

BEST PRACTICES FOR CARE OF CHILDREN ORPHANED BY AIDS

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INTRODUCTION

Over the last quarter century, HIV/AIDS has grown from a health crisis into a global economic and developmental crisis. At the end of 2005, an estimated 38.6 million people were living with HIV/AIDS. Of this number, 2.3 million were children under the age of 15, and 10 million were young people between the ages of 15 and 24. UNAIDS estimates that 1,800 children are infected every day (mostly through parent-to-child transmission) and more than 6,000 young people are infected daily. Over ninety percent of HIV-positive children live 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 15.2 million children are living without one or both parents because of AIDS. Sub-Saharan Africa has the highest proportion of children who are orphans. As more and more parents living with HIV/AIDS succumb to their disease, the number of children orphaned by AIDS will only increase. If infection rates are not reversed, it is projected that there will be 40 million orphans by 2020.

AIDS affected children are ill prepared to face the future; they are required to care for themselves, their siblings and their 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

The United Nations Convention on the Rights of the Child (UNCRC), Article 1, defines a child as a person under the age of 18 years. UNAIDS defines a child who has been orphaned due to AIDS as a child under 18 years old who has lost one or both parents to AIDS

affected children and offers suggestions for best practices. The best practices outlined in this paper for the care of children orphaned by AIDS are based on the rights of the child as stipulated in the United Nations Convention on the Rights of the Child (CRC).

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 with succession planning to prepare their families to cope with the death of a parent. For example, helping to identify guardians, putting in place mechanisms which will guarantee childrens' inheritance, and preparing 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.
- Poor access to low-cost anti-retroviral treatment for children living with HIV (compounding problems with poor access to drugs to prevent mother-to-child transmission of HIV).
- AIDS-related stigma and inadequate knowledge about HIV/AIDS and its transmission, which has sometimes resulted in orphans being rejected or abandoned by their communities.
- 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 of caring and providing for orphans.

GENDER ISSUES WITH CHILDREN AFFECTED BY AIDS

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

- Their biology and physiology: girls are more susceptible to sexual transmission of HIV because their vaginal tissue is more sensitive to tearing, making it easier for the virus to enter the bloodstream.
- Their culture: culturally defined gender roles often limit the personal decision-making power and access to HIV-prevention information and resources of girls and young women.
- Their age and status: young, uninfected girls are in demand as sexual partners by older men and are often victims of coerced sex.

- Their position within the family: when a family member falls ill, the female child is usually the first to drop out of school to care for the sick and for her siblings.

IMPACT OF HIV/AIDS ON ORPHANED CHILDREN

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

Economic Constraints

AIDS has an impact on the social and economic status of affected families, leaving the children more vulnerable than those from families not affected by HIV/AIDS. As household resources are redirected towards health care and funeral costs, less money is available for children's schooling, leaving many orphans and affected children with no choice but to withdraw from school. Without education, children's opportunities for the future are limited, placing them at greater risk of exploitation and poverty. A study conducted in 34 countries indicated that orphans were about 13% less likely than non-orphans to attend 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 drastically in severely affected countries, greatly increasing demand for public health care services, and reducing other health services, especially for children. Accurate diagnosis of HIV status and access to treatment for HIV-positive children is a challenge for resource-poor countries. While access to antiretroviral treatment has expanded greatly in recent years - thanks in part to the UNAIDS' '3 by 5' initiative, the Global Fund, and the President's Emergency Plan for AIDS Relief - children still only represent about 7% of all people being treated in sub-Saharan Africa, 8% in Latin America and the Caribbean, and only 4% in Asia (median values). Health service constraints also affect access to treatment for pregnant HIV-positive women to prevent mother-to-child transmission of the virus,

contributing to more children acquiring the virus at birth.

Stigma

Children orphaned by AIDS 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 children orphaned by AIDS could spread the virus to other children.

Increased Child Mortality

Children are dying not only as a result of mother-to-child HIV transmission, but also because AIDS takes away their means of support - their parents and caregivers. 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. In countries hardest hit by HIV/AIDS, United Nations Population Division estimates that child mortality rates are almost twice as high as they would be in the absence of HIV/AIDS .

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 supplies.

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 “living on the streets” 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 and are unable to provide the affection, attention, security, and social network that families and communities can provide. Children also lose access to their parent's properties and experience poor socialization and loss of cultural roots when removed from their home communities. If children cannot be supported by their extended families, they would likely receive better support through

foster placements, local adoption, or smaller-scale residential care in home-like settings. Of course, situations vary, and some children fare better in a children's home or an orphanage than they would in alternative arrangements.

A FRAMEWORK FOR THE PROTECTION, CARE AND SUPPORT OF CHILDREN ORPHANED BY AIDS

Build the Capacities of Families

Families and extended families are the first source of support for children orphaned by AIDS. Strengthening the family's ability to provide the care, and emotional and psychosocial support that orphaned children need will contribute towards the healthy development of children, as well as communities, affected by AIDS. Strategies to help equip families to support and care for orphaned children include: creating support groups, helping with succession planning, providing life skills training for young people, and creating opportunities to improve a household's income generation.

Mobilize and Support Community-based Responses

Many times, families and extended families are simply unable or unwilling to provide adequate care for an extra child in their household. In these situations, grassroots community groups step in with supportive programmes and services. A strong community social safety net is vital in the response to HIV/AIDS, especially in areas of generalized epidemics where the number of orphans due to AIDS show no signs of abating. Community support can be mobilized through programmes that reduce the stigma associated with HIV/AIDS, encourage communities to take responsibility for child protection, and coordinate supportive activities such as respite care, visits to affected households, and informal schooling.

Ensure Access to Essential Services, such as Education, Healthcare, and Birth Registration

Children orphaned by AIDS face greater difficulties accessing basic services due to stigma, isolation, and the economic consequences of HIV/AIDS. The response to the needs of children orphaned by AIDS must prioritize the protection of their basic rights, such as the right to education, health services, nutritious food, safe water, and birth registration,

for example. Without these essential services, children orphaned by AIDS will continue to be at greater risk of abuse and exploitation, and will be unable to cope with the tremendous challenges facing them in society.

Ensure that Governments Protect the Most Vulnerable Children

Governments must adopt and strictly enforce national policies and action plans to protect the broad range of needs of children orphaned by AIDS. This means designing a coordinated response between ministries overseeing education, health, social welfare, finance, and other sectors that play a role in the fight against HIV/AIDS. Mechanisms must be in place to ensure these policies are consistently adopted at decentralized levels of government and that resources are channelled down accordingly so that they reach the communities and children that they are designed to protect.

Raise Awareness at All Levels to Ensure a Supportive Environment

Through advocacy and social mobilization, the silence, stigma, and fear surrounding HIV/AIDS must be broken down to allow for an effective local and national response to the pandemic. An enabling environment is essential to allow people to challenge their false perceptions about HIV and AIDS, and to ensure that care and support programmes and services for children orphaned by AIDS are successful and sustainable. Strategies include engaging influential leaders to reduce stigma and silence, building stakeholders' awareness through a comprehensive situational analysis, and supporting social mobilization efforts at the community level.

Source: The Framework for the protection, care and support of orphans and vulnerable children living in a world of HIV and AIDS (UNICEF/UNAIDS, 2004).

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.
- 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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