

Best Practices for Care of AIDS Orphans



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Introduction

In just over two decades, HIV/AIDS has grown from a health crisis into an economic and developmental crisis. By the end of 2000, there were more than 36.1 million people living with HIV/AIDS, including 1.5 million children under the age of 15. Ninety percent of those infected live in developing countries, 75% in Sub-Saharan Africa. As HIV/AIDS impacts on communities, children are often the most adversely affected. The devastating impact of the disease threatens the very fabric of the society—the family—as parents and caregivers die and leave children behind. It is estimated that more than 13.2 million children have lost a mother or both parents to the pandemic. AIDS affected children are ill prepared to face the future; they are required to care for themselves, their siblings and the dying parents, in an environment of discrimination that denies them protection of their basic human rights. Some organizations, communities and individuals have developed strategies to help HIV/AIDS affected orphans and vulnerable children. This paper provides background information on issues around programming with orphans and other HIV/AIDS affected children and provides suggestions for best practices, which were discussed and adopted at the ICAD Annual General Meeting and skills building workshop, September 8 to 9, 2001. The best practices for care of AIDS orphans discussed in this paper are based on the rights of the child as stipulated in the United Nations Convention on the Rights of the Child (CRC).

Defining Orphans

The United Nations Charter of the Rights of the Children (UNCRC), Article 1, defines a child as a person under the age of 18 years. UNAIDS defines an orphan as a child under 15 years who has lost a mother or both parents. The definition, however, omits paternal orphans and orphans aged 15 to 17 years. The actual number of orphans and vulnerable children affected by HIV/AIDS is greater than currently reported UNAIDS estimates.

HIV/AIDS - A Snapshot of the Pandemic

- As of the end of 2000, 36.1 million people were living with HIV/AIDS, broken down as follows: Sub-Saharan Africa: 25.3 million; Asia and the Pacific: 6.4 million (including 3.7 million in India); Latin America and the Caribbean: 1.8 million; and 1.5 million in developed countries.
- Close to 1.4 million of those infected are children under 15; 10.3 million are 15 to 24 years of age.
- In 2000, about 5.3 million people around the world became infected with HIV, 600,000 being children under the age of 15.

- UNAIDS estimates that 15,000 people are HIV infected every day, including 1,700 children under 15 and 7,000 young people between 15 and 24 years of age.
- AIDS has killed 21.8 million people, 3 million in the year 2000 alone.
- More than 4 million children under the age of 15 have been infected by HIV/AIDS; 3.8 million have already died.
- Since the start of the epidemic, 13.2 million children have lost a mother or both parents. If infection rates are not reversed, it is projected that there will be 40 million orphans by 2020.
- Before the onset of AIDS, about 2% of all children in developing countries were orphans. By 1999, less than 2 decades into the pandemic, orphaned children in some African countries made up 10% of children.
- At the end of 1999, the estimated number of orphans living in some of the worst affected countries were: 970,000 in Nigeria; 900,000 in Ethiopia; 623,000 in Zimbabwe; 447,000 in Zambia; 371,000 in South Africa; 211,000 in Burkina Faso; 74,000 in Haiti; and 53,000 in Namibia.¹

Responding to the Needs of Orphans

The response to the HIV/AIDS pandemic has resulted in a number of initiatives to mitigate the impact of HIV/AIDS on orphans and their caretakers and communities. Organizations undertaking this work have included informal, traditional or grassroots groups, religious or faith-based organizations, social support groups, savings clubs and self-help groups. Others are more formal organizations with external support from bilateral and multi-lateral donors, large non-governmental organizations and other agencies. In some cases, viable practices to care for orphans have been established. The successes and challenges have included:

Successes

- An improved quality of life for orphans, including psychosocial support.
- Protection from exploitative labour practices and other forms of child abuse.
- Assisting parents as to what will happen after their deaths. For example, to identify guardians, to enable children's inheritance, and to prepare children to face new challenges.
- Capacity-building for children, youth, communities and other organizations to better equip them to support orphans and vulnerable children.

Challenges

- Scarce resources and, at times, inadequate provision for orphans' basic needs.
- Inadequate knowledge about HIV/AIDS and how it is transmitted which has sometimes resulted in orphans being rejection or abandoned.
- Lack of resources to motivate and enable volunteers and caregivers to look after orphans and vulnerable children.
- Caregiver stress and burnout.
- Inadequate methods for identifying the neediest children, especially in cases of donor-funded projects.
- Exploitation of orphans who are sometimes used for cheap labour by caregivers.
- Lack of coordination between existing projects and services which has led to duplication of services and waste of meagre resources.
- Lack of effective policies to protect orphans and other vulnerable children.
- Too many elderly people burdened with the responsibility to care and provide for orphans.

Gender Aspects of HIV/AIDS

HIV/AIDS affects the whole society, but girls are particularly vulnerable due to a number of factors:

- Their biological make-up, a contributing factor especially if exposed to sex at a young age.
- Their gender, which is discriminated against in some cultures.
- Their age and status: young, uninfected girls are in demand as sexual partners by older men (for example, the premium age for sex workers in Asia is between 12 and 16, and in Burkina Faso, HIV prevalence rates among girls and women of 15 to 24 is five to eight times higher than that of boys)².
- Their position within the family: when a family member falls ill, the female child is the first to drop out of school to care for the sick and for her siblings³.

Impact of HIV/AIDS on Orphaned Children

HIV/AIDS impacts on children on many levels, directly and indirectly, economically and socially.

Economic Constraints

AIDS affects the social and economic status of affected families, leaving the children more vulnerable than other children. Surveys done in the worst hit countries indicate that income for households affected by HIV/AIDS is reduced by up to 40 to 60% (See *UNAIDS 1999: A Review of Household and Community Responses to the HIV/AIDS Epidemic in the Rural Areas of Sub-Saharan Africa*). Poverty is exacerbated when breadwinners become too ill to work; children assume adult roles to supplement income. Some drop out of school. In rural Zambia, 64% of orphans compared to 48% of non-orphans are not enrolled in school.

Psychosocial Problems

Children living in HIV/AIDS affected households suffer psychologically as they care for ill family members and watch them die. Many orphans experience anxiety, depression and despair as they endure the loss of parental support and nurturing.

Reduced Health Services

Due to the high number of HIV/AIDS patients, the burden of disease has increased up to sevenfold in severely affected African countries, greatly increasing demand for public health care services, and crowding other health services, especially for children. In some countries HIV/AIDS patients occupy more than 60% of hospital beds⁴.

Stigma

AIDS orphans are ostracized, discriminated against and often denied social, emotional, economic, and educational support due to the shame associated with the disease or irrational fear that orphans could infect other children⁵.

Increased Child Mortality

Children are dying not only as a result of mother-to-child HIV transmission, but also after AIDS takes their parents and caregivers - their means of support. Orphans and vulnerable children are more likely to be malnourished, less likely to be breastfed, and have less access to health care. The improved health trends of the recent past are being reversed due to increased maternal and child mortality.

Food Insecurity

As productive members of families succumb to HIV/AIDS, household incomes fall, leading to reduced food availability and insufficient and less nutritious food supplies⁶.

Child-headed Households, Street Children and Associated Problems

The number of child-headed households is on the increase as parents and caregivers die, leaving orphans unprotected, poorly socialized and under-educated. Consequently, more and more children are ending up living in the streets in order to survive, where they are at risk of engaging in child sex work and of exposure to sexual abuse.

Children's Homes and Orphanages

In extreme cases, some orphans end up in children's homes. Generally, homes are seen as the last option for orphans. Orphanages tend to be under-financed. For example, in Cambodia the government spends US\$4 per child per month⁷. More importantly, children lose their parent's properties and experience poor socialization and loss of cultural roots when removed from their home communities⁸.

Child Rights

The magnitude of HIV/AIDS, compounded by poverty, is compromising the protection of children's basic human rights as outlined in the CRC (see appendix A: The Rights of the Child in the Context of HIV/AIDS). All countries but two—the United States of America and Somalia—have ratified the CRC. However, most countries are yet to fully implement the CRC, or institute policies that safeguard orphans. Also, legal systems in developing countries are weak, expensive and located in urban centres, which limits access by the poor⁹.

HIV/AIDS and Children in Canada

The number of AIDS-related deaths is declining in Canada, due to access to medical care and availability of anti-retroviral drugs. In spite of this, infection rates are on the increase¹⁰. Various organizations across the country are involved in providing services to orphans and people living with HIV/AIDS, that include both physical and emotional support. However, a survey prepared for the National HIV/AIDS Network indicates that child-care services are inadequate, and that community-based HIV/AIDS organizations offering services to children living with HIV/AIDS face similar challenges to groups in developing countries, although not to the same degree¹¹. For example, some children still experience discrimination in accessing day care, appropriate health care, and community services. In addition, fear of disclosing status because of the stigma associated with HIV/AIDS is a particular concern among Aboriginal communities and new immigrants.

Conclusion

HIV/AIDS severely affects orphans and vulnerable children. Best practices in HIV/AIDS programming must include programs for those most affected - the orphans.

Principles of Best Practices in Programming to Support HIV/AIDS Orphans and their Families A Consensus Statement

Human Rights

All policies and programs should be based on a clear understanding of the rights set out in the Convention on the Rights of the Child. Programming should promote, protect and support the rights and freedoms of children with respect to inheritance, participation, confidentiality, and freedom from discrimination and exploitation, and need to work with communities to achieve a shared understanding of the principles of children's rights.

Child Participation

Programs should involve orphans and vulnerable children in decisions that affect their lives, and need to equip children with life skills to enable them to face new challenges. The child's psychosocial needs should be acknowledged and supported.

Community Focus

Programming should focus on strengthening families and communities to provide them with skills and tools so they can plan and manage support that will enable orphans and other vulnerable children, including those outside of traditional communities (such as street children), to achieve their rights. Programming should be culturally sensitive and relevant to local situations. Orphans should be supported within communities and families, rather than being placed in orphanages or foster homes. Policies should involve consultation with all sectors in the society, with full participation of those affected.

Continuum of Care

Care for children affected by HIV/AIDS, including orphans, is a process that must begin when parents first discover their status. It must prolong and support the parent-child relationship and allow for succession planning. Programming should strengthen and enable social and health service systems to address concerns of orphans and vulnerable children through integrated and comprehensive service provision, information, advocacy and partnership.

Non-discrimination

Programming must reduce, rather than increase, stigmatization of HIV/AIDS affected orphans, by not singling them out for assistance, but by focusing on all vulnerable children. HIV/AIDS orphans should have a right to protection, confidentiality and privacy, and access to basic services such as health and education without discrimination.

Gender

Programming should adopt a gender-sensitive approach in recognition that the girl child is particularly vulnerable to HIV/AIDS, in terms of both infection and impact. More girls and women are infected than boys and men. Girls are more often expected to care for the sick family members.

Appendix A: The Rights of the Child in the Context of HIV/AIDS

All children under the age of 18, whether they are infected with HIV, live in households or communities affected by AIDS, or live with the threat of HIV, are recognized by the United Nations Convention on the Rights of the Child, which has spelled out principles for reducing the vulnerability of children to infection and to protect them from discrimination because of their real or perceived HIV/AIDS status. This human rights framework can be used by governments to ensure that the best interests of children with respect to HIV/AIDS are promoted and addressed:

- Children's right to life, survival and development should be guaranteed.
- The civil rights and freedoms of children should be respected, with emphasis on removing policies which may result in children being separated from their parents or families.

- Children should have access to HIV/AIDS prevention education and information, both in and out of school, regardless of their HIV/AIDS status. Measures should be taken to remove social, cultural, political or religious barriers that block children's access to these services, as well as access to the means of prevention.
- Children's rights to confidentiality and privacy with respect to their HIV status should be recognized. This includes the recognition that HIV testing should be voluntary and done with the informed consent of the person involved, which should be obtained in the context of pre-test counselling. If children's legal guardians are involved, they should pay due regard to the child's view, providing the child is of an age or maturity to be able to make informed decisions.
- All children should receive adequate treatment and care for HIV/AIDS, including those for whom additional costs may be incurred because of their circumstances, such as orphans.
- States should include HIV/AIDS as a disability, if disability laws exist, to strengthen the protection of people living with HIV/AIDS against discrimination.
- Children should have access to health care services and programmes, and barriers to access should be removed, especially those that are encountered by vulnerable groups.
- Children should have access to social benefits, including social security and social insurance.
- Children should enjoy adequate standards of living.
- Children should have access to HIV/AIDS prevention education and information. No discrimination should be suffered by children in leisure, recreational, sport, and cultural activities because of their HIV/AIDS status.
- Special measures should be taken by governments to prevent and minimize the impact of HIV/AIDS caused by trafficking, forced prostitution, sexual exploitation, inability to negotiate safe sex, sexual abuse, use of injecting drugs, and harmful traditional practices.

Source: *The Role of the Committee on the Rights of the Child and Its Impact on HIV/AIDS: Problems and Prospects, presentation by the World Health Organization Global Programme on AIDS and Child Rights: The Impact on the Asia-Pacific Region, Bangkok, Thailand, 21-26 November 1995.*

Ethical Issues That Underpin Work with Children and Young People Affected by AIDS

All children's programmes should promote the rights and interests of children and young people, and restore or maintain their dignity.

- The best interests of the child should always be put first.
- Children's rights to make decisions for themselves should be respected at all times. Care should be taken to ensure that children understand the implications of their participation. Children must be empowered with the knowledge that they can refuse to participate.

- Children's rights to confidentiality and freedom from discrimination should not be compromised by participating.
- Children should participate in an environment where they feel safe with their own peers and where they do not feel threatened, frightened or used.
- Children should not be portrayed in a negative or disadvantaged way.
- Children should not be exploited for commercial, medical or research purposes.
- Children, parents and care givers should be involved in negotiating policies to ensure that they are child-focused.

Source: *The Children and AIDS International Non-Government Organization Network (CAINN)*

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Endnotes

¹ UNAIDS. Fact Sheet June 2001.

² UNDP. www.undp.org/hiv/burkinafaso.

³ UNICEF. 1998.

⁴ UNDP. Implications for Poverty Reduction, 2000.

⁵ Williamson, 2000. Gaps in Services for Families living with HIV/AIDS 2001.

⁶ UNDP. Implications for Poverty Reduction, 2001.

⁷ UNICEF. 2000.

⁸ Mukoyogo and Williams. 1991.

⁹ Save the Children. UK's working paper 2001 on the Situation of the Children Affected by HIV/AIDS in poor countries.

¹⁰ HIV/AIDS Health Canada surveillance report June 2000.

¹¹ www.resnat.ca/e/research.html