

INTERNATIONAL SOCIAL SERVICE & UNICEF

*IMPROVING PROTECTION FOR  
CHILDREN WITHOUT PARENTAL CARE*

**Care for Children  
Affected by HIV/AIDS:  
the Urgent Need for  
International Standards**

This paper is one of a series that deal in greater depth with selected complex issues broached in the Working Paper prepared by UNICEF and International Social Service on "Improving Protection for Children without Parental Care: a Call for International Standards" . The purpose of this paper is to identify the particular concerns which would need to be addressed by these standards in light of the HIV pandemic. It is also intended to highlight how the growing impact of HIV on children contributes to the urgency for these standards to be developed and applied.

November 2004

v2

## **1. HIV/AIDS puts children at especially high risk of lacking parental care**

By 2003, 15 million children had already lost one or both parents to HIV/AIDS.<sup>i</sup> An additional large group of children live in families or communities where adult illness and death, as well as the stigma surrounding HIV/AIDS, have brought additional hardships. Family coping mechanisms include placing children with relatives, foster families or in residential institutions in the belief that their material needs will be met.

Infants from affected families may be at increased risk of abandonment. In Thailand, for example, the probability of being abandoned by an HIV positive mother was found to be five times that of non-infected mothers in the early stages of the epidemic<sup>ii</sup>. HIV is also sometimes used as a justification for removal of children from their parents, with cases of children of HIV positive mothers being taken from their families at birth reported in some countries. There are between two and three million children under 15 years old currently living with HIV/AIDS. Such children are often placed in foster or residential care, because of a real or perceived need for care, or due to abandonment. .

Increasing problems in their original families, as well as difficulties encountered in new living arrangements with extended family members or others, may also contribute to children leaving home and migrating on their own, and/or living and working on the street. While such pressures and outcomes are not specific to the impact of HIV on families, the added burden families face, especially in high prevalence areas or where HIV is highly stigmatised, undoubtedly makes this outcome more likely and increasingly common. In Zimbabwe, where the high HIV prevalence means that a majority of orphaned children have lost their parents due to AIDS, an urban-based study found that orphans are over-represented among homeless children by a factor of two.<sup>iii</sup>

## **2. Children without parental care may be at increased risk of HIV**

HIV is also a major risk for children who already lack parental care, whatever the reason. Children living on the street or in other unprotected situations are likely to be at greater risk of HIV due to factors such as low self-esteem, poor socialisation skills, and lack of vocational skills, which increase the likelihood of risky behaviours as well as of abuse. Children in ostensibly protective but unregulated foster or residential care may also be at particular risk of sexual abuse, whether by carers, staff or other children, and therefore *inter alia* of infection. This situation has been documented in, for example, juvenile detention centres and children's homes.

These risks are further compounded for children affected by HIV. The increased hardships created by HIV can lead girls into power-imbalanced relationships, including transactional sex. In Uganda, girls who were orphans were found to have an earlier sexual debut than others.<sup>iv</sup> Such forms of exploitation, harmful as they are in themselves, have the added impact of increasing the risk of girls contracting HIV. In addition, children affected by HIV/AIDS have a greater tendency to leave school in many settings, which also reduces their exposure to the protective benefits of schooling.<sup>v</sup> In sum, non-existent or unregulated care exacerbates the spread of HIV/AIDS, making the adoption of appropriate standards all the more vital.

### **3. The dilemmas of arranging care for children affected by HIV/AIDS**

The HIV/AIDS pandemic poses unprecedented long-term dilemmas for those taking responsibility for organising out-of-home care for children – further underlining the need for recognised international guidelines and standards in this sphere. On the one hand, the traditional response of kinship care is becoming increasingly overwhelmed: there are fewer and fewer adult family members available to look after an ever-increasing number of affected children. As a result, some relatives – often elderly widowed grandmothers – are attempting to take care of a dozen or more children, usually in dire material circumstances that may be unsustainable in the medium term. Appropriate alternatives, on the other hand, may be difficult to identify. The wider community will likely be suffering a similarly catastrophic situation, so even where the stigma of HIV/AIDS can be overcome, non-related carers will be in no better position to take in children. In the great majority of severely affected countries, formal family-based care solutions are virtually unknown and would take both considerable time and resources – including financial support – to develop in any significant manner. Even existing residential facilities are often unwilling to take in children whose parents are living with or have died of HIV/AIDS – and all the more so if the children themselves are HIV-positive. This leaves fertile ground for the establishment of “specialised” residential units – often foreign-funded – for the children concerned, that can increase their undue marginalisation from society. Such a development is yet another example of how HIV/AIDS has, in little more than a decade, completely negated progress in child welfare: in this case, countries that were successfully on the path towards providing non-institutional care for more and more of their children are experiencing a renewed growth of recourse to residential solutions. Such a complex situation, analysed in greater detail in the following sections, creates major dilemmas for those who are to plan and organise out-of-home care for children affected by HIV/AIDS. This only reinforces the argument in favour of internationally-recognised guidelines and standards in this sphere.

### **4. The impact of HIV/AIDS on recourse to informal care**

Informal fostering and kinship care, already a common response to temporary or permanent incapacity of parents to care for their children, has become increasingly common. In Sub-Saharan Africa, where HIV is a major, and often the most significant, cause of orphaning, over 90% of orphans live with a relative.<sup>vi</sup> Of course, these arrangements are generally preferable to other alternatives, since children maintain a sense of family belonging and may continue to reside in their original community. There is also evidence from Sub-Saharan Africa to suggest that close relatives are likely to provide better care than more distant ones or than non-related foster carers, at least with respect to access to education,<sup>vii</sup> food provision and domestic chore allocation.

While kinship care is thus often the best option, there are several ways in which HIV may have an impact on the care children receive in their extended family. In highly affected communities, fewer adults are available to care for an increasing number of orphaned children, and many of them are older and beyond their most economically productive years. For example, in many of the most affected countries in Eastern and Southern Africa, over 50% of all orphaned children are cared for by their grandparents.<sup>viii</sup> Similar findings have been reported in Thailand.<sup>ix</sup>

Dependency ratios<sup>1</sup> are higher in households caring for orphans than those which are not: in sub-Saharan Africa the median ratio is 1.5 for non-orphan households, and 1.8 for households with orphans.<sup>x</sup> This translates into fewer financial resources available per child, and less time for caregivers to provide care and attention to children as they struggle to make ends meet. In an effort to distribute the burden of care, orphaned siblings may be separated in different households,<sup>xi</sup> further compounding their sense of loss. Furthermore, the stigma associated with

---

<sup>1</sup> Dependency ratio is defined as the sum of children under 18 and persons 60 years or older divided by the number aged 18-59 years.

HIV may have a negative impact on the perception of the child taken in by the extended family, and contribute to poorer treatment or lesser integration into the household. Indeed, exploitation, abuse and neglect are not uncommon in informal kinship care situations. This and other issues of kinship care in relation to international standard setting are discussed in more detail in another paper prepared in this UNICEF/ISS series.

Informal foster care by unrelated families is a less common, but not insignificant form of response to children orphaned by AIDS, especially in Sub-Saharan Africa. In Cameroon, Nigeria, Ethiopia and Kenya, for example, over 5% of orphans are not related to the head of the household in which they live, and an equal or larger number are furthermore described as foster children (who may or may not be related).<sup>xii</sup> However the pressures on these informal foster families are much the same as those described for the extended family above. In addition, in some societies informal fostering is already a common practice, but often “based on a tradition of exchange between families” and not necessarily on “perceptions of the child’s best interests”<sup>xiii</sup>. Concerns over exploitation of the children (as domestic workers, for example), sexual abuse and unfavourable treatment or neglect in comparison to the caregivers’ biological children are frequently reported. Such risks may be increased in the presence of HIV, when families placing children in the care of others have less to offer in return, and due to stigma.

## **5. The impact of HIV/AIDS on recourse to institutions**

The use of institutional care is increasing in some high HIV prevalence countries. Even in countries where the use of institutions is not a traditional response, growing concern about the HIV orphaning crisis and the availability of external support is leading to their proliferation. Both child rights frameworks and child development literature make clear that institutional care is rarely the most desirable response; and should generally be used as a stop-gap rather than permanent measure, while working towards reunification or family placement. Institutional care is also expensive, and thus concentrates funds available for the care of orphans and other at-risk children on a small group. In Tanzania for example, it has been documented that the cost per child in residential care is six times the cost of supporting a child in a foster family.<sup>xiv</sup> Concerns about conditions in residential care institutions, such as poor health and hygiene standards, lack of attention to the needs of individual children, lack of review of placements, as well as violence and abuse are common in many settings and discussed in detail in the UNICEF/ISS Working Paper.

Recognition of these concerns has led to decreasing use of institutional care throughout the industrialised world. Significant efforts are underway to develop alternatives in many countries of the former Soviet Union and Eastern Europe, where residential placements had previously been used as a first-line social welfare response, as well as in several sub-Saharan African countries. In some of the most HIV-affected countries, however, the trend now appears to be reversing. In Uganda, for example, the number of children in residential care fell as of the early 1990s but then increased by 66% between 1998 and 2001.<sup>xv</sup> A study on the response of faith-based organisations to the impact of HIV/AIDS on children in Sub-Saharan Africa found that support for orphanages was becoming increasingly popular among certain denominational groups, with over half of the institutions identified by the study having been established since 1997.<sup>xvi</sup> Institutional care is often driven by external donors and the local private sector who are seeking tangible and visible ways to assist. Lack of guidance and regulation from government, which remains accountable for responding to children in need of care, helps perpetuate these responses. Also, in regions where institutional care is already an established response, such as Eastern Europe, parts of Asia and Latin America, there is a risk that the gains of de-institutionalisation efforts may be lost if residential placements are viewed as the most appropriate response to HIV/AIDS affected children.

As resources grow ever scarcer in poverty- and HIV-stressed families and communities, institutions serve as magnets when other care and family support options are unavailable. Indeed, this

tendency may explain why the majority of children in residential care in many countries do, in fact, have a living parent or other relatives. Currently few services are available to support original and extended families to care for HIV-affected and other at-risk children, nor are regulations in place in many countries to ensure that institutional care is used only in appropriate situations and in conjunction with ongoing efforts to reunify children with their families.

Nevertheless, experience has shown that institutional care need not be an inevitable outcome of large-scale orphaning crises. In Rwanda 12,704 orphaned or separated children were in institutional care in the year following the genocide; with a much larger number having been orphaned or otherwise separated from their families. A policy of family tracing, reunification and fostering led to a rapid reduction of the numbers of children being cared for this way, and a successful reintegration of children back into the community. By 2000 less than 5,000 children remained in institutional care.<sup>xvii</sup> Although Rwanda is now also suffering from the effects of a widespread HIV pandemic, the number of children in institutional care has not increased substantially, due to the continued application of the policies developed in the mid- to late 1990s.

In some cases, institutional care may include the establishment of orphanages and hospices for children living with HIV/AIDS. State intervention to remove children from their families is generally based on therapeutic concerns, but does not appear to take into account the preference for family upbringing nor the possibility of effectively supporting children living with HIV within their families. The isolation of HIV positive children from other children in out-of-home care settings also perpetuates stigma and increases their marginalisation from others.

## **6. *The impact of HIV/AIDS on child-headed households***

In communities where AIDS and/or conflict have already taken the lives of many adults, there is greater likelihood of older children taking responsibility for younger siblings, in order to keep their family together. This response may also be common where government social services are not well developed, where community cohesion is weak, and where stigma contributes to the hesitation of the extended family and others in the community to care for orphaned children. It may also grow as a result of knowledge that support for such initiatives is available from NGOs or other agencies.

The appropriateness of child-headed households as a legitimate form of care for children without parental care is a matter of current debate. A number of advantages and disadvantages are associated with this form of care. On the one hand, it allows sibling groups to remain together and retain their family home. Some children see it as preferable to fostering, or to being placed in a family where they may experience discrimination, and all fear immediate or subsequent separation from siblings in such alternative situations. On the other hand, child-headed households face difficulties in earning a sufficient livelihood, are likely to lack experience in dealing with problems, and are especially vulnerable to abuse and exploitation.<sup>xviii</sup>, <sup>xix</sup>

In some settings however, 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 their legal recognition “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.<sup>xx</sup> What seems clear, at least under present conditions, is that spontaneously-established child-headed households need to be supported and protected – and certainly not arbitrarily dismantled – but at the same time should not be considered as a “care option” to be promoted as such.

## **7. How international standards could foster implementation of new strategies**

Against this background, there is obviously a need for innovative strategies – as well as the resources to implement them – if children affected by HIV/AIDS are not to be treated in a manner that jeopardises their rights and contradicts accepted good practice in child care. Such strategies must include: countering the removal of a child from parental care solely for reasons directly linked to the parents' HIV/AIDS status; provision of sufficient resources (including, of course, treatment) and support to parents to enable them to continue to care for their children; provision of support to kin and others who could provide family-based care when maintenance of children with their parents is impossible; information and other campaigns to overcome stigma; and effective promotion of policies restricting the establishment of residential units, with the requirement that the potential resources involved be re-directed to family-based schemes.<sup>xxi</sup>

Undoubtedly, the existence of fully-fledged international standards on out-of-home care that both set basic generic principles and take account of the special situation of children affected by HIV/AIDS, would constitute an important tool for promoting the adoption and implementation of appropriate policies, strategies and programmes. International standards could help provide more detailed guidance to countries coping with the care issues which are brought about – or intensified by – the HIV pandemic. The UNICEF/ISS Working Paper provides a list of issues for which internationally-agreed guidelines or minimum standards do not exist and are needed, almost all of which are relevant in the context of HIV/AIDS. Those of particular importance in this regard include:

- Services to be provided for maintaining children in safety with their parents wherever possible;
- Conditions to be met when children are to be removed from parental care;
- Processes and mechanisms enabling the children (and, where applicable, their parents) concerned to have a real say in the care option chosen, and to be consulted regularly throughout the period in which out-of-home care is provided;
- Permanency planning;
- Protection in informal care situations;
- Selection, training, monitoring and support for foster carers;
- Recourse to, and conditions in, residential care;
- Responses to child-headed households.

In order to respond to the specific concerns raised in this paper, both international and national standards and guidelines should also explicitly address:

- The importance of provisions to prevent separation. In the case of parents or children living with HIV – and other chronic illnesses – access to health care and related services can prolong lives and make it possible for parents to remain with their children, and siblings to remain together;
- Mechanisms for supporting and monitoring kinship care as well as other forms of informal foster care which can be met by a majority of countries and which help ensure greater protection for children living in such care arrangements;
- Care options and legal mechanisms to ensure appropriate support for abandoned children, and prevent unneeded separation of children from their peers or other discriminatory treatment;
- Guidance on appropriate use (if any) of medical considerations in the determination to remove children from care or to isolate them within their care environment;
- Guidance on the appropriate use of different care options, including innovative options for older children, such as child-headed households and other supported, independent living arrangements;
- Standards relating to inheritance and succession rights as an integral part of permanency planning.

Agency-approved guidelines in this sphere are certainly useful but alone may not carry the weight needed. Standards approved at the highest international level, ensuring appropriate attention to children affected by HIV/AIDS within the generic context of out-of-home care for children, are required to maximise implementation and compliance at national level.

ooOoo

---

References:

- <sup>i</sup> UNAIDS, UNICEF, USAID, (2004). *Children on the Brink*.
- <sup>ii</sup> UNICEF (2002) "Securing a Future: Mekong Children and HIV/AIDS, UNICEF Bangkok.
- <sup>iii</sup> Mawoneke, S., A. Sexton, and K. Moyo. (2001). *AIDS and Street Children in Zimbabwe*.
- <sup>iv</sup> Bagarukayo, H., Shuey, D., Babishangire, B., Johnson, K. (1993) An operational study relating to sexuality and AIDS prevention among primary school students in Kabale District, Amref, Entebbe.
- <sup>v</sup> UNAIDS, (2004) *Facing the Future: Report of the United Nations Secretary General's Task Force on Women, Girls and HIV/AIDS in Southern Africa, South Africa*.
- <sup>vi</sup> UNICEF, (2004) *Africa's Orphaned Generation*, New York.
- <sup>vii</sup> Case, Ann, Christina Paxson and Joseph Ableidinger, (2004) *Orphans in Africa: Parental Death, Poverty and School Enrollment*, Princeton University.
- <sup>viii</sup> UNICEF, 2004, op. cit.
- <sup>ix</sup> Paul, G (2001) *When the boomerang returns: a qualitative study of socio-economic impact of HIV/AIDS on older people in Northern Thailand*.
- <sup>x</sup> UNICEF (2004), op. cit.
- <sup>xi</sup> Namphanya-Serpell, N. (2001) 'Children Orphaned by HIV/AIDS in Zambia: Social and Economic Risk Factors of Premature Parental Death.' Paper presented at conference entitled 'Orphans and Vulnerable Children in Africa: Victims or vestiges of hope,' Uppsala, Sweden, 13-16 September 2001 as cited in UNICEF, *Africa's Orphaned Generation*.
- <sup>xii</sup> UNICEF (2004). op. cit.
- <sup>xiii</sup> Mann Gillian (2001) as referenced in David Tolfree's *Whose Children* (2003).
- <sup>xiv</sup> World Bank (1997) *Confronting AIDS: Public Priorities in a Global Epidemic*, Washington DC.
- <sup>xv</sup> Ugandan Ministry of Labour, Gender and Social Development, (2003) *Uganda Country Report for Stockholm Conference on Residential Care*, University of Stockholm.
- <sup>xvi</sup> World Conference of Religions for Peace and UNICEF, *Study of the Response by Faith-Based Organisations to Orphans and Vulnerable Children*, 2004.
- <sup>xvii</sup> Diona, Giogia, Charles Kalinganire, and Felix Muramutsa, (2001) *The Rwandan Experience of Fostering Separated Children*, Save the Children, Stockholm.
- <sup>xviii</sup> Tolfree, David, (2003) *Whose Children? Save the Children Sweden*.
- <sup>xix</sup> Luzze, F. (2002) *Survival in child headed households: a study on the impact of the World Vision support on coping strategies in child headed households in Kakuuto county, Rakai District, Uganda*, Oxford Centre for Mission studies/World Vision, University of Leeds.
- <sup>xx</sup> South African Law Reform Commission (2002), Discussion paper 103.
- <sup>xxi</sup> A wide range of strategies are reviewed in, for example, Williamson, Jan (2004) *A Family is for a Lifetime, Part I – A discussion of the need for family care for children impacted by HIV/AIDS*, The Synergy Project (submitted to US Agency for International Development, Office of HIV/AIDS).