ('Adolescents Stand Firm') is open to young people between the ages of 13 and 20 who have lost at least one parent to AIDS.⁸⁰ The group is a spin-off of HUMULIZA, a programme providing psychosocial support for orphaned children. The goals of VSI were determined by the young people themselves: to support each other during good and bad times; to create, plan and promote income-generating activities; to build unity and mutual cooperation; to help the elderly; and to support each other by practising good manners and behaviour. Club members work together to provide funds for peers in need. This may include helping with the cost of the customary meal following a funeral or pitching in to build a house for another member. One of the most important aspects of VSI is the sense of family that it creates.

In Angola, youth-led NGOs in 10 provinces encourage young people to make HIV prevention part of their lives and to bring that determination into their communities. In three provinces, the pilot project trains young peer-to-peer counsellors and educators. Local NGOs are mentored by larger and more experienced national NGOs who advise and assist in the design and implementation of innovative approaches to education about HIV and AIDS. The youth-led NGOs have created messages, skits, music, theatre performances and other ways of speaking out on HIV prevention. They have used outreach strategies, including radio mini-dramas produced in local languages, to frame messages helping to end the stigma and discrimination surrounding the disease.⁸¹

In Sinje refugee camp in Liberia, girls' and boys' clubs were set up by Save the Children to address the problems faced by large numbers of separated children. The clubs initially addressed issues of sexual violence and early marriage, sexuality and unwanted pregnancy, and gradually evolved into a broader programme of activities. The girls' and boys' clubs supported foster children, both formally through child advocates and informally, with the help of young people who had been made aware of children's rights and child protection issues. The clubs formed part of a wider range of community-based protection mechanisms that were established, including a mutual support group of foster parents.

Box 8. The importance of children's participation⁸²

Children and young people can be powerful agents of change. When young people are given the opportunity to express their views and participate in a meaningful way in HIV and AIDS prevention, care and support programmes, their confidence and self-esteem grow. They learn important communication, negotiation and practical skills and assume civic responsibility. They become informed citizens with the power to make a real difference in their communities.

Communities also benefit when young people are involved in programme design and implementation. Their unique perspective, invaluable information and insight can help to ensure that projects are relevant, effective and long lasting.

To ensure that young people are informed and effective participants, they need long-term support and guidance, particularly when addressing sensitive issues concerning the spread of HIV and AIDS. When young people understand the impact and implications of their efforts in the community, they can be more effective in building awareness and tolerance.

In Nepal, Save the Children UK mobilized large numbers of young volunteers in several districts to become involved in a wide range of activities aimed mainly at raising awareness of HIV and AIDS, including visiting the homes of people living with AIDS. The volunteers themselves eventually assumed full responsibility for this initiative and took over the training and mobilization of other young volunteers.

These initiatives demonstrate that children and young people, in particular, have an important role to play in strengthening community responses to HIV and AIDS. Young people have a unique ability to respond creatively and constructively to their own needs – and to take on responsibility for supporting and protecting the rights of other children in equally difficult circumstances.

Support for effective local responses

A supportive environment is needed to ensure that local authorities and non-governmental and community-based organizations can effectively respond to the needs of AIDS-affected families and communities. Experience indicates a number of key features of such a supportive environment, including:

- a practical registration system for community-based organizations;
- technical and institutional support to strengthen administrative, financial and staff management procedures;
- technical support for planning, implementation and review of activities;
- reliable, direct and flexible funding; and
- decentralization of State authority and responsibility to the local level, to help ensure that policy and programme development reflect community interests, particularly those of people living with and directly affected by HIV and AIDS.

Thailand, a country with one of the longest-duration HIV epidemics in Asia, has for more than 10 years worked to support effective prevention and care at the community level through decentralized funding and decision-making initiatives. It has also developed more effective partnerships between government and civil society. A case study on the Thai experience identified a number of key actions that helped to create an effective decentralized response to HIV and AIDS in the north: establishing a multisectoral, decentralized HIV/AIDS Prevention Committee chaired by the Deputy Minister of Health; providing direct grants to organizations working in northern Thailand; providing NGO/CBO funds through regional screening committees; and promoting formal NGO/CBO roles in HIV and AIDS prevention and care.⁸³ The study noted that agencies closer to affected persons (e.g. NGOs and peer support self-help groups) were now receiving funds that could be used more flexibly. The decentralization initiative, delegation of decision making and direct funding were also found to be associated with a dramatic increase in the number of non-governmental organizations and self-help groups formed by people living with and affected by HIV and AIDS.

Coordinating responses among national and local NGOs is crucial, not only to monitor the impact of efforts within the community, but also to avoid parallel or duplicate efforts. Various mechanisms may effectively promote complementarity in the work of the many different types of organizations – including local associations, workplace- or enterprise-based organizations, service groups and faith-based organizations – that support care for children and families affected by HIV and AIDS. In a number of countries, such as Angola and the Democratic Republic of the Congo, child protection networks have been established, bringing together key agencies and organizations to develop strategies to respond to a wide range

of child protection issues and activities, including HIV and AIDS awareness and prevention.

In most communities affected by HIV and AIDS, however, non-governmental and community-based organizations need greatly increased support to coordinate for an effective and efficient use of their resources.

4.3 BUILDING MUTUAL SUPPORT MECHANISMS

Group-based credit and savings programmes are among the better-known examples of community structures that are made possible through the power of the collective. They bring together individuals and families to pursue a common objective. A basic tenet of the relationship of mutual support is that members collectively pledge to repay loans.

One such scheme, which focuses primarily on women and orphans, was established by the Uganda Women's Effort to Save Orphans (UWESO). It is administered through groups of five women, who each support one another and guarantee each other's loans. Training is provided, focusing on group formation, financial management and topical issues, such as health, sanitation, nutrition, agriculture and HIV and AIDS. Functional literacy is offered where needed. 'Children's Days' are held to provide an opportunity for further discussion and training in children's rights issues and HIV and AIDS. The rate of loan repayment has been high and the scheme has brought results: better food security and school attendance, a greater degree of financial independence and an enhanced sense of confidence among group members.⁸⁴

Savings and credit group meetings also provide important opportunities for educational and capacity-building activities. These may include sessions on literacy, health, HIV prevention, sanitation, nutrition and agriculture, all of which are important for families affected by HIV and AIDS. The sessions address underlying factors, such as poverty, and at the same time more immediate issues, such as illness and diet quality.⁸⁵ When children or their families come together in groups, they develop a collective strength: as individuals improve their situation, the group itself develops an ability to make things happen. Groups also make it easier for national initiatives and international programmes to channel support and resources to children in need.

Community-based systems of social protection, such as health micro-insurance, are another example of the way that group dynamics strengthen the organization of communities. These systems are usually set up by existing groups, including village or neighbourhood associations, women's organizations, informal trade associations or cooperatives. Building on existing structures, they strengthen links within the community and create a sense of common purpose, while providing a degree of coverage for risks such as illness and death. In the case of health micro-insurance, members pool resources by paying a regular contribution – typically less than US\$5 per person per year – and agree on the benefits package that the fund will cover.

In parts of Burkina Faso, HIV prevalence ranks among the highest in the West African subregion. Yet a number of communities have been in the forefront of using micro-insurance in the fight against HIV and AIDS. In Zabre, members of the Leere Laafi Bolem health micro-insurance scheme, established in 2001, agreed to include services for people living with AIDS, thereby enabling them to be treated for opportunistic infections like tuberculosis. To ensure the viability of the scheme, they limited the number of annual claims per beneficiary. More recent schemes go further in explicitly covering HIV- and AIDS-related treatments. Members of a scheme in the rural village of Komki-Ipala, some 40 km from the capital Ouagadougou, decided to contribute an additional US\$0.50 per person per month to help people living with HIV and AIDS gain access to treatment, including antiretroviral drugs. The amount is significant for those involved and the decision to make this additional contribution reflects their willingness to share responsibility for the care of people living with AIDS.⁸⁶ The establishment of a micro-insurance scheme increased the village's organizational strength, making it better equipped to work with the in-country partner, the International HIV/AIDS Alliance – Initiative privée et communautaire contre le SIDA au Burkina Faso – and to direct external support to households with orphans and vulnerable children.⁸⁷

The impetus for strengthening the organization of families and communities can come from within communities, or from outside; typically, it is a mix. Even the most impoverished communities have substantial capacities to make significant contributions once they are engaged.⁸⁸ External agencies must identify existing human, organizational and financial resources in the community and then build upon them, taking care not to undermine existing structures.

At the same time, a spontaneously organized community response will benefit from additional resources and technical assistance. In Rwanda, for example, a church group delivered resources to families affected by HIV and AIDS by paying the enrolment fee for 50 individuals to join the health micro-insurance scheme in Matayz.⁸⁹ In West Africa, most health micro-insurance schemes are the result of local initiatives that have benefited from assistance in conducting initial feasibility studies, capacity building and management of schemes. The contributions remain entirely in the hands of the members.

External support need not undermine ownership. In some cases, micro-insurance schemes have administered grants to support families in need who were identified by the members of the scheme. These usually cover membership contributions for families that cannot afford them. This approach places trust in the members. It also means that institutions providing support for the groups can reach a much higher number of families than they would if they had to identify needy families themselves.

4.4 MOBILIZING NETWORKS AND PARTNERSHIPS

Communities cannot and should not be expected to bear the burden of care for children orphaned by AIDS on their own. That responsibility needs to be shared with other partners, including all levels of government, the international community, civil associations and faith-based organizations. Raising awareness is the first step in ensuring these various actors do their part, but increased awareness is not enough. Although many national and international civil society organizations and an increasing number of governments are ready to provide support to these children, they do not always know the best way forward. Coordinated efforts among partners are required to enable effective national-scale responses.

A key step in mobilizing partnerships is ensuring local ownership so that resources reach children in ways that strengthen families and communities and keep children as close as possible to their family environment and home community. For example, assistance for poor families can be delivered in the form of direct transfers (a social welfare benefit) or through a community-based organization or local government. When planning such assistance, national governments should consider the extent to which each option strengthens the ability of local support structures

Box 9. Gender in community-based programming⁹⁰

Women are overwhelmingly the primary caregivers of those suffering from AIDS-related illnesses and of children left behind. Countless women in AIDS-affected communities are heading households and shouldering the additional responsibility of supporting their families financially. Many women are infected themselves. They suffer overwhelming hardship with little or no acknowledgement of their efforts or support.

Women need both practical and emotional support to meet the overwhelming challenges they face. They need access to credit, programmes that reduce demands on their labour (e.g. water programmes), legislation to protect their rights to property and inheritance, and better access to health services and psychosocial support. As primary caregivers of orphans and other vulnerable children, women also need support in addressing children's concerns and advice on planning for the future.

Women also make up the vast majority of volunteers in community-based programmes. Providing women with opportunities to develop leadership skills can help them promote child care issues to the top of the local political agenda. Increasing participation of men as volunteers in community mobilization programmes is also an important strategy to support women and families.

to fulfil their responsibilities towards families, while also building sustainability within the community.

In Tanzania, local support for the most vulnerable and excluded children is provided by the Orphans and Vulnerable Children (OVC) Committee, a subcommittee of the village government's standing committee on social services. This community-based programme is implemented by The Government of Tanzania Department of Social Welfare and local authorities, with support from UNICEF. Children in need are identified by the local population. In some communities, an individual – almost always a woman – is selected in each hamlet (consisting of 10 to 15 households) to identify orphans and vulnerable children and provide them with care and support. The OVC Committee manages a village fund for orphans and vulnerable children, and the programme matches the contribution made by the village. On average, the village contribution amounts to

approximately US\$100 per village per year, although in some cases it has reached US\$1,000. A contribution is also made by the local government. The funds are commonly used to meet health, food and educational expenses for the children. Sometimes funds are used to improve housing, cultivate small plots of land or purchase clothing. To date, the scheme operates in 17 of the country's 119 districts.⁹¹

The Tanzanian programme builds on existing structures, with a view to strengthening them, increasing the likelihood that these structures will continue to function over time. Sustainability will depend, in part, on continued contributions by external agencies, but the real challenge is to develop links through which external actors can encourage better organization within communities so that adequate resources effectively reach children.⁹² As time goes on, communities can improve their management of resources and attract additional resources, leaving them better able to care for children and fulfil their human rights. The explicit responsibility and participation of several different actors strengthens the safety net, makes the community better able to cope and, crucially, ensures uninterrupted care and protection for children, even if one source of support disappears.

There are a variety of examples that illustrate the importance of linking community-based initiatives to permanent support structures. The STEPs experience in Malawi (see Box 10) is significant in the way it provides sustained and strategic support to communities to identify and prioritize concerns and to recognize and reinforce existing structures and responses. The programme also provides training and technical support, which strengthen skills and facilitate organizational development.

In some instances, the existence of community-based structures that bring together children orphaned by AIDS, or families struggling to care for them, can encourage external organizations to provide support and resources. For example, the Neighbourhood Care Points in Swaziland (see section 4.1) created the demand and provided the channel for the World Food Programme (WFP) to secure food aid for the children. In 2004, WFP began to use the Neighbourhood Care Point system to target food assistance to the most vulnerable. In some cases, the community teams devoted to the integrated management of childhood illness have also been linked to the Neighbourhood Care Point. As a result, an

organization that provides adult education is beginning to provide non-formal education activities at some of the Neighbourhood Care Point sites.

Innovative approaches are being taken in different countries to support families, households and communities to cope with the increased burden of care for affected children. A growing body of documentation and assessment of these efforts is contributing to the identification of effective strategies and lessons learned in their implementation. In Botswana, South Africa and Zimbabwe, an action-research programme supported by the W.K. Kellogg Foundation is exploring alternative models for psychosocial support, social and economic assistance and community capacity building in affected communities.⁹⁴ Partners in the Our Children Our Future programme include national and local governments, communities, NGOs, faith-based organizations and international agencies. Building on an evidence base of local surveys and censuses, regular monitoring and assessment of progress and impacts, the programme holds significant potential for enhancing knowledge about effective interventions.⁹⁵

The above experiences demonstrate that, ultimately, the most effective responses at the community level are locally grounded, sensitive to context and defined, implemented and monitored by the people most directly concerned.

4.5 THE LEADERSHIP ROLE OF NGOs

As illustrated by a variety of examples in this report, NGOs play a vital role in developing and promoting strategic partnerships to care for children affected by HIV and AIDS. The effectiveness of these efforts depends upon an NGO's ability to establish vital roots within the community. In some cases, NGO activities have been driven by external resources that have failed to fully link with local actors. The success of NGO initiatives depends on their ability to engage both with community leaders and with government partners, and to promote local ownership.

In the area of advocacy, NGOs are often most effective if they engage with other partners and if strategies are adopted not only to mobilize the media but also to lobby governments to promote policies, enact appropriate legislation, release resources and undertake other actions to overcome the challenges raised by the AIDS pandemic.

Among the broad range of NGOs, faith-based organizations merit special attention. A study conducted in six African countries examined their vital role in responding to the problems of children affected by HIV and AIDS.⁹⁶ Often relying mainly on their own resources and their own people, faith-based organizations reach large numbers of children in a variety of settings and offer a wide

Box 10. The STEPs programme in Malawi⁹³

STEPs – Scaling-up HIV/AIDS Interventions through Expanded Partnerships – establishes community-based coalitions to address the multifaceted challenges of the AIDS crisis. The coalitions typically consist of traditional and religious leaders, community-based workers from various ministries (education, health, agriculture, etc.), local businesses, other community-based organizations and interested individuals.

STEPs works largely through existing government-endorsed structures and with support from Save the Children USA. Village AIDS Committees first identify the vulnerable, often using Participatory Rapid Assessment (PRA) techniques. Based on the findings of the situation analysis, priority actions are identified and form a 'package' of HIV and AIDS prevention, care and mitigation, which varies according to the specific context. The Committees also monitor activities and mobilize resources.

Village AIDS Committees are supported by Community AIDS Committees, which in turn are established or strengthened by District AIDS Coordinating Committees. STEP's works with these structures to provide a 'cascading' pattern of training and capacity building. At each level, generally four technical subcommittees – responsible for orphans, young people, home-based care and prevention – are established.

The aim of STEP's is to achieve national coverage through strategic partnerships with NGOs, faith-based organizations and the government. At the national level, STEP's is represented in various forums, such as the Malawi National Task Force on Orphans, the Task Force on Young People's Issues and Prevention of HIV and the Malawi HIV/AIDS Participation Programme.

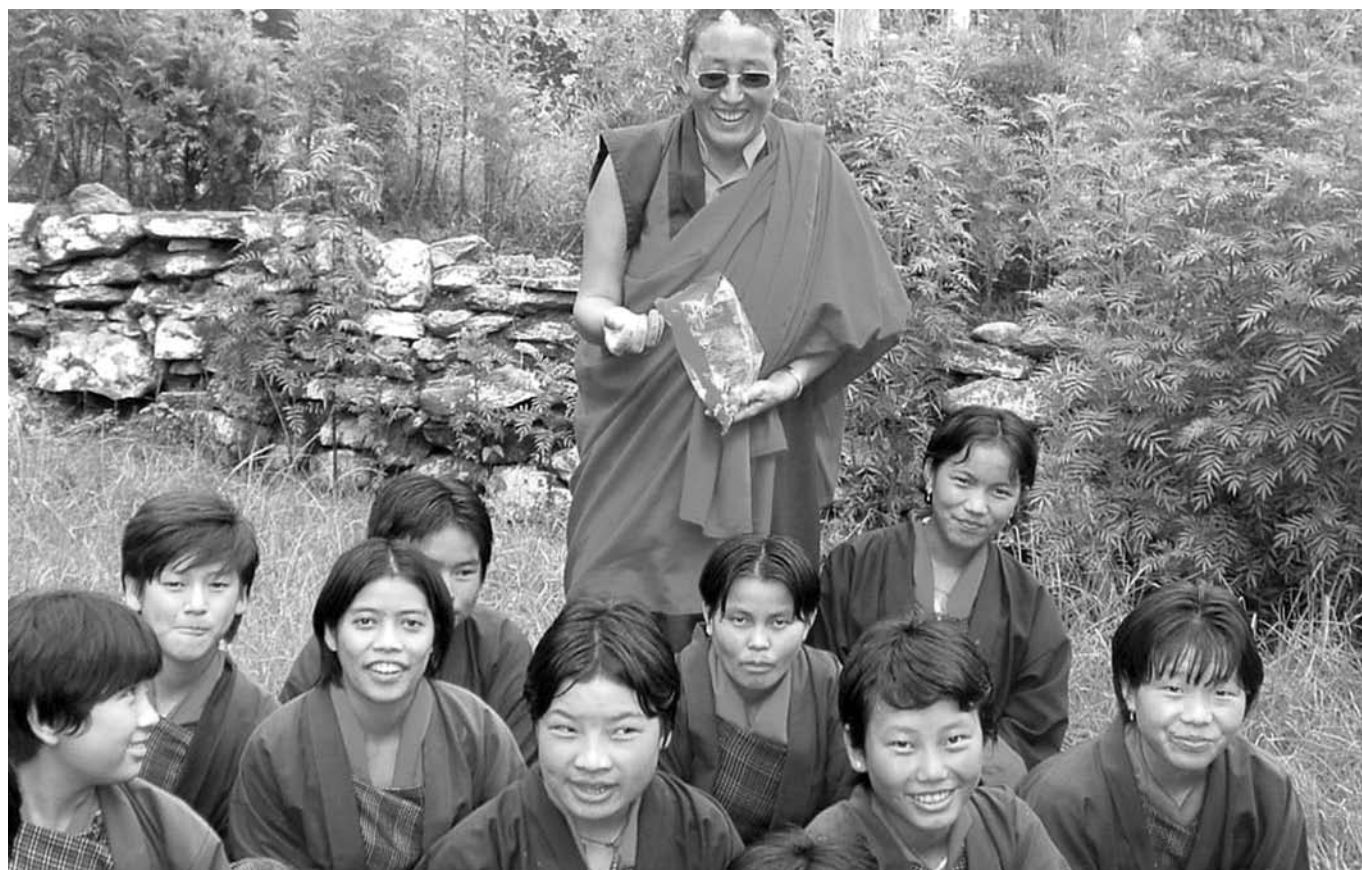
range of responses, including material support, school assistance, HIV-prevention activities, visiting and home-based care, counselling and psychosocial support, medical care, income generation and vocational training, day-care centres, religious education, foster care and adoption. The actions of faith-based organizations are often a driving force in the response to HIV and AIDS, establishing roles for other organizations in community-based care and support.⁹⁷

Faith-based organizations are strongly positioned to provide support because of their often extensive organizational networks of local churches and congregations that reach even the most remote areas. For example, the Caritas Orphanaid Programme in Swaziland provides technical as well as financial support and coordinates the work of local congregations in this effort.⁹⁸ By further strengthening the links within their networks, faith-based organizations can make a crucial contribution to scaling-up work with children orphaned by AIDS.⁹⁹

Many faith-based organizations support institutional care for children in different forms. It has been suggested that where, for example, a tradition exists of centres providing a period of residential reflection and study for boys, these

settings might be adapted as a means of care for parentless children.¹⁰⁰ While this model holds a risk of replicating some of the damaging features of institutional care, there may nonetheless be a place for spiritual centres as a means of support for family-based care in the community.

In many societies, monks and nuns are accorded great respect within local communities and can therefore be powerful allies in the response for children affected by HIV and AIDS. In Thailand, Sangha Metta (*sangha* is a community of Buddhist monks, and *metta* means 'loving kindness') educates and trains monks, nuns and novices to help combat the stigma, superstition and misinformation attached to HIV and AIDS and to help families and children affected by the disease. The project, based at Wat Sri Supha, a Buddhist Temple in Chiangmai, trains monks and nuns in HIV and AIDS awareness raising, discussion, counselling and other relevant skills. It also supports local initiatives based in temples. Using what they have learned through training and by sharing experiences, the monks and nuns help community leaders assess and plan for the impacts of HIV and AIDS and to organize awareness-raising activities. Public donations to the temple are used to give scholarships or material support to families affected by the disease.¹⁰¹



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Box 11. Cash transfers helping poor families cope

Cash transfers, provided on a regular and predictable basis, can provide crucial support to families affected by HIV and AIDS. 'Unconditional' cash transfer programmes include transfers to poor households, child support grants, orphan care grants, disability grants and social pensions, among others. Such transfers are made by government or non-governmental organizations to individuals or households identified as vulnerable by a set of transparent criteria. Their objective is to alleviate poverty, provide social protection or reduce economic vulnerability. Other types of transfers may be of a 'conditional' nature, aimed at promoting particular behaviours such as school attendance.

Research conducted for UNICEF on cash transfer schemes in 15 countries in eastern and southern Africa¹⁰² shows that cash transfers achieve their intended objectives, with little evidence of misuse and abuse.¹⁰³ The findings demonstrate that the transfers are used in a variety of ways – from purchasing food, groceries, clothes and seeds to paying for school fees and health costs. Much of the spending benefits children, both directly and indirectly. Even pensions targeted at elderly people help vulnerable children, since increasing numbers of children living in communities affected by HIV and AIDS are cared for by their grandparents. The study also concluded that cash transfers did not create dependency.

Cash transfer schemes of different types have been introduced or are being piloted in countries around the world.¹⁰⁴ Evidence is growing that they can help tackle hunger, increase living standards and improve the education and health of the poorest families. Some studies indicate that the sex of the beneficiary appears to result in different outcomes for girls and boys.

A study in South Africa found that a household's receipt of an old-age pension improves the nutritional status of children, particularly girls, if it is received by a woman.¹⁰⁵

Analysis of the Bolsa Escola programme in Brazil, which provides grants to poor families on the condition that children in the household attend school, indicates a positive effect on school enrolment, the degree of impact depending on the level of the grant provided.¹⁰⁶

Evaluation of the PROGRESA programme in Mexico, which has provided cash benefits to poor households since the late 1990s, shows that the transfers have reduced the poverty gap, reduced child stunting and rates of adult and childhood illness in participating households, and increased school enrolments, particularly among girls.¹⁰⁷

A study examining cash transfer schemes for children orphaned by AIDS highlights the mix of advantages and disadvantages of different mechanisms, such as household transfers, community transfers and school or education vouchers, arguing for approaches tailored to the situation and needs of particular groups.¹⁰⁸

Experience indicates that for cash transfer schemes to have sustained impact, they need to be scaled-up and institutionalized within government structures and integrated into a comprehensive package of social protection interventions and employment incentives. A critical supporting requirement is for strengthened birth and death registration systems, so that those who are eligible to receive support, including orphan care grants, have the necessary documentation to collect benefits. Taking cash transfers to scale will require sustained financing, administrative and management capacity and strong political commitment.¹⁰⁹

5. CARE BEYOND THE FAMILY OR COMMUNITY OF ORIGIN



In some severely affected communities, the care of orphaned children may involve moving them to another community or finding alternative care solutions, including fostering arrangements, adoption and residential care. All arrangements must take into account the child's best interests.

The Convention on the Rights of the Child highlights the critical importance of the family as the natural environment for the growth and well-being of the child. Nowhere is this truer than in coping with the AIDS pandemic. The Convention also foresees that circumstances may require alternative solutions to family care to safeguard the best interests of the child. These include foster care, adoption and, as a last resort, placement in suitable institutions for the care of children if and when such placement is in the best interests of the child. The Convention recognizes the critical relevance of the best interests of the child as a guiding principle for the consideration of these measures, while stressing the importance of paying due regard to ensuring continuity in the child's upbringing and the child's ethnic, religious, cultural and linguistic background (Article 20).

When children cannot be cared for by their family or when, in the child's own interest, the child cannot remain in that environment, a multi-pronged approach is required to serve the best interests of the child and ensure an alternative family environment:

- promoting and expanding accessibility of adoption;
- making known the limitations of institutionalization;
- avoiding unnecessary institutionalization, by explicitly treating institutionalization as a last resort; and
- promoting alternative care strategies through de-institutionalization.

5.1 ADOPTION

Adoption is usually defined as the legal transfer of parental responsibilities to a single adult or couple. In practice, the distinction between adoption and fostering is blurred – for example, when fostering becomes permanent (de facto adoption) or when a child is adopted through traditional rather than legal means. Adoption does differ from fostering in that fostering generally implies a shared responsibility among the biological family (if it still exists), foster parents, the local community and the agency administering foster care, and it is generally regarded as temporary. Adoption

means that the adoptive adults assume full parental responsibilities.

Legal national adoption may be the most appropriate way of providing a child with long-term care and protection, while ensuring continuity in the child's upbringing within his or her cultural and national identity. In situations where it is apparent that a child has no parents or alternative care-givers within the extended family or local community, adoption affords the safeguard of a legal transfer of parental responsibilities. This gives the child an established identity and family ties and the caregivers a clear and long-term primary responsibility. Studies in industrialized countries where adoption is well established demonstrate very high success rates, especially when decisions have been guided by the best interests of the child and children are adopted at a young age.¹¹⁰

Decisions about adoption are directly linked to serving the best interests of the child. This dimension remains of critical relevance in the case of children affected by HIV and AIDS. When solutions at the national level are in no way suitable to ensure the care of the child, and with all relevant safeguards in place, including respect for the best interests of the child, intercountry adoption may be considered.¹¹¹

Legal national adoption is not an available option in many countries with HIV and AIDS epidemics, either because the legal structures for adoption do not exist or because they are not accessible. In some cultures, the value attached to blood ties has resulted in the lack or under-development of adoption services, but there is evidence that the concept of adoption can be adapted to fit particular sets of circumstances. In Islamic countries, for example, where legal adoption is not permitted, a care practice known as *kafalah* exists, which does not involve a change in kinship status.

In many countries affected by HIV and AIDS where legal adoption is available, it appears to be under-utilized as an alternative care arrangement. In countries of the former Soviet Union, for example, where there is a strong tradition of institutionalized care, it is unclear to what extent adoption is presented as an option for children orphaned by AIDS. When publicity about the plight of institutionalized children in countries of Central and Eastern Europe and the Commonwealth of Independent States was followed by a rise in intercountry adoptions from some of these countries, this was not generally matched by a similar increase in national adoptions.¹¹² One reason for

this difference may have been the weak national adoption programmes in Central and Eastern Europe, which are frequently unable to match the resources available to international adoption agencies. In many African countries, appropriate legislation and policy exist, but communities largely rely upon informal adoption in the extended family rather than on legal adoption. With traditional social safety nets seriously weakened, there is a need to raise awareness about legal adoption and to create greater acceptance for adoption within the general population.

Responding to the growing number of abandoned children in communities affected by HIV and AIDS, the Child and Family Welfare Society of Pietermaritzburg (South Africa) decided to promote legal adoption in an effort to make adoption more acceptable and accessible to the wider public.¹¹³ An information campaign was launched that was designed to appeal to different racial groups and to promote an understanding of adoption. Steps were taken to adapt policy and practice in a number of areas, specifically to:

- provide a welcoming and positive response to people inquiring about adoption;
- make the process of assessing prospective adopters non-threatening;
- amend selection criteria so as to include, for example, people with minimal formal education, low socioeconomic status, modest housing conditions and small or irregular incomes;
- avoid discriminating against people who were single or unmarried;
- make adoption services more accessible for people in rural locations; and
- respect cultural norms.

The effort required a high degree of collaboration with judicial bodies, other agencies, including those working on birth registration, and health and child protection services. Despite the constraints within the legislative and court systems, the welfare society had considerable success in developing a more culturally sensitive service that made adoption more accessible and appropriate to families. As a result, many children who had been consigned to institutional care were given the benefit of a secure family.

Experience indicates that the components of a successful national adoption programme include:

- development of appropriate legislation and policies to make adoption accessible, child-

centred and guided by the child's best interests, and which conform to relevant international standards and safeguards;

- public campaigns to help popularize adoption and to erode social and cultural barriers;
- support to adoption agencies to promote adoption policy and practices guided by the child's best interests and to implement guidelines and procedures designed to safeguard and monitor the protection of children's rights;
- development of temporary foster care as an alternative to placement in hospitals or institutions while awaiting adoption.

5.2 INSTITUTIONAL CARE

'Residential care' or 'institutional care' refers to group living arrangements in which care is provided by paid adults who would otherwise not be regarded as traditional caregivers in that particular society. The form and quality of such care vary widely. Arrangements range from large, typically impersonal, public institutions to smaller centres, often run by NGOs or faith-based organizations, and 'children's villages', in which children are grouped in small family-style units.

Data on children orphaned by AIDS and placed in institutional or residential care have been very limited.¹¹⁴ According to one source, about 1 to 3 per cent of children orphaned by AIDS in southern Africa live in orphanages.¹¹⁵ Yet in some countries and regions of the world, residential care is perceived as a viable alternative to family care. Many children's homes, children's villages and orphanages have been established in communities severely affected by HIV and AIDS.

In the view of most child and human development experts, institutional settings are typically inadequate and even unjustifiable (see Box 12). Developing countries with long experience of residential care have seen the problems that arise when children placed in institutions become young adults and must integrate into society. Some of the children do not want to leave, expecting to continue living in residential care where their basic needs are met. Others look forward to their freedom, but simply cannot cope. These young people lack the cultural and practical knowledge and skills needed to integrate with autonomy and confidence into a community. Such experience with orphanages led the governments of Ethiopia and Uganda to adopt policies of de-institutionalization, opting instead to support family care.¹¹⁶

Box 12. The problems of institutional care

The decision to place a child in an institution is often driven by a child's circumstances and the family's perception of their choices, rather than by the best interests of the child. Studies have shown that institutional care results in three main adverse effects for children: emotional and psychosocial disturbance, developmental delays and learning disabilities, and medical problems.¹¹⁷

When children are institutionalized, they are isolated from their families and communities, sometimes for life. These ties, especially important in Africa and Asia, provide an essential sense of connectedness and belonging. Although the vast majority of children in residential care have one or both parents living, institutions often fail to keep adequate documentation on children in their care, making it difficult for children to maintain contact with families and communities. This isolation has a profound effect on the child's sense of personal and family identity. Some even lose the ability to speak their first language. Even children in short-term institutional care are at risk. Evidence demonstrates that once children are admitted into resi-

dential centres, it becomes progressively more difficult for them to maintain ties with their extended family, as well as to move them into family-based care.¹¹⁸

Numerous studies indicate that children in institutions do not receive sufficient personal care, attention, affection and stimulation. In fact, child neglect, harsh and rigid discipline, maltreatment and abuse are widespread, even in well-resourced institutions in high-income countries.

The effects of institutionalization on children become increasingly clear when it comes time for children to leave. Many institutionalized children experience problems in adjusting to life outside the institution. They may end up in other types of institutions, including detention centres and psychiatric institutions, or living on the street. In Russia, for example, one in three children who leave residential care becomes homeless, one in five ends up with a criminal record and one in 10 commits suicide.¹¹⁹

In some countries, institutional care is the principal alternative for children unable to live with their own families. In India, for example, if there are no relatives prepared to care for an orphan, the child is likely to find refuge in an orphanage or live on the street.¹²⁰ This is also the case in Latin America and in many countries of Eastern Europe and the former Soviet Union. Indeed, in a number of this latter group of countries, it is common for children who are infected by HIV to be classed as 'disabled', resulting in them being placed in institutions for children with disabilities.¹²¹

Institutional placement as an economic and social coping strategy can be attractive to some families, because they anticipate that their children will have better access to services or receive material goods that the families feel they cannot provide. Yet support for residential institutions may undermine family and community coping strategies. In communities under severe economic stress, increasing the number of places in residential care may result in children being pushed out of households in order to fill those places. According to a study in Zimbabwe, "The ready availability of institutions to provide long-term care for orphaned children may encourage

some relatives to forego their responsibility to care for orphaned children."¹²²

Many communities, however, do not support institutionalization. Research in AIDS-affected areas of Malawi found that adults in most communities opposed the development of residential institutional care.¹²³ This study also found that the children themselves were unanimous in the view that, although residential institutions may offer better material conditions, it was more important to them to have a sense of belonging and be prepared for adulthood. In South Africa in 2002, the National Association of People Living with HIV/AIDS responded negatively to proposals to develop a children's village in Roodenpoorte for children orphaned by AIDS.¹²⁴

From a purely economic perspective, institutional care is not a viable solution. Residential forms of care are from 5 to 20 times more expensive than foster care by unrelated caregivers. Often the substantial costs of infrastructure and buildings, trained staff and appropriate regulatory mechanisms are not included in cost estimates.¹²⁵ In Tanzania, the cost per child can be about US\$1,000 per month – almost six times the cost



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of supporting a child in a foster home.¹²⁶ In Zimbabwe, it is estimated that in order to provide care for 10 per cent of the country's orphans, more than 1,200 new institutions, each housing 50 children, would have to be built every year. Given the millions of children projected to be orphaned as a result of AIDS by 2010, reliance on residential institutional care is neither affordable nor sustainable.¹²⁷

5.3 INSTITUTIONALIZATION AS A LAST RESORT

The Convention on the Rights of the Child calls for the consideration of other alternatives before placement in an institution and asserts that children who are placed in institutions have the right to "a periodic review of the treatment provided ... and all other circumstances relevant to his or her placement" (Article 25). The Convention therefore encourages the periodic consideration of the need for such a placement, its relevance for the care and protection of the child, and its conformity with the child's best interests. In the case of abandoned infants, it is sometimes argued that temporary care in a residential institution is unavoidable while adoption arrangements are being considered. However, empirical evidence on the impact of institutional care

indicates that young babies have the highest risk of serious long-term developmental impairment due to an institutional experience. A study in the United States found emergency foster care to be a preferable alternative to institutional placement in most cases.¹²⁸ In Thailand, one organization working in an AIDS-affected community avoided institutionalization for infants during this developmentally crucial period by promoting the return of abandoned children to extended families and the recruitment of foster families to provide short-term care pending adoption.¹²⁹

Many children are abandoned because they are infected with HIV. In Russia, between 20 and 25 per cent of children born to HIV-positive mothers are abandoned at birth. Many of these children are left in hospitals, deprived of adequate personal as well as medical care.¹³⁰ A similar situation is reported in Thailand.¹³¹ In Romania, where nearly 5,000 children born between 1987 and 1990 became infected with HIV, primarily from blood transfusions and other medical treatments,¹³² large numbers of infected children live in overcrowded and poorly staffed orphanages. Today, Romania is home to half of all paediatric AIDS cases in Europe.

Some countries are taking steps to regulate the

conduct and provision of services of residential care for orphans. The increasing rate at which children are being orphaned and abandoned in Lesotho prompted the Department of Social Welfare in the Ministry of Health and Social Welfare, supported by UNICEF, to develop, in March 2006, specific guidelines and standards regulating residential care for orphaned and vulnerable children. The guidelines mandate the Department of Social Welfare to assess, register and monitor residential care dwellings. A time frame is set within the guidelines by which all existing homes should be in compliance with the set standards. Thereafter, homes should be licensed, registered and accredited by Social Welfare. The guidelines and standards, which still need to be officially adopted by the government, will be used countrywide among all service providers for children and define clear roles and responsibilities for all parties.¹³³

When children are not able to live with their families, they should be afforded as near as possible environments that approximate those of families.¹³⁴ In Constanta (Romania), Casa Speranta ('House of Hope') is a powerful model that promotes the integration and re-integration of children living with HIV into the family and community.¹³⁵ HIV-infected and uninfected children live together in family units with trained foster mothers, and HIV and AIDS awareness is incorporated into children's daily lives. Casa Speranta also integrates HIV-positive children into the wider community and challenges the severe discrimination that HIV-infected children face in Romania. Local public schools have accepted many of the children and some have been adopted or fostered.

In South Africa, the Child and Family Welfare Society of Pietermaritzburg responded to the abandonment of HIV-positive children by developing an approach that would avoid long-term care in hospitals or institutions. The strategy complemented the society's adoption programme, which did not place children infected by HIV (see section 5.1). The HIV status of abandoned children was determined through pre-adoption medical screening. Children testing positive for HIV were placed in a foster care project. Because of the significant incidence of 'false positives', children were re-tested, and those who tested HIV-negative were put forward for adoption. Sometimes, their foster carers became the adoptive parents. Initially, the project intended to place a 'cluster' of children in each foster home, with groups of foster homes in turn forming additional clusters in an effort to provide mutual support among the children and

caregivers. Yet the stigma and anxieties surrounding HIV and AIDS proved to be less of a barrier than anticipated and the response to recruitment, which mainly targeted black communities, faith-based organizations and nurses, was unexpectedly positive. As the programme progressed, existing foster caregivers helped to enlist other caregivers, indicating a preference for mature women experienced in parenting. Training was offered, with a strong emphasis on HIV and AIDS awareness, information and practical aspects of care. Foster caregivers were eligible for an allowance through the state foster care grant, for which they could apply. Apart from 'start-up' kits (for which sponsorship was obtained), no material assistance was provided. Increasingly, however, it proved necessary to recruit families who were financially better off. It was quickly realized that most foster caregivers would not be able to cope with more than one child. Some foster caregivers rallied networks of social support, for example from a church community, resulting in clusters of both children and adults within mutually supportive networks. The foster placements were supervised and supported by welfare society staff. The majority of children placed were under two years of age, and it was clear that these children thrived much more than those who remained in institutional care.¹³⁶

The South African experience is significant because of its success in recruiting foster caregivers for a group of children who are generally considered the most difficult to place. It is not clear that this project would have been viable without the financial support provided by the foster care grant. The programme also relied on ongoing monitoring and support provided by agency staff. In contrast, some residential institutions in Africa, recognizing that they cannot take in the growing number of orphans or provide this level of programme support, have focused on providing outreach and day support to orphans and vulnerable children living in the community.

5.4 PROMOTING ALTERNATIVES TO INSTITUTIONAL CARE

In response to growing concerns about the impact of institutional care on children's development, there have been moves to close institutions and to develop family- and community-based responses. De-institutionalization affects a range of different groups in the population – from young orphans to people with disabilities and senior citizens.

The high-income industrialized countries began de-institutionalization in the 1970s, with varying degrees of success.¹³⁷ Italy has been a leader in the effort to replace residential institutions with more child-centred and community-based solutions. In 2001, Italy passed a law aiming to close all of its 475 orphanages by 31 December 2006, and to place children currently living without family care in family homes (*case famiglie*). The law also created a database of all children awaiting adoption. The Istituto degli Innocenti in Florence became the first European institution to care for orphaned children in the middle of the 15th century. Transformed from a residential care institution, it is still in the forefront of child care innovation, testing ways of promoting the placement of children in family contexts.¹³⁸

In the 1990s, the Russian region of Samara significantly increased its capacity for foster care and guardianship, nearly doubling the number of guardians. Among the key measures taken in this relatively well-off region were: paying caregivers; providing index-linked benefits; and

offering a range of supports for children including health camps, extra schooling and financial housing support at age 18. Additionally, foster care programmes were set up to serve children with complex needs – an estimated three out of five children. The number of children involved in programmes rose rapidly from 200 in 1996 to 1,109 in 1999. This was partly due to more flexible eligibility criteria for caregivers (e.g. accepting single parents and eliminating requirements for higher education), and the provision of generous social support for them. Between 1992 and 1999, Samara closed three infant homes and three preschool children's homes, while actively promoting adoption and introducing a range of family support services to children. One notable outcome was the drop in re-referrals of children left without parental care – only 14 per cent at the end of the period. This suggests that when community-based support and alternatives are available, parents may be less likely to abandon children or to place them in institutions.¹³⁹

Between 1992 and 1997, Uganda was able to



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substantially reduce the number of children living in institutions through a special programme for reunification of separated children with their families and by enforcement of existing policies and standards for care in institutions.¹⁴⁰ In 1992, Save the Children UK and the Uganda Department of Probation and Welfare carried out a survey which found that the large majority of children in the country's orphanages had living parents or close relatives who, with limited support, could provide for their care. It was found that about half of the residents of children's homes had both parents living, another 25 per cent had one parent living, and 20 per cent had known relatives.

The number of orphans in Uganda during this period was already large due to armed conflict, and was rapidly increasing due to AIDS. In keeping with Ugandan traditions and international child welfare practice, the Department of Probation and Welfare established a policy that favoured family and community-based care for orphans,

with institutional care being a last resort. Between 1992 and 1997, the department and Save the Children carried out a programme that reunited 1,700 institutionalized children with their families, significantly reducing the number of children in residential care. Thirty substandard institutions were also closed and the level of care in remaining facilities was increased. Follow-up contacts determined that the care had improved for the great majority of reunited children.

These examples show that it is possible to shift the balance and restore children from institutions to family-like solutions and more socially integrated and developmentally constructive settings. However, it requires political will and the identification of feasible alternatives. In the case of children left behind due to AIDS, there is a need to monitor their situation and to ensure their rights are safeguarded, including the right to grow up in a family environment. Local and national governments must also effectively regulate and monitor those institutions within their jurisdiction.

6. CHALLENGING NATIONAL GOVERNMENTS AND THE GLOBAL COMMUNITY



Policies and practices that safeguard the broad range of children's rights as well as meet the urgent needs of families and communities are crucial to effectively respond to the HIV and AIDS crisis, particularly to the critical situation of children orphaned by AIDS. Major policy change is possible, even in exceptionally difficult circumstances.¹⁴²

Broad-based national and global leadership is required to build family and community capacities. Leadership must unite politicians, government, NGOs and civil society, the media, faith-based organizations, academics, women's groups and human rights activists, and children and young people themselves as they together grapple with the damage inflicted by HIV and AIDS on children, their families and communities.

Some governments have for a number of years demonstrated strong leadership and inventive partnerships. Botswana established the National Orphan Programme in 1999 in partnership with NGOs, community-based organizations and the private sector. The programme aims to develop policies, including a review of government child protection policies; build and strengthen institutional capacity; provide social welfare services; support community-based initiatives; and monitor and evaluate activities. The programme also includes a national orphan registration database. A number of other sub-Saharan African countries have brought partners together and developed National Plans of Action for orphans and vulnerable children using a rapid assessment, appraisal and action planning process.

In many countries, however, there have been insufficient political will, governmental leadership and effective coordination between different ministries. Reviews of government policies on children affected by HIV and AIDS demonstrate that issues critical to these children are only partially reflected in policy discussions and policy documents. For example, among 36 sub-Saharan African countries reviewed in 2004, 18 had national action plans specifically for orphans.¹⁴⁵ Such plans or policies are important to facilitate more effective decision making and resource allocation for this group. Similarly, children affected by HIV and AIDS are, in general, not given a high priority in development policies and programmes in other regions.

Actions at the national level for children left behind by AIDS must be complemented by strengthened support at the global level. The

Box 13. The role of prevention in care, treatment and support

Several assessments (Lao PDR, Viet Nam, Nepal, Thailand) have underscored the importance of linking prevention with care for orphans and children affected and made vulnerable by HIV and AIDS.¹⁴³ This connection helps break the 'vicious circle' that traps children and families affected by AIDS, and also helps reduce transmission and the longer-term burden of care. People living with HIV have a critical role to play in prevention by giving a human face to HIV and AIDS, and also as advocates for support, social justice and solidarity.

A 2004 report of the Global HIV Prevention Working Group, *HIV Prevention in the Era of Expanded Treatment Access*, notes that as access to antiretroviral therapy expands, millions of people will be drawn into health care settings, providing critical opportunities to simultaneously expand access to HIV prevention.¹⁴⁴

The report recommended:

- Integrating HIV prevention and treatment through all health care settings.
- Increasing attention to prevention for people living with HIV.
- Increasing participation of organizations of people living with HIV.
- Increasing efforts to reduce stigma and discrimination.
- Revising prevention strategies for HIV-negative people.
- Simultaneously scaling up prevention and treatment activities.
- Expanding effective treatment to young people, women and others facing barriers to health care access.

international community – especially high-income countries – must help national governments make children orphaned by AIDS a priority and support them in addressing children's concerns and ensuring the fulfilment of their rights. The central challenge is to promote shared responsibility for these children and coordinated actions to rebuild the resilience of affected families and communities and strengthen the safety nets that protect children.

Review of experience shows that national governments and actors at the international level can take a number of concrete actions to support the efforts of families and communities.

A key requirement at the **national level** is to **incorporate the concerns of orphans and other vulnerable children into relevant plans, policies and frameworks**, including Poverty Reduction Strategy (PRS) processes and proposals for international funding. National policies, systems (e.g. birth and death registration systems) and legislation (e.g. on children's legal status, adoption, fostering and property and inheritance rights) must also be reviewed to ensure they protect the rights of the most vulnerable children. Coordinating mechanisms are essential to enable the effective engagement of civil society, NGOs and the private sector in national efforts against HIV and AIDS. National actions must be supported by an effective process to monitor and assess progress.¹⁴⁶

To enable implementation of plans and policies it is essential that national governments **mobilize and allocate adequate resources** to ensure the realization of children's rights. Priority attention should be given to children at greater risk, including those affected and infected by HIV and AIDS. National budgets, including the use of international resources, should reflect this commitment, especially in the areas of health, education and social development. Actions to help children and their families to remain in their communities must be effectively supported, such as through alternative fostering models and other innovative care approaches. In addition to financial resources, efforts against HIV and AIDS require increased human resources, including efforts to build the capacity of health professionals, community-level workers and caretakers.

Among specific areas for government action, the crisis of HIV and AIDS has highlighted the importance of **increased investment in social protection initiatives**. Effective social protection requires governments to work with local authorities, community-based organizations and the international community to strengthen and institutionalize measures that reduce the economic and social vulnerability of the poor. In addition to the provision of health, education and other social services, income support is needed through such measures as foster grants, pensions and other cash transfers, health and education fee waivers, school feeding and similar schemes, in relation to the local context (see Box 11). Such measures are now being increasingly implemented in countries affected by HIV and AIDS, supporting and complementing initiatives for universal free access to ARV treatment.

The **international community** plays a critical role in supporting and facilitating action at the national and local levels. Important initiatives have been taken in recent years to raise the level of aid, including in the social sectors. However, additional efforts are needed to **increase targeted assistance for children, including those affected by HIV and AIDS**. Making children a priority means expanding aid to supplement the efforts of developing countries to address HIV and AIDS, particularly in regions whose resources to deal with the epidemic are severely limited. Such assistance must be provided in ways that strengthen the capacity of governments, communities and families.

Global partnerships are effective in mobilizing attention and resources in the fight against HIV and AIDS. Supplementing and building upon these, additional efforts are needed to **strengthen child-centred partnerships and initiatives**. The gains for children in all international initiatives can be maximized if children are kept prominently in view when deciding on strategies and on the allocation of resources. Partnerships also assist in the harmonization of funding modalities and in facilitating the flow of resources from different sources within the framework of national plans. As a prominent example, the growing support of international companies through corporate social initiatives and the significant contributions by major philanthropies has highlighted the importance of public-private partnerships in efforts against HIV and AIDS.

A principal mechanism for the allocation of international resources to countries affected by HIV and AIDS is the Global Fund to Fight AIDS, Tuberculosis and Malaria. Created in 2001 to finance a decisive increase in resources in the fight against these three diseases that kill more than six million people each year, the Fund represents an innovative partnership among governments, civil society, the private sector and affected communities. As of 2005 the Fund had pledged US\$5.9 billion and committed US\$3 billion for programmes in 128 countries, representing some 20 per cent of the total international investment in programmes fighting HIV and AIDS.¹⁴⁷ However, needs remain for increased support for programmes designed to meet the needs of affected children, including for the care of children orphaned by AIDS.¹⁴⁸

A useful tool for translating the above efforts into results for children affected by HIV and AIDS is the *Framework for the Protection, Care*

and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS. The Framework was developed through an extensive consultation process, involving governments, UN agencies, non-governmental and faith-based organizations, academic institutions, the private

sector and civil society. It provides guidance for the care and protection of children affected by HIV and AIDS, centred on families and communities, with emphasis on monitoring and strengthening of the national response (see Box 14).

Box 14. The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS¹⁴⁹

Key strategies:

- Strengthen 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.
- Mobilize and support community-based responses.
- Ensure access for orphans and vulnerable children to essential social services, including education, health care and birth registration.
- Ensure that governments protect the most vulnerable children through improved policy and legislation and by channelling resources to families and communities at risk.
- Raise awareness at all levels through advocacy and social mobilization to create a supportive environment for children and families affected by HIV/AIDS.

Guiding principles for programming:

- Focus on the most vulnerable children and communities, not only those orphaned by AIDS.
- Define community-specific problems and vulnerabilities at the outset and pursue locally determined intervention strategies.
- Involve children and young people as active participants in the response.
- Give particular attention to the roles of boys and girls and of men and women, and address gender discrimination.

- Strengthen partnerships and mobilize collaborative action.
- Link HIV/AIDS prevention activities and care and support for people living with HIV and AIDS with support for vulnerable children.
- Use external support to strengthen community initiative and motivation.

Indicators for monitoring national response:

- Orphans and vulnerable children policy and strategy index.
- School attendance ratio, orphans as compared to non-orphans.
- Access to health care, orphans as compared to non-orphans.
- Malnutrition ratio, orphans as compared to non-orphans.
- Proportion of orphans and vulnerable children who receive appropriate psychosocial support.
- Basic personal needs and material well-being, including proportion of orphans who live together with all of their siblings.
- Proportion of households with orphans and vulnerable children who receive free basic external support.
- Government expenditure per child on orphans and vulnerable children.
- Birth registration of children and widows who have experienced property dispossession.
- Proportion of children living on the street or in institutional care, indicating family breakdown.

7. CONCLUSION



Millions of children are facing the tragedy of losing one or both parents to AIDS. If one parent is infected with HIV, there is high probability that the other parent is also infected, and so entire families are facing the threat of illness and death. The emotional anguish of children who lose one or both of their parents due to any cause is compounded by the burdens and threats that these children may face in caring for siblings, obtaining food and shelter, accessing health care or staying in school. These children are also at increased risk of economic exploitation, under-age recruitment, sexual abuse, violence and stigmatization.

The seriousness and urgency of the crisis cannot be overstated. Yet despite the large numbers of children affected, despite the fact that many families have been shattered by HIV and AIDS, much can be done to prevent further harm and support existing responses. Swift and determined action is required. With proper care, support and protection, mustering the combined efforts of the local, regional and global communities, children orphaned and affected by the pandemic can rebuild their hope for the future and lead healthy, productive and fulfilling lives.

This study has reviewed the situation of children orphaned and otherwise affected by HIV and AIDS, and alternatives for their care and support. It has then considered evidence on effective interventions and strategies. Key recommendations emerging from this analysis are the following, for actors at all levels:

- 1. Carefully analyse local situations to assess the needs and capacities of children and families affected by HIV and AIDS.** Analysis must be based on a clear understanding of the local situation, taking into consideration economic stress, nutritional status, emotional impact, stigmatization, access to health care facilities and treatment, access to schooling and the role of the extended family in providing care for orphans and other vulnerable children. It must also consider factors related to culture, gender, urbanization and migration that affect the ability of families and communities to respond effectively.
- 2. Dramatically improve access to treatment, including ARV therapy.** Efforts must be substantially strengthened to prolong the lives of parents and other caregivers infected with HIV in order to prevent orphaning and improve parents' capacity to care for their children. Within the same care strategy and programmes, treatment must also be made available to infected children.
- 3. Support home-based care to strengthen families and keep them together.** Providing a range of formal and informal health and psychosocial care inside the home, including, for example, nursing and medicine and meal delivery, reduces the need for hospitalization and also engages local communities, helping to build greater awareness and solidarity with persons infected with HIV. Support for effective home-based care must include nutrition services and opportunities for income generation.
- 4. Ensure that children orphaned or made vulnerable by HIV and AIDS attend school and stay in school.** Ensuring school attendance by children affected by AIDS as well as other vulnerable groups requires specific targeted strategies such as school fee elimination and in-kind support, school feeding programmes, community-based child care, and home-based services so the burden of care for the family is not shifted onto children. Flexible school schedules are also necessary to accommodate children who may assume additional responsibilities at home. It is important that schools also create a protective and supportive environment for children, taking steps to address the specific needs of girls, and to prevent discrimination and stigmatization.
- 5. Promote alternative care arrangements when family care is not possible.** Strengthening the extended family is a preferred option for children who have lost their parents, but if relatives or community members are not available or able to provide care, then other options such as fostering or adoption should be considered and promoted. A multi-pronged approach is needed to ensure that children's best interests are always served. This may include, for example, awareness campaigns to promote domestic adoption and the need to respect relevant safeguards; legal measures to protect children and ensure that their views are given due weight; and long-term measures to promote respect for cultural differences and norms. Institutionalization of abandoned children should be considered only as a last resort and for the shortest possible duration.

- 6. Pay urgent attention to the situation of children who are living in households without adult care.** Children may prefer to stay together, even under arduous circumstances, in order to maintain their close relationships with siblings and communities. Careful consideration is needed to determine what actions will support these children's best interests, safeguard their rights and provide them with adequate assistance, protection and care.
- 7. Engage children and young people in the design and implementation of initiatives that respond to HIV and AIDS in their communities.** Engaging children and young people in peer education and prevention and awareness campaigns, including adolescent-led initiatives, holds a tremendous untapped potential. Young people should be encouraged to talk with and learn from each other, to determine how best to minimize the risks of HIV infection. With proper guidance and support, children can apply their knowledge, creativity and energy to achieve dramatic results through innovative community action to prevent and respond to HIV and AIDS.
- 8. Assess and analyse experience in order to identify effective interventions for children affected by HIV and AIDS, as a basis for taking responses to scale.** Many projects and activities to support children affected by HIV and AIDS are being implemented and, with varying degrees of evidence, are presumed to be effective at the local level. However, additional attention must be given to monitoring, evaluation and research – to assess the effectiveness of programmes in reaching vulnerable children, to understand what works, and why, in different situations, and to confirm the efficiency of resource use. Only on this basis is it possible to plan for sustainability, to expand and adapt project models in other settings and to guide the critical process of bringing successful interventions to scale.

- 9. Promote leadership against HIV and AIDS at the national level, with increased international support.** National governments' political commitment to children affected by HIV and AIDS must be reaffirmed, and translated into action. The partnership of the international community, which is already playing an important role, must be expanded to focus attention on children's concerns. A focus on children must be incorporated within national plans, programmes supported by international assistance and in international initiatives.

Central to the success of all of these efforts is a collective and collaborative response. No single answer is sufficient to address the crisis facing children, families and communities affected by HIV and AIDS. All partners must join together in the effort to prevent and end the devastation caused by the epidemic. Community- and family-based action supported by national and international policies, programmes and resources is essential to respond effectively and provide adequate assistance, protection, care and support to the millions of children who have been orphaned by AIDS.

While urgently addressing the present catastrophe of HIV and AIDS, we must anticipate a greater impact in the years to come due to family and societal break-up, economic disruption and orphaning of children. We must prepare to face that challenge with informed action to safeguard the rights and protect the future of millions more children whose lives are at stake.

LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretroviral therapy
AMREF	African Medical and Research Foundation
CBO	Community-based organization
CEE	Central and Eastern Europe
CIS	Commonwealth of Independent States
COIN	Centro de Orientación e Investigación Integral (Dominican Republic NGO)
ESCO	Eastern Self-Reliant Community-Awakening Organization (Sri Lanka NGO)
FOST	Farm Orphan Support Trust of Zimbabwe
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
HIV	Human Immunodeficiency Virus
IRC	UNICEF Innocenti Research Centre
MAP	Multi-country AIDS Programme
MDGs	Millennium Development Goals
NGO	Non-governmental organization
OVC	Orphans and vulnerable children
PRA	Participatory Rapid Assessment
PRS	Poverty Reduction Strategy
STEPs	Scaling-up HIV/AIDS Interventions Through Expanded Partnerships (Malawi)
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
UWESO	Uganda Women's Efforts to Save Orphans (NGO)
VSI	Vijana Simama Imara Organization (Tanzania NGO)
WFP	World Food Programme
WHO	World Health Organization

NOTES

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