# The Power of Early Childhood as a Healing Force in the AIDS Crisis

Paper for Presentation to World Forum on Early Care and Education Montreal, 19<sup>th</sup> May 2005

M. J. Kelly, Luwisha House, Lusaka mjkelly@zamnet.zm

This World Forum is about children. It is about children in their most critical formative years, between the ages of zero and eight, a period that is crucial for the development of a child. The first eight years, and even more so the first three, are pivotal for the health, emotional stability, mental development, social competencies, and future productivity of the child (Dunn, 2004; Young, 1996). Investments in early child development programmes are beneficial to all children, but are particularly effective in freeing disadvantaged children from ever-recurring cycles of poverty, gender imbalance, exclusion and failure.

But this Forum is also concerned with another major child-related issue, the stranglehold that HIV/AIDS exerts on the survival and well-being of children and their care-givers. In parts of the world where resources are seriously constrained, programmes relating to early child development are already few enough. In low income countries only 10 percent of children may be enrolled in pre-schools, compared with 70 percent in high income countries (World Bank, n.d). But the situation is even worse in places where HIV and AIDS are rampant. Most of the HIV/AIDS programmes tend to focus on adults and youth while the needs of children are often overlooked. Even where concern is expressed and action taken to address the needs of orphans, the tendency is to focus on orphans who have arrived at schoolgoing age. Only too frequently do we find that the situation of those who are younger is neglected in the naïve belief that families and communities are responding adequately to the needs of these very young children.

But although HIV and AIDS are sweeping across many societies like a relentless, gigantic tsunami, situations that generate hope are arising within the early childhood scene. These are still all too few, but they show that responding to the needs of very young children and listening to them can bring healing within the AIDS crisis and generate resources that will strengthen individuals, families and communities in their struggle with the pandemic.

# The Severity of the AIDS Crisis

Almost a quarter of a century after the world first became aware of the existence of the intransigent condition that came to be known as AIDS, the epidemic still appears to be out of control:

- It continues to rampage through existing and new populations, with an estimated 5,000,000 new infections occurring each year; that is, on the average, somewhere in the world, one new HIV infection occurs every six seconds.
- An estimated 3,000,000 individuals die each year from AIDS-related illnesses.

- Within countries, the percentage of infected adults (in the 15–50 age range) is rising to levels that hitherto were considered impossible. Swaziland has a prevalence level of more than 37%, while HIV testing of women at ante-natal clinics in Botswana has shown that about half the women aged 25–29 are infected (National AIDS Coordinating Agency, 2003).
- Anti-retroviral therapy has brought dramatic improvement in the survival rate and quality of life of infected individuals, but extending the treatment to all who are in need poses innumerable challenges.
- Behaviour change programmes directed towards preventing further HIV transmission have met with very limited success.

HIV/AIDS hits hardest at young people in the prime of their productive and reproductive lives. In doing so, it sweeps young parents away and leaves in their wake a legacy of orphaned children. Globally, by the end of 2003, AIDS had resulted in some 15 million still living children below the age of eighteen being deprived of mother or father or both parents. Four out of every five of these orphans are in Africa. In addition, the orphans are young: it is estimated that 15 percent of those in Africa are aged 0–4 and 35 percent are aged 5–9 (Dunn, 2004).

For many years, reports from various countries spoke of the challenges orphaned children face in meeting their basic human needs for food, shelter, security, health care and social well-being. More recently the reports have begun to speak about the emotional and psychological problems that orphans experience when a parent manifests the symptoms of AIDS and later when the parent dies (Box 1). These children know a profound and enduring sense of immense personal loss, pain, sadness and deep-rooted hurt (Family Health International, 2002). The World Declaration on the Survival, Protection and Development of Children (UNICEF, 1990) states that for children "their time should be one of joy and peace, of playing, learning and growing" (article 2). For millions of orphans, their time of childhood is quite the opposite.

# Box 1: Children stunned by the loss of a parent

Seven-year old Viola from Juba, Sudan

I am not happy. I don't have a mother and have little food. Every day I talk to my mother but I don't hear her voice. I want to have a mother like my friends do.

Duangkaew, aged 72, Thailand, feels helpless when confronted by his granddaughter's uncomprehending grief at the death of her father from AIDS

My granddaughter, who was then only five years old, dragged a chair over in front of the coffin and just sat there, alone. It was such a pitiful and heartfelt sight to see. My wife and I could not bear it. We went up to hug her and console the little girl, feeling her sorrow that she should lose both her parents in such a short time.

Source: HelpAge International, 2003, page 19

#### **Telling Their Stories**

Countries where prevalence rates exceed five percent face new and massive challenges in responding to the needs of the millions of orphans to which the AIDS pandemic gives rise. While some countries have encountered an orphans challenge arising from a conflict situation, no country is well prepared to deal with the orphans issue on the scale that AIDS is occasioning. Already, in many parts of Africa one in every five children is an orphan, and that percentage could rise in the years ahead.

This situation poses its own unique challenges to early childhood development (ECD). Because ECD tends to be so firmly rooted in family and community care, the most promising responses to the orphans challenge must also be family and community based. The effectiveness of many such responses depends greatly on understanding the problem from the child's perspective. Responding to children's physical needs for food, shelter, clothing, medical services, and access to clean water and sanitation, is always a challenge, but at least the needs are fairly well understood. Responding, however, to their emotional, psychological, and spiritual needs is very much more difficult because the nature of these needs is not so clearly defined.

Given that every day sees a substantial increase in the number of its children who become orphans, Zambia undertook an initiative in 2002 to develop greater understanding of the emotional and psychological needs that children experience when a parent dies. The aim was to develop a tool that would help children and caring adults deal more effectively with the emotional losses arising from a parental death. The approach used was to ask children to share their experience of loss, grief and transition—through music, art, dance and the telling of their stories.

The children who participated in the project found the experience to be therapeutic, supportive and transforming in a very positive manner. During their period of associating with one another and with their adult guides, they revealed what the grieving process meant for them and as they did so they learned to cope with it more effectively. Their set of stories (CARE International Zambia, 2003) is an important contribution from early and middle childhood to a deeper understanding of a major way in which the AIDS pandemic is affecting the lives of children. It is a contribution that brings healing at the very heart of the AIDS crisis in the way it equips care-givers and concerned adults to respond more effectively to the emotional needs of children at a time of great trauma.

Siyanga Mzoka's story (Box 2) brings out the way a young child needs to take part in the general family mourning process, participate in the funeral rites for a deceased parent, and know where his parents are buried. Local customs and practices may not cater adequately for these needs, but not meeting them will make it difficult for the child to come to terms with the loss and may result in socially undesirable behaviours. Telling his story benefited Siyanga in enabling him to cope better with his grief and anger. But it also benefited care-givers, and through them other children, in underscoring the need children experience to participate in rites of passage and grieving and not to be excluded from these on the grounds that they are "only children".

## Box 2: Siyanga Mzoka's Story

Siyanga Mzoka was five years old when his father was drowned in a fishing accident. After his father's death he and his mother went to live with his grandmother, the mother of his mother.

"That's when my mother became sick. She didn't like to eat much. One day she was so ill that she didn't eat any food at all. My grandmother told us not to sleep in the house that night. My mother died alone, in the night.

"After she died, they took her body away before I could see her. I would have liked to see her body before they took her to the mortuary. It makes me very sad that I didn't see her.

"They did not let me go to the funeral. They said to us, 'you are children and you are not supposed to attend a funeral'. I was very angry because even when my father died we did not go to the funeral. I do not even know where they buried my father and my mother. I often think, 'if this can happen to my mother and father, what will happen to me when I die'."

Source: CARE International Zambia, 2003, page 43

The story of Fridah Cubby (Box 3) highlights many of the tragedies that children face in the AIDS situation: the need to take on the responsibility of caring for their sick parents (see also below, pages 10,11); being alone with a parent when the parent dies; the frequently unattainable imperative of school attendance; and the all-embracing sense of great loss. But her story has a further significance. Fridah was a young adolescent when her story was published and she was asked at that time what message she would like to share with adults. Her response was remarkably clear:

- Halt the preventable growth in orphan numbers:
  - ~ by keeping parents, especially mothers, alive;
  - ~ by helping HIV-infected parents live in a positive and responsible way.
- Provide a decent life for every child.
- Ensure that every orphan has a safe, healthy and well-educated childhood.
- Help the old people who care for the young.

## Box 3: Fridah Cubby's Story

Fridah was born in 1991. Her mother died in 1999. Fridah tells how it happened:

"When my mother was sick, I looked after her. One day she was very ill and I found a taxi to take her to the hospital. She died in the taxi on the way to the hospital. Before she died, she said goodbye and kissed me. She said, "You should concentrate on going to

school". That was the last thing my mother said to me. ... I really loved my mother. I still love her. I miss her very much."

Source: CARE International Zambia, 2003, page 21

Reflection on her experience, triggered off by telling her story, helped this young girl distil these salient lessons and express her deep desire that her trauma should never be repeated for any other child. Much of the pain of the AIDS crisis would be alleviated if this child's words of wisdom could be turned into practice. Children frequently understand what a situation calls for, but only too often adults fail to hear and take action on what they are saying.

#### Challenges that HIV/AIDS Poses for Early Childhood Development

By pointing to areas of critical concern in the orphans crisis, Fridah Cubby helps focus our attention on some major issues that have potential to undermine what one would wish to achieve through ECD. HIV/AIDS confronts the world and all who are committed to ECD with the challenges of:

- Preventing the transmission of HIV from parent to child,
- Paying great attention to the well-being of the parent-child pair,
- Responding to the needs of HIV infected children for treatment and care, and
- Responding to the needs of children who are otherwise affected by the AIDS pandemic.

The transmission of HIV from an infected parent to an infant usually goes by the misnomer of mother-to-child transmission (MTCT). But the situation in many parts of the world is that the majority of HIV-positive women have contracted the virus within marriage from their husbands. In areas as diverse as India, Cambodia, and many parts of Africa, marriage is proving to be a high-risk situation, with women who remain faithful to their husbands being infected by their sole sexual partner. In such circumstances, what is happening in cases of peri-natal transmission is transmission of the virus from the father to the mother and through her to the infant. It would be more correct to designate such transmission as parent-to-child (PTCT), but in deference to accepted usage this paper will continue to use the acronym MTCT.

Transmission of HIV to an infant occurs during pregnancy, during labour, or through subsequent breastfeeding. In the absence of interventions, 15–30 percent of infants born to mothers who are HIV-positive will also be infected with HIV. Breastfeeding by infected mothers increases the risk by 5–20 percent, raising the total risk among their infants to 20–45 percent (WHO, 2004). Happily, these risks can be greatly reduced by administering some form of anti-retroviral treatment to the mother during pregnancy and labour and to the infant during the first weeks of life. The adoption of these procedures has resulted in new infections in children being almost a thing of the past in many parts of the world. It is estimated that in 2003 less than 1,000 children became infected with HIV in North America and Western Europe and less than 100 in Australia and New Zealand (WHO, 2004).

Unfortunately the situation is very different in the poorer countries of the world where, in 2003, an estimated 700,000 children were newly infected with HIV, that is, approximately 1,900 every day. About 90 percent of these infections occurred in Sub-Saharan Africa. About half of these newly-infected infants die before their first

birthday, and the majority of the rest before they reach the age of five. In addition to being haunted by this spectre of possible premature death, early childhood care and development in these countries have the added burden of responding to the AIDS condition of the infected children, whether they live for only a short time or for several years.

This situation is outrageously wrong. The majority of infections occurring through MTCT are preventable, needless and unacceptable. Interventions to prevent MTCT reward the hope that the scourge of HIV/AIDS can be overcome, especially for children. These interventions represent a vital healing force in the AIDS crisis. They can be fairly easily applied and are not very costly. Yet they are not being implemented on the scale that is required. At the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS held in June 2001, the world committed itself to reducing the proportion of infants infected by HIV by 20 percent by the end of 2005 and by 50 percent by the end of 2010 (UNGASS, 2001, article 54). But with only about 10 percent of pregnant women in Sub-Saharan Africa having access to clinics oriented to preventing MTCT and less than one percent in the most heavily affected countries (apart from Botswana) (Save the Children, 2004), it is clear that the target for 2005 cannot be attained.

To some extent, the transmission of HIV infection from parents to infants and young children continues because of inadequate resources and weak healthcare systems. But even more critical is the reluctance of many pregnant women to make use of resources and facilities that are available. The very strong stigma that attaches to being HIVinfected effectively blocks the women from coming forward for counselling and testing and taking the necessary medications. Rather than risk public disclosure and possible stigma, women prefer to take no action, even though the outcome may be sickness and death for both themselves and their infants. A consequence is that drugs that could prolong the lives of mothers and save the lives of their infants are being returned unutilised to central medical stores because of inadequate take-up. This unfortunate situation seems likely to continue until there are enough role models in communities, women who have had the courage to acknowledge their HIV status and seek treatment, with the result that they and their children are seen to remain in good health. For this to occur there is need for massive educational programmes for young parents together with interventions that empower women of child-bearing age to prevent HIV infection in the first place. The formal school system can play a significant role in the delivery of such programmes.

## The Well-being of the Parent-Child Pair

In reflecting on her experiences, Fridah Cubby (page 4, above) asked adults to take steps to keep mothers alive. This is a highly salient request in the context of mothers who are HIV-positive or have already progressed to the condition of AIDS. Preventing the transmission of HIV infection to their children but doing nothing more for the mothers themselves could lead to two situations: children becoming orphaned because their mothers die of AIDS, and other pregnant women losing interest in seeking assistance. Almost intuitively, Fridah saw that it was necessary to go beyond the prevention of MTCT and to provide care, support and treatment for mothers. The healthy development of a child is greatly influenced by the health and well-being of its mother. The child's development and well-being are also influenced to a

considerable extent by having a healthy father who is economically productive and can support his family.

Because of the importance of the parent-child pair, there is growing international recognition that what is needed is a holistic programme of care, support and treatment addressing the needs not only of the child but also of the child's mother and father. Determined steps must be taken to keep the child alive and free from HIV infection. But efforts must simultaneously be made to do the same for mothers and fathers, though comprehensive and integrated programmes that address the whole range of their health needs. The objective of these programmes is to engage people in an HIV care programme at an early stage to maintain their health, rather than waiting for the advanced stages of illness. These extended programmes addressing more holistic family well-being were launched by the United Nations in December 2001. Because they go beyond the prevention of MTCT (PMTCT) they are known as PMTCT+. However, ensuring long-term follow-up and monitoring of mothers and their families is proving a major challenge, with the result that, to date, there is only a limited number of pilot PMTCT+ programmes (Save the Children, 2004).

Because AIDS deaths are most likely to occur for women between the ages of 25 and 35 and for men between the ages of 30 and 40, the pandemic is very destructive of families, particularly young families. But this very onslaught on the family has rebounded on the pandemic in the way it has heightened world recognition of the importance of the family and its centrality in providing for the protection, upbringing and development of children. The United Nations has affirmed that "the family is the basic unit of society and as such should be strengthened ... so that children can grow and develop in a safe and stable environment and in an atmosphere of happiness, love and understanding" (UNICEF, 2002, page 20). Family-centred PMTCT+ programmes are in conformity with this global determination to give the family comprehensive protection and support. Doubtless, the HIV/AIDS pandemic is devastating, but by touching children and families it has signed its own death warrant. It will eventually be overcome at the family level and because of what the family means to society. This is one of the greatest hopes that ECD and all it stands for can hold out in the midst of the AIDS crisis.

#### **HIV-Infected Children**

To date, more than 3 million children worldwide have died from an HIV-related illness, while globally about 2.5 million children are living with the disease (WHO, 2004). Because of the immaturity of a child's immune system, HIV progresses to AIDS more rapidly in children than in adults. As a result, a very large proportion of the children living with HIV/AIDS need treatment, but as things stand at present there is very little prospect that they will receive it.

There are several reasons for this. Governments, communities and families do not attach sufficient priority to anti-retroviral treatment for children. Managers of sites that are attempting to roll out ARV treatment for children are concerned that they are missing significant numbers of children in need, particularly children from poorer families, and note that community and family attitudes and structures affect access and continuity of care for children at many levels (Horizons, 2005).

There are also technical problems. The diagnosis, care and treatment of AIDS in infants and young children encounter a range of complexities, from the absence of affordable ways to ascertain whether HIV antibodies found in children under eighteen months of age are their own or their mothers' to the non-availability of correct dosage sizes and combinations of paediatric anti-retroviral medications. Infant medication is given in either syrup or tablet form. The syrup is bitter and the infant may spit it out; in addition it is expensive and generally needs refrigeration, so that on both counts it exceeds the resources available to the majority of care-givers in resource-poor settings. Tablets suitable for infants and small children either have not been developed or are enormously expensive. Because of this, care-givers in poorer communities must take tablets or capsules meant for adults, break them into pieces and judge what might be the right dosage for a particular child's height and weight (Lewis, 2005). Towards the end of 2003, South Africa approved a comprehensive care and treatment plan for HIV and AIDS, but this plan has been criticised because, among other things, it does not recognise the importance of simplifying dosage regimens for children to promote adherence, the need to obtain palatable and easy to ingest medication for children, and the huge social challenge of ensuring at least one responsible person capable of administering the child's medication (Children's Institute, 2004).

There is need to overcome these barriers to anti-retroviral treatment for children. This is an issue to which the pharmaceutical industry does not give enough attention. But pressure must be brought to bear on the industry so that it concerns itself with developing "child-appropriate treatment regimes and administration procedures" (Save the Children, 2004, page 29) that will ensure adherence and enhance the prospects of child survival. In the years following the International AIDS Conference held in Durban, South Africa, in 2000, a massive civil society campaign succeeded in bringing about extensive reductions in the prices of anti-retroviral drugs. There is need for a similar demonstration of public concern in the area of paediatric anti-retroviral formulations so that the special needs of infants and young children living with HIV/AIDS can be addressed.

#### **Listening to Children**

The post-Durban campaign for wider access to cheaper anti-retroviral drugs was in some respects triggered off by the voice of a child. Speaking at the opening ceremony for the Durban AIDS Conference, an 11 year old boy, Nkosi Johnson, who had been living with HIV/AIDS since infancy, appealed for the more ready availability of drugs and for an end to AIDS-related discrimination (Box 4).

#### Box 4: The AIDS Testament of a Child

I was born HIV-positive. ... My (biological) mommy was obviously also infected and could not afford to keep me because she was very scared that the community she lived in would find out that we were both infected and chase us away....

My (foster) mommy Gail and I have always been open about me having AIDS. And then my mommy Gail was waiting to hear if I was admitted to school. Then she phoned the school, who said we will call you and then they had a meeting about me. Of the parents and the teachers at the meeting 50% said yes and 50% said no. And

then on the day of my big brother's wedding, the media found out that there was a problem about me going to school. No one seemed to know what to do with me because I am infected. ... I am very proud to say that there is now a policy for all HIV-infected children to be allowed to go into schools and not be discriminated against....

I hate having AIDS because I get very sick and I get very sad when I think of all the other children and babies that are sick with AIDS. I just wish that the government can start giving AZT to pregnant HIV mothers to help stop the virus being passed on to their babies....

When I grow up, I want to lecture to more and more people about AIDS. ... I want people to understand about AIDS—to be careful and respect AIDS—you can't get AIDS if you touch, hug, kiss, hold hands with someone who is infected.

Care for us and accept us—we are all human beings. We are normal. We have hands. We have feet. We can walk, we can talk, we have needs just like everyone else—don't be afraid of us—we are all the same!"

Source: http://www.simplytaty.com/bios/nkosi.htm

Less than a year after the Durban Conference Nkosi Johnson died from his AIDS illnesses. The following year he was posthumously awarded the World's Children's Prize for the Rights of the Child in recognition of his fight for the rights of children living with HIV/AIDS and for wider access to anti-retroviral treatment.

The courage and determination of this child and his foster mother helped change the face of a world where AIDS treatment was extraordinarily expensive and where remaining alive if infected with HIV was the prerogative of the rich (Box 5). Having survived from infancy to middle childhood with HIV and AIDS, Nkosi Johnson brought a powerful message of hope and healing to the troubled world of the pandemic.

Box 5: The Voice of a 12-year-old Ethiopian Girl

It's simple—if you have money you will be cured.

If you don't have money you will die.

If my mother dies, I will be alive.

If my mother dies, what will become of me?

Source: Save the Children (UK), 2005, page 5

Nkosi Johnson's victory in seeing an end to discrimination in South African schools did not extend immediately to other countries. In 2003, primary schools in Nairobi, Kenya, refused admission to HIV-positive children coming from the Nyumbani Orphanage. The Orphanage took the Kenyan Government to court over the issue and eventually won a judgement that prohibited public schools from refusing admission to

HIV-positive children (Associated Press, 2004). Once again, children with adult support won the battle against discrimination.

Stigma and discrimination are issues that dog the AIDS crisis at every turn. As far back as 1988 Jonathan Mann, director of the Global Programme for AIDS, noted that HIV/AIDS was actually a complex of three epidemics:

- 1. The silent, invisible epidemic of HIV infection;
- 2. The visible, incurable condition of AIDS illness;
- 3. The pervasive situation of adverse social reactions to persons affected by the disease (Walrond, 2000)

The third epidemic of stigma and discrimination contributes powerfully to maintaining the first and second. Early childhood considerations helped bring an end to its worst manifestations in education. One would hope that greater sensitivity to the needs of infants and young children will also contribute to ending the tragedy where infected mothers will not seek treatment because they fear stigma and discrimination.

#### HIV/AIDS and the Needs of Non-infected Children

It is clear that children who are HIV infected and children who have lost a parent to AIDS are deeply affected by the AIDS pandemic. But HIV and AIDS affect a much wider group of children. These include:

- Children whose parents have AIDS
- Children in households where there is AIDS, but the parents are healthy
- Children whose care-giver has died from AIDS
- Children in a household where there are no adults
- Children in a household where there are only elderly care-givers
- Children in households caring for other orphans
- Children in households no longer able to look to wealthier relatives for security in time of need
- Children who are exploited for their labour.

Children in AIDS-affected households: Children living in households where there is HIV or AIDS are affected in several adverse ways by the disease. Its presence in a household generally leads to a significant drop in income. In practice this means that fewer resources will be available for meeting the nutrition and other needs of young children and hence the greater likelihood of malnutrition and its manifestation in stunted development. The child's development also suffers because of the way adult attention focuses on those who are ill, limiting the time that can be devoted to child care. A study found this to be so in Botswana where parents who provided care for household members with AIDS spent much less time with their own children than other parents who were not giving care—48 percent of AIDS care-givers spent two hours or less per day with their own children (Heymann, 2003).

AIDS in a household may also lead to children becoming care-givers for their sick parents, other sick adults or their younger siblings. In 7 percent of a sample of AIDS-affected households in South Africa, a child was the primary care-giver for a sick adult (Save the Children, 2004). Caring for a parent who has AIDS may place a very heavy burden on a young child. "Coping with a parent who is weak and requires food to be cooked or water to be brought is one thing. Coping with a parent's severe diarrhoea, declining mental functions and mood changes is quite another" (Barnett

and Whiteside, 2002, page 206). A further impact on older children is that they may have to leave school to care for an ailing parent, while all children run the risk of contracting tuberculosis or other opportunistic infections through close interaction with parents who are ill (KANCO, no date).

Children and home-based care: It is not always the case that the burden of AIDS care falls entirely on the children or others belonging to the household. Because hospitals and other public health facilities have not been able to cope with the increasing demands that the epidemic has meant for them, a large number of those who are ill because of AIDS are now cared for in their own homes by volunteers and social workers through various home-based care (HBC) initiatives. Some of these focus mainly on providing spiritual, social and support services, together with some basic nursing care, while others provide more comprehensive medical services (SAT, 2004). Meanwhile, independently of the HBC initiatives, other programmes have been developed to respond to the needs of children affected by HIV and AIDS.

However, it is now being increasingly recognised that support, both for those with AIDS and for the children in an affected household, would be better promoted by a more integrated, holistic and comprehensive programme addressed to the needs of those with AIDS and all those in their households. Such an integrated approach would reflect more faithfully the way communities and families actually operate, without division of responsibilities. This integrated approach recognises that children are affected by HIV/AIDS long before their parent dies. Children also benefit because the close and trusting relationship they can establish with HBC carers may persist, to the advantage of the child, after the death of the parent (SAT, 2004). In essence this is a community response to HIV/AIDS and "since families and communities are the first lines of response, enabling them to do more to protect and care for children is much more significant to children than support from other service providers" (World Bank, 2003, page 20). Integrating support for children into HBC initiatives gives hope that greater attention will be paid to the needs of very young children, including those in households where there is much sickness but few resources.

Households with no adults: HIV/AIDS has also led to the emergence of a relatively new structure known as the child-headed or sibling household. This is a household where all adult members have died and the children must fend for themselves, frequently under the guidance of the oldest among them. This may be a boy or girl aged 14 or less who, by unspoken consent, assumes economic and quasi-parenting responsibility for the others. Sibling households frequently establish themselves because brothers and sisters who have lived and worked together in caring for their sick and dying parents want to preserve their sense of identity, worth and dignity by remaining together. Access to basic food, health, education and social needs is on a very precarious footing for children in such households. In many cases, everybody in the household, including even the youngest, must work to generate the resources needed for survival. In such circumstance, there is almost no prospect of ensuring attention to early childhood needs.

Households with elderly care-givers: At the other end of the spectrum are children in households where there are only elderly care-givers. Because of HIV/AIDS much of the middle generation may be completely absent, leaving only the old and the young to care for each other. The proportion of orphaned children living with their

grandparents is rising in countries where HIV prevalence is high—in 1992, one fifth of Zambia's orphans lived with their grandparents, but by 2002 grandparents were caring for one-third of all orphans. In many cases grandparents or other elderly caregivers do not have the capacity or the resources to respond to the needs of children. Driven by an overwhelming sense of worry and concern for the young, and almost under protest, they have undertaken child care responsibilities in their old age. But they are among the first to recognise that they are not really equal to the task (Box 6). Their strength is that they are likely to care for the children with an abundance of nourishing love, but many are hard pressed to go beyond this.

# Box 6: The Voices of Elderly Care-givers

Looking after orphans is like starting life all over again, because I have to work on the farm, clean the house, feed the children, and buy school uniforms. I thought I would no longer do these things again. I am not sure if I have the energy to cope (65-year-old man, Zimbabwe, the main care-giver of three school-aged children)

In the good old days, when there were deaths of parents, it was easy to incorporate one or two orphans. But when you have nine, what can an old man like me do? (76-year old man, Zambia)

I am so afraid of what the future has in store for these orphans. If I were to die and leave them, there would be no one to look after them (62 year old woman, Zimbabwe)

Sources: WHO, 2002, pages viii and 9

HelpAge International, 2003, page 6

Households that have accepted orphans: Finally, it must be noted that when families take in the orphaned children of deceased relatives, there is very seldom any increase in household resources to cater for the additional members. This may also be the case where members of the community informally adopt orphaned children because there is nobody else to care for them. Since many of these families are already poor it means that their inadequate resources must be stretched even further. This places all of the children at risk, with reduced likelihood that any of them will have access to as much food, clothing, medical services, social care, and parental attention as they need. The orphans may suffer more deprivation than the children belonging to the family, but even these latter will not have all their needs adequately attended to. In such situations, very young children may not receive as much adult care, attention, stimulation and interaction as they need for their development, but may have to make do with what they can get from older siblings. This will not always be sufficient. Moreover in the majority of cases it will be provided by girls who will thereby suffer the double disadvantage of being deprived of rightful opportunities for play and exploration and of being moulded into the female stereotype of "the one who cares for the infants and young ones".

#### A World Fit for Children

Clearly, the ECD needs of infected and affected children are being severely compromised by the HIV/AIDS pandemic. Their basic human needs are under threat.

Their emotional needs are jeopardised. Their physical and psychological development is at risk. Since the period between zero and eight years makes such salient impacts on the future health, cognitive development, cultural competencies and productivity of an individual (Dunn, 2004), the AIDS crisis is jeopardising the future as well as the present generation.

One can only speculate about how this "AIDS generation" (Kiragu, 2001) will develop and the kind of adults its members will become. In particular one can ask how children growing up through the deprivations that HIV/AIDS magnifies will function when they themselves become parents. Many have never experienced the prolonged attention, stimulation, love and nurturing needed for integral human development. Many have never known the love of a parent within settled family surroundings. How then will they behave when their time of parenting comes? In some circles there is concern that the growing number of orphans may present a threat to national and international security. While there is little certainty that this will be so in terms of physical security, one cannot discount the possibility that the growing generation of AIDS infected and affected children may portend a threat to society's understanding and protection of its basic unit, the family.

Unfortunately, society's response to this situation is inadequate. Despite the seriousness of the circumstances, the condition of orphans and vulnerable children receives little attention in national policies and plans. In Zambia, an official report from one wing of government has accused the entire government bureaucracy of not giving sufficient priority to orphans and vulnerable children and has found that assistance to children was being hampered by inadequate funding and a lack of coordination among policies (Zambia, 2004). Zambia is not alone in this failure to give little priority and attention to the needs of the most vulnerable members of its population.

Even worse, however, is the situation for early childhood development. To the extent that programmes and policies are in place for orphans, they tend to concentrate on orphans of school-going age and older. The needs of those in the 0–8 age range are very often ignored. Even the ravages of the HIV/AIDS pandemic have not yet been sufficiently successful in placing these needs squarely on the agenda. This comes out clearly in an analysis of what are known as Poverty Reduction Strategy Papers (PRSPs), the basic documents that are to guide poverty reduction policies and programmes in the poorest countries. A World Bank review of these key documents brings out two remarkable features: the tendency for PRSPs to be sketchy in dealing with HIV/AIDS, and their minimal attention to the problems of orphans and vulnerable children (Bonnel, Temin and Tempest, 2004). The authors note (page 18) that "as policy documents, PRSPs do not demonstrate a clear commitment to children, young people and HIV/AIDS". Given this scenario, it is hardly surprising that the review does not mention early childhood even once. Nevertheless, the lack of policy attention to this crucial area is very unsatisfactory.

There are signs, however, that even this situation is changing. A multi-country workshop on ECD and HIV/AIDS, held in Dar Es Salaam, Tanzania, in April 2004, declared participants' commitment to accelerate action in support of the special needs of young children in HIV/AIDS programmes. The delegates, representing governments and NGOs from Ghana, Malawi, Rwanda, Tanzania, and Zambia,

further called for an intensification of investments and programmes for early childhood and for concrete action designed to turn policy into action (World Bank and UNICEF, 2004). Within the various countries what is most urgently needed is improved awareness of the importance of ECD and recognition of its salience for positive human and economic returns. There is also need for better information and knowledge of the consequences of HIV/AIDS for young children, and for greater capacity in extending psychosocial support to families.

A further promising development has been the preparation by the World Bank, in conjunction with UNICEF and UNAIDS, of a set of operational guidelines for supporting ECD in multi-sectoral HIV/AIDS programmes in Africa (World Bank, 2003). This is in accord with the commitment made by world leaders in May 2002 when, at a special meeting of the United Nations, they set for themselves the visionary task of creating a world fit for children (UNICEF, 2002). For ECD, this entails developing and implementing policies and programmes for the enhancement of children's physical, social, emotional, spiritual and cognitive development. This necessitates the provision of appropriate support and services to parents, the expansion and improvement of early childhood care and education, and attending to the status, morale, training and professionalism of early childhood educators. Countries ravished by HIV/AIDS are making slow progress in these directions. For millions of children this progress is too slow.

# The Opportunity in Crisis that HIV/AIDS Presents for ECD

Perversely, although HIV/AIDS has worsened the situation for very young children it has also underscored the urgency of making greater short-term and long-term commitments to catering for needs in these early years. The earliest years are crucial for development. Historically they have not received adequate attention or funding, particularly in resource poor settings. But the AIDS crisis has brought the early years into greater prominence. The focus that HIV/AIDS throws on child development in infancy and early childhood has shown that continuing the current neglect will place the future of individuals, families, communities and countries in jeopardy. Other research has shown that investing in ECD programmes brings numerous social and economic returns. Such benefits are desperately needed in the world's poorest countries—the countries where millions of children are poor, malnourished and at risk, the countries where the child population is expanding at a rapid rate, and very often the countries where HIV/AIDS is most prevalent.

Undoubtedly, HIV/AIDS and its impacts are calamitous. But they do not necessarily lead into a developmental cul-de-sac. The crisis presents a special opportunity for growth, reform and development. It underlines the crucial importance of ECD and other all-too-frequently-neglected areas. It presents the challenge of strengthening policy and practical approaches to ECD. It underscores the need to have the vision and will to do so, even while responses are being made to the pandemic and its impacts.

And one final tantalisingly desirable benefit: focusing on early childhood in response to the many negative impacts of HIV and AIDS offers some hope that the AIDS pandemic itself might be more quickly overcome. It has long been acknowledged that the way to halt HIV/AIDS is to focus on young people. This is an admirable strategy, but it has not yet yielded the expected returns. Part of the reason may lie in the fact

that the focus on young people has not extended to those aged 0–8. Building the physical, psychological, emotional, spiritual, social and health competencies of very young children, in the context of the multitudinous attacks that HIV/AIDS makes on their well-being, might well be the key that the world needs to unlock the door to greater success in the global struggle against HIV/AIDS. If this were to happen, then early childhood would indeed prove itself a powerful healing force in the AIDS crisis.

#### References

- Associated Press, 2004. Kenya High Court Orders AIDS Orphanage and Government to Try to Work Out Problems with HIV Kids in State Schools. Report, 7th January 2004
- Barnett, T. and A. Whiteside, 2002. *AIDS in the Twenty-First Century. Disease and Globalization*. Basingstoke: Palgrave MacMillan.
- Bonnel, R., M. Temin and F. Tempest, 2004. Poverty Reduction Strategy Papers: Do they matter for Children and Young People made vulnerable by HIV/AIDS? Results of a Joint UNICEF and World Bank Review. Africa Region Working Series Paper No. 78. Washington, DC: The World Bank.
- CARE International Zambia, 2003. *Telling our Stories*. A tool to help children deal with loss, grief and transition. Lusaka: CARE International Zambia (with Family Health International and USAID).
- Children's Institute, 2004. *Anti-retroviral rollout in South Africa. Where do children feature?* Discussion paper. University of Cape Town: Children's Institute (and Save the Children, Sweden)
- Dunn, A., 2004. HIV/AIDS: What about very young children? *Exchange—Findings* No. 2, July 2004 (Exchange www.healthcomms.org).
- Family Health International, 2002. *Voices from the Communities. The impact of HIV/AIDS on the lives of orphaned children and their guardians.* Lusaka: Family Health International.
- HelpAge International, 2003. Forgotten Families. Older people as carers of orphans and vulnerable children. London: HelpAge International (Web: www.helpage.org) and International HIV/AIDS Alliance.
- Heymann, J., 2003. The Impact of AIDS on Early Childhood Care and Education. UNESCO Policy Briefs on Early Childhood, No. 14, June 2003. Paris: UNESCO.
- Horizons, 2005. Paediatric ARV Roll-out in South Africa. Report of a Consultative Workshop, 21 January 2005, Johannesburg, South Africa. University of Cape Town: Horizons Program/Population Council.
- KANCO (Kenya AIDS NGOs Consortium), no date. *Child Centred Approaches to HIV/AIDS. Community coping strategies for children and young persons*. Nairobi: The Kenya AIDS NGOs Consortium (www.kanco.org).
- Kiragu, K., 2001. *Youth and HIV/AIDS: Can We Avoid Catastrophe?* Population Reports, Series L, No. 12. Baltimore: The Johns Hopkins University Bloomberg School of Public Health, Population Information Program, Fall 2001.
- Lewis, S., 2005. Address to a UNICEF Conference on Children Orphaned by AIDS. Barcelona, February 7, 2005.

- National AIDS Coordinating Agency , 2003. *Botswana 2003 Second Generation HIV/AIDS Surveillance*. *A Technical Report*. Gaborone: National AIDS Coordinating Agency.
- SAT (Southern African AIDS Trust), 2004. *Children and Home-Based Care*. *Integrating support for children affected by HIV and AIDS into home-based care programmes*. Share Series. Shaping HIV and AIDS Responses. Harare: Southern African AIDS Trust.
- Save the Children, 2004. Beyond the Targets. Ensuring that children benefit from expanded access to HIV/AIDS treatment. London: International Save the Children Alliance.
- Save the Children (UK), 2005. *One in Two. Children are the key to Africa's future*. London: Save the Children UK.
- United Nations General Assembly Special Session (UNGASS), 2001. *Declaration of Commitment on HIV/AIDS*. New York: United Nations.
- UNICEF, 1990. First Call for Children. New York: UNICEF.
- UNICEF, 2002. A World Fit for Children. New York: UNICEF.
- Walrond, E. R., 2000. Regional Policies in Relation to the HIV/AIDS Epidemic in the Commonwealth Caribbean. In G. Howe and A. Cobley (eds.) *The Caribbean AIDS Epidemic*. Kingston: University of West Indies Press.
- WHO, 2002. *Impact of AIDS on Older People in Africa. Zimbabwe Case Study*. Geneva: World Health Organisation.
- WHO, 2004. Anti-retroviral Drugs for Treating Pregnant Women and Preventing HIV Infection in Infants. Guidelines on Care, Treatment and Support for Women Living with HIV/AIDS and their Children in Resource-Constrained Settings. Geneva: World Health Organisation.
- World Bank (with UNICEF and UNAIDS), 2003. Operational Guidelines for Supporting Early Child Development (ECD) in Multi-Sectoral HIV Programs in Africa. Washington, DC: The World Bank.
- World Bank and UNICEF, 2004. Meeting the Special Needs of Young Children: The Way Forward. ECD HIV/AIDS Workshop, Dar es Salaam, Tanzania, April 12–16, 2004. Workshop Report. Washington, DC: The World Bank.
- World Bank, no date. Early Child Development. The First Step to .... Education for All (Flyer). Washington, DC: The World Bank, Education Advisory Service.
- Young, M. E., 1996. *Early Child Development: Investing in the Future*. Washington, DC: The World Bank.
- Zambia, 2004. Situation Analysis of Orphans and Vulnerable Children 2004. <a href="http://www.sarpn.org.za/documents/d0001199/OVC\_Sitan\_Zambia\_2004\_nocover.pd">http://www.sarpn.org.za/documents/d0001199/OVC\_Sitan\_Zambia\_2004\_nocover.pd</a>. Lusaka: Ministry of Sport, Youth and Child Development.