

# *Coordinators'* notebook

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An International Resource for Early Childhood Development



THE CONSULTATIVE GROUP  
ON EARLY CHILDHOOD  
CARE AND DEVELOPMENT



Rwanda/1552-083/Jean-Luc Ray

*HIV/AIDS and  
Early Childhood*

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**Meeting young children's developmental needs is essential to produce the sound and stable citizens a society needs, especially those societies hardest hit by AIDS.**

## Introduction

KATHY BARTLETT AND LOUISE ZIMANYI,  
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**AIDS**-affected children from birth to eight (those infected with HIV; affected by HIV/AIDS through infection or the illness/loss of one or both parents and/or family members; orphaned due to AIDS; or made vulnerable by the AIDS pandemic) face threats to normal human development beyond those of physical survival. The deprivation of consistent, responsive care and interpersonal and environmental stimulation in children's critical early years of life leads to measurable increases in malnutrition, morbidity, and mortality; this neglect also inhibits healthy psychosocial and cognitive development. Over the long-term, deficient psychosocial and cognitive development among AIDS-affected children will have very real significance for the societies in which they live. Meeting young children's developmental needs is essential to produce the sound and stable citizens that every society needs—especially those societies hard hit by AIDS.

Consider the following statistics:

- Two out of three children born to HIV positive mothers will not be infected with HIV, nor will they die of AIDS (UNICEF 2000). New Mother-to-Child-Transmission (MTCT) initiatives will further increase survival rates by lowering transmission of the virus.
- *Children on the Brink* (July 2002) describes the following trends:
  - More than 13.4 million children have lost one or both parents to the epidemic in sub-Saharan Africa, Asia, Latin America, and the Caribbean—a number that will increase to 25 million by 2010.
  - Africa has the greatest *proportion* of children who are orphans. In 2001, 34 million children in sub-Saharan Africa were orphans, one-third of them due to AIDS. Because of AIDS, the number of orphans is increasing dramatically. By 2010, the number of orphans will reach 42 million. Twenty million of these children—or almost six percent of all children in Africa—will be orphaned due to AIDS. In 2001, twelve countries in

sub-Saharan Africa were home to seventy percent of the orphans.

– Asia has the largest *number* of orphans. India has the largest number of AIDS orphans of any country in the world, standing at 1.2 million in 2001, and predicted to rise to two million in five years and 2.7 million in ten years. Due to Asia's large population, the number of orphans in Asia is much larger than in Africa. In 2001, there were sixty-five million orphans, with approximately two million orphaned by AIDS. The populations in many Asian countries are so large, however, that even at a low prevalence, the number of people with HIV/AIDS (leading to even greater numbers of orphans due to AIDS) threatens to surpass the numbers in some of the most severely affected African countries.

■ The Center for Disease Control estimates that one in every three children orphaned by HIV/AIDS is under five (CDC 1). What this means in the thirty-four countries currently hardest hit by the epidemic is that by 2010, nearly fifteen million children under five will be orphaned by AIDS and many more will be living with sick parents and exhausted caregivers in impoverished conditions.

It is critical that we continue to not only focus efforts on the needs and the rights of children to survive but also on children's rights to be protected and cared for beyond survival. At the same time the failure to ensure children's rights creates opportunities for HIV infection, HIV/AIDS creates opportunities for the violation of children's rights to survival, protection, and development. This is at a time when increased poverty, abandonment, rejection, discrimination, or the added burden of responsibility for themselves and other family members already puts children at increased risk for abuse and exploitation.

For decades, international AIDS efforts have focused on prevention and treatment. There is, however, a dearth of substantive research, programmes, and policies which respond to the diverse needs of young children affected by AIDS, particularly in developing countries.

The Consultative Group on Early Childhood Care and Development (CGECCD) is increasingly concerned with the lack of attention to children,

particularly under the age of five years, impacted by the HIV/AIDS pandemic and is responding in various ways:

This issue of the *Coordinators' Notebook* outlines and begins to look at five things that need to be better and more widely understood to help ensure that orphans and vulnerable children under five have a proper place on international, national, and local AIDS agendas:

- The scale of the problem
- The likelihood of survival for young children in AIDS-affected households
- The consequences of inadequate care for young children
- The special vulnerabilities of the under-five age group in AIDS-affected areas that need attention to ensure sound survival
- The kinds of action programming most feasible and most likely to affect sound survival and development.

We hope this issue will stimulate further discussion about effective and efficient action to improve the lives of young children affected by AIDS, including finding out more about the work that others are doing in this area as it relates to policy, research, and programming. We would also like to hear from those trying to develop pilot programmes for communities that address the multiple issues involved. You may reach us at [info@ecdgroup.com](mailto:info@ecdgroup.com) or send a note to our mailing address.

In addition, we would hope to complement and coordinate this information with the proposed work of the Consultative Group over the next year to 1) systematically compile and disseminate information and lessons learned around the work on HIV and the young child within and, most importantly, beyond the CGECCD consortium; 2) get Early Years issues on the agendas of International meetings and National level planning meetings related to HIV/AIDS and *visa versa*; and 3) to develop proposals to take the work forward (joint action by the CG consortium and other interested organisations/networks). The overall aim is to build up momentum during this next year through a series of coordinated and linked meetings, discussions, and dissemination/communication efforts by the CG consortium to culminate in a major, high-profile meeting. Please visit [www.ecdgroup.com](http://www.ecdgroup.com) for updates on our progress.



Mexico/MEX487/Jean-Luc Ray

**One in three children orphaned by AIDS is under 5. By 2010 in 34 countries hardest hit by AIDS, nearly 15 million children will be orphaned by AIDS.**

## The Two Who Survive

*The impact of HIV/AIDS on young children, their families and communities.*

DIANE LUSK AND CHLOE O'GARA

**W**ithin the AIDS crisis, there is a virtual absence of attention to and information on the impact of HIV/AIDS to children under the age of five and their various caregivers.

Although there is considerable attention to important issues such as prevention and treatment, maternal/child transmissions, and the impact on the broader education system, there is virtually total neglect of the broader and longer-term issue of the care and nurturing of the youngest children (and especially children under three years) in families and communities

impacted by HIV/AIDS. For example, in the Declaration of Commitment on HIV/AIDS agreed upon at the United Nations General Assembly Special Session on HIV/AIDS (June 2001), there is broad reference to the special assistance that children orphaned, affected, and made vulnerable by HIV/AIDS need, however there is no specific reference to the very youngest children. In addition, the ongoing series of Children on the Brink Reports (USAID, 1997, 2000; UNAIDS, UNICEF, USAID 2002) dramatically highlights the impact of HIV/AIDS on



children and outlines key strategies to help families and communities but does not address the complex and different needs of children of varying ages.

The Center for Disease Control (CDC 1999) estimates that one in every three children orphaned by HIV/AIDS is under five and that by 2010, in thirty-four countries currently hardest hit by the epidemic, nearly fifteen million children under five will be orphaned by AIDS and many more will be living with sick parents and exhausted caregivers in impoverished conditions.

A further key point is that what happens to these young children will certainly be a factor related to eventual demand for schooling. If they are not cared for or nurtured or even helped to survive—they will not be ready and able to learn and make use of any formal or non-formal education opportunities.

In undertaking this overview we conducted a literature review asking for case studies, but little direct programming for children under five was found. It is not that young children are specifically excluded in most programmes—except in school-based and school-fee raising activities—but rather they are not programmed *for*. The needs of children under five are distinct, especially those needs which arise from HIV/AIDS. The work of the Consultative Group has already shown that damage done in the early years cannot be undone, and that children under five need targeted programming. Children whose lives have been devastated by AIDS are no exception.

For decades international AIDS efforts have focused mainly on prevention and treatment. Programming for the mitigation of the impact of this disease is just beginning, and has so far been focused primarily on adults and school-aged children. Two types of programmes that do bring volunteers in touch with the under-fives are home-based care (HBC) and home-visiting programmes. In HBC programmes, community health workers or other volunteers train caregivers of AIDS patients in self-protection, hygiene, patient bathing and feeding, medication, and some counselling. Home-visiting volunteers visit households to offer spiritual support, counselling, and often small material donations of cash, food, or soap to caregivers from their own pockets. Both types of programmes are well-suited to providing support for children under five, yet in a recent thirty-page manual developed for home-based care training in Kenya, no mention was made of children at all, nor is there any evidence that home-visiting programmes include any special attention to children.

Where communities do focus on children, the most common efforts involve fundraising for school fees. For example, the Children in Need Network (CHIN) lists seventy-three organisations assisting children in especially difficult circumstances in Zambia; while most target orphans, only four have a component which addresses the needs of under-fives.



**Orphans and children made vulnerable by AIDS need to have a proper place on international, national, and local AIDS agendas.**

Communities often see school as both children's and families' best hopes for the future, and give education the highest priority. Communities may also feel immediately pressured by the sight of out-of-school children; the threat of street gangs seems very real. Finally, in many places where resources are scarce and people are not sure that children from AIDS-affected households will survive at all, young children may not appear to present the best return on invested energy and funds.

At least five things need to be more widely understood to help ensure that orphans and vulnerable children under five have a proper place on international, national, and local AIDS agendas:

- The scale of the problem
- The likelihood of survival for young children in AIDS-affected households
- The consequences of inadequate care for young children
- The special vulnerabilities of the under-five age group in AIDS-affected areas that need attention to ensure sound survival
- The kinds of action programming most feasible and most likely to affect sound survival and development

Many of the following arguments will not be new to readers of the *Coordinators' Notebook*—what is new in this issue of the CN is a presentation of the logic and facts specifically related to the AIDS epidemic. We hope they will be useful in both your advocacy and programming efforts.

## Scale

The scale of AIDS impact on young children is so enormous that it is difficult to address in thought, let alone action. As World Bank President James

Wolfensohn expressed to the U.N. Security Council in January of 2000, "HIV/AIDS is having more impact than all the wars of the twentieth century combined." Not only are an estimated forty million living with HIV today, including almost three million children under the age of fifteen (UNAIDS, UNICEF, USAID, 2002), but according to the recently released report, *Children on the Brink* (UNAIDS, UNICEF, USAID, 2002), by the end of 2001, 13.4 million children currently under fifteen years of age lost a mother, father or both parents to AIDS. This number will increase to twenty-five million by 2010. In 2000 alone, AIDS newly orphaned approximately 1.8 million of the world's children—about 5,000 children orphaned each day (CDC 1999, 2).

The number of young children *affected* by AIDS is, and will be, greater still. Many are very directly affected; others less directly. Children who have not yet been orphaned live with parents who are ill, and bear not only the grief, worry, and reduced circumstances that sick parents inevitably bring, but these children often become primary caregivers for both parents and younger siblings during their parent's illness. The children of adult caregivers of AIDS patients—most caregivers are poor women (Participatory Assessment Group 1999)—lose the time, attention, energy, and income their mother used to provide. Children whose mothers work long hours or travel to cities to replace the income of a sick family member lose her comfort, security, and care. Children in households that take in the orphans of relatives find that food, attention, and care are spread very thin.

Yet more children are affected through the weakening and collapse of child services: AIDS is seriously eroding health and educational systems. In the first ten months of 1998, for example, 1,300 teacher deaths—twice the total for all of 1997—were recorded in Zambia. Children also lose out on education when teachers and health workers become ill or die, or when they are absent for long periods caring for sick relatives and attending distant funerals.

The Center for Disease Control estimates that one in every three children orphaned by HIV/AIDS is under five (CDC 1999). In the thirty-four countries currently hardest hit by the epidemic, this means that by 2010, nearly fifteen million children under five will be orphaned by AIDS and many more will be living with sick parents and exhausted caregivers in impoverished conditions.

The time frame of the AIDS disaster for children is as unique as its scale. Large-scale orphaning from war, famine, and other diseases have been relatively short-term, one-time problems. National and international agencies have some experience to bring to these crises. People living with AIDS, however, may continue to live and bear children for about ten years after infection (the time it takes the average person who contracts the virus to succumb to full-blown AIDS,

## MAGNITUDE OF ORPHANING

- 13.4 million children currently under the age of 15 years of age lost a mother or father or both to AIDS, most in sub-Saharan Africa (UNAIDS, UNICEF, USAID, 2002).
- By 2010, an estimated 106 million children in 88 countries (sub-Saharan Africa, Asia, Latin America and the Caribbean) are projected to lose one or both parents with 25 million of this group orphaned due to HIV/AIDS (UNAIDS, UNICEF, USAID, 2002).
- With few exceptions, the number of children being orphaned in the countries currently hardest hit by AIDS will through at least 2010 (USAID 2000).
- HIV-positive infants and children (approximately 30% of children born to HIV+ mothers) are excluded in estimates of orphans; estimates are also adjusted for under-five mortality rates for each country. The number of orphans under 5 years of age at any given time, then, may be underestimated.
- Each year approximately 1.6 million children become orphans; 1 in 3 of these children is likely to be under 5 years old (UNICEF/UNAIDS 1999).
- United Nations' statistics show that 35 countries have experienced a doubling, tripling, or quadrupling (as in Botswana) of the number of orphans between 1994 and 1997 (UNAIDS 2000).
- Last year, 3.8 million people in Africa contracted the virus (World Bank 2001). The U.S. Census Bureau projects a total population loss of 118.9 million people in 24 heavily infected sub-Saharan African countries by 2015. In at least 7 sub-Saharan African nations, infection levels in the general population are 20% or higher: 1 in 3 adults in Botswana; 1 in 4 adults in Zimbabwe and Swaziland; 1 in 5 adults in South Africa, Lesotho, Namibia, and Zambia. Most of those infected are of reproductive age, likely to live on average 10 years: all their children will become orphans. In Africa, only Uganda and Senegal seem to have curbed their growing epidemics (USAID 2000).
- In at least 8 countries of sub-Saharan Africa, between 1 in 5 and 1 in 3 children under 15 have lost one or more parents.
- In Brazil, 10,400 children have already been orphaned as of 1998, and during that year about 137,000 more children had mothers living with HIV.
- In the Americas, 2.7 million people are currently living with HIV; 1.4 in Latin America, 390,000 in the Caribbean, and nearly 1 million in North America. Every day some 600–700 new HIV infections occur in the region; estimates put the number of deaths from AIDS at 100,000 in the year 2000 alone (PAHO 2000, 1).
- In the Caribbean an estimated 1 out of every 50 people is infected (PAHO 2001).
- As of May 2000 the total number of AIDS cases reported in the Americas showed an increase of more than one-third in a 3-year period (PAHO 2000).

## THE IMPACT OF AIDS ON CHILDREN, FAMILIES, AND COMMUNITIES

### Survival

- AIDS-related mortality will eliminate the gains made in child survival over the past 20 years in the 34 hardest hit countries
- Orphans are more likely to be infected with HIV through birth and breastfeeding
- Orphans are more likely to contract HIV in later life as they are more likely to be sexually abused and forced into exploitative situations, such as prostitution, as a means of survival

### Chronic malnutrition

- Loss of productive adults means that labour to produce or buy food is lost
- Orphan caregivers are predominantly poor women with less access to property and employment to buy or produce food
- Research in Tanzania has shown that the loss of either parent and deaths of other bread-winning adults will worsen the stunting of children

### Psychosocial trauma

- Long periods of uncertainty and anxiety, as well as intermittent crises, as HIV-positive parents pass through phases of illness
- Stress as they witness their parents' deterioration and death
- Trauma of witnessing parents' pain in countries where pain alleviation medicines are unavailable or costly
- Immense grief, anxiety and depression watching parents die
- Guilt over helplessness to save parent or reduce parent suffering; they are often blamed for causing pain

### Separation from siblings

- Rejection by foster siblings, schoolmates, teachers, friends, and health centres due to stigma and fear
- Anxiety about source of livelihood and ability to remain with family after parent's death
- Loss of family home, multiple relocations, uncertainty about home and shelter
- Shame and fear due to stigma

### Education

- Orphans are more likely to drop out of school for a variety of reasons and are removed from school to help with farm or household work
  - Rejected by school administrators, teachers, or peers
  - Unable to attend school due to lack of funds to pay for school fees, uniforms, and supplies
  - Recent data assembled by UNICEF shows that the proportion of double-orphaned children in school is lower than that of non-orphans in every country for which data are available, and is markedly below in some countries
  - Research in Tanzania has shown that maternal orphans and children in households with recent adult deaths have delayed primary enrolment
  - In Zambia, one study reported that for urban areas, 32% orphans vs. 25% non-orphans are not attending school; in rural areas 68% orphans compared with 48% of non-orphans
- ### Shelter
- Loss of rights to home through inheritance rights or relative stealing

- Forced out of homes through fear of contagion or witchcraft
- Sent away to earn income in city, becoming street children

### Love, attention, affection

- Removed from normal family life
- Loss of caring adults who can protect, teach, mentor, and love
- Often treated harshly or abused by step or foster parents, suffering physical, sexual, and emotional abuse
- Many live in child-headed or elderly-headed households with caregivers who are too old or too young and/or impoverished to provide for them emotionally as well as financially
- Neglect
- Denied friends and social life due to fears of AIDS contagion and stigma

### Pressed into work

- To care for younger orphans and foster siblings
- To care for ill and dying parents
- To add income to foster household
- To add farm and domestic labour to foster households
- Pressured into sex to help pay for necessities their families can no longer afford or to support self and siblings in child-headed households

### Health services

- Elderly or child-headed households lack basic knowledge of important health interventions
- Impoverished households lack health service fees, money for medicine and transportation

(USAID 2000), and few countries have curbed their epidemics. The scale and intensity of orphaning is expected to accelerate through at least 2010 and remain high through 2030. Nothing has prepared us for this.

## Likelihood of Survival

For young children who are or become HIV-positive early in life in the thirty-four developing countries

hardest hit by AIDS, survival expectations are very short. AIDS kills children far faster in developing countries than in the West. In Europe, eighty percent of HIV infected children survive at least until their third birthdays, and more than twenty percent reach the age of ten. In Zambia, however nearly half of the HIV infected children in one study were dead by the age of two (Panos 1997). Massawe and Taylor (1999) report that fifty to seventy-five percent of infected children in developing countries die before their fifth

birthday. The U.S. Census Bureau estimates that, in the hardest hit countries, half of HIV-positive infants will die before their first birthday; most of the rest will die before their fifth birthday (USAID 1999).

The impact on projected under-five mortality is devastating, as can be seen by the following:

- **Kenya:** by the year 2010 an expected increase in under-five mortality from forty-five deaths per 1,000 live births to 105 deaths (USAID 1999).
- **Malawi:** by 2010, an increase in under-five mortality from 190 to 232 per 1000 live births (USAID 1999).
- **Zimbabwe:** by 2010 the mortality rate among children under the age of five will be three and a half times higher than it would be without HIV/AIDS (UNICEF 1999).
- **Namibia:** by the year 2005, AIDS will be responsible for forty-eight percent of deaths of children under age five in Namibia (IRIN 1999).
- **South Africa:** by the year 2005, AIDS will be responsible for fifty percent of deaths of children under five (UNICEF 1999).

However, the large majority of infants born to HIV-infected mothers are HIV-negative. *Two of three children born to HIV-positive mothers can survive.* About twenty percent of infants born to HIV-infected mothers are infected before or during delivery. HIV-infected mothers who breastfeed their infants infect an additional fourteen percent, about one in seven (LINKAGES 1998). These estimates, based on average transmission rates in several studies, closely correspond to the reported rates of transmission, for example, in Kenya, thirty-four percent of infants born to HIV positive mothers are infected (NASCOP 1998); in Uganda the rate is twenty-seven percent.

Two-thirds of children born to HIV-positive mothers can physically survive; unfortunately, however, their survival is often threatened in other ways. Survival may be drastically affected by a family's beliefs about the likelihood of the child's prolonged survival. Families coping with the economic and emotional costs of sick and dying parents and children have few resources, and if they believe their efforts will be futile, family members may fail to spend life-preserving resources on the very young.

The belief that HIV-positive mothers inevitably pass the infection to their children is common in Southwestern Uganda: forty-four percent of orphan caregivers interviewed doubted that a child born to an HIV-infected mother could escape infection (Mast et al. 1996). A worst-case set of beliefs influencing young orphan care were recorded by a study in rural Mossi areas of

Burkina Faso where infection of an infant was seen as inevitable and systematic, occurring *in utero* if the mother had AIDS; respondents believed that "no care should be taken of children born to women with AIDS" and that "such children should be abandoned and left to die" (Taverne 1999). These beliefs are also reported in Zimbabwe, where *de facto* triage means that children of sick parents are not admitted to hospitals. The presumption, even among medical personnel, is that these children will not survive and therefore scarce health care resources should not be invested in them.

The ground-breaking twenty-three country study of orphaning, *Children on the Brink*, recommends that information campaigns "be used to help mothers understand that not all of their children are necessarily HIV-positive"—an indication that this belief in "automatic" mother-to-child transmission is very widespread (Hunter and Williamson 1997). When caretakers believe that the orphans they care for must be infected themselves, their commitment to provide adequate food and health care from nearly empty pockets is seriously challenged.

## Consequences of Inadequate Care

Research, agency reports, and news articles about AIDS orphans and vulnerable children generally treat the whole birth-fifteen age span as an integral group, with the incidence of orphans as the main concern. The inclusion of "orphan care" in an article or report title typically refers not to nutrition, health, stimulation, and love, but to the physical housing of orphans—i.e., are they living in child-headed households? with grandmothers? on the street? School attendance is sometimes highlighted for school-aged children; young adolescents are often the focal points



México: PHO/2-083/Armando Waak

**Two-thirds of children born to HIV-positive mothers can physically survive, however their survival is often affected by a family's beliefs about the likelihood of the child's prolonged survival.**





Kenya: Aga Khan Foundation/1373-015/Kathy Bartlett

**Young children need simple interpersonal and environmental stimulation to prevent long-term cognitive and psychosocial consequences.**

for prevention research and programming. Some mother-to-child transmission reports deal with the total context of feeding children under two (National Food and Nutrition Commission Ndola District Health Management Team 1999; LINKAGES 2000) but address only the incidence of breastfeeding and survival rates.

Abandonment represents the far end of the spectrum of inadequate care, and it is usually fatal in AIDS-affected countries. Many HIV-positive women in Kenya abandon their newborns in the hospital where they delivered (even though such infants may not be HIV-positive); in the public hospitals, where resources for these abandoned babies are limited, the majority die within a few months (Petito 1996). Johannesburg, South Africa reported 120 abandoned infants in the first half of 1998, two-thirds of whom were HIV-positive.

Little is known directly about the state of care of young orphans, but a variety of factors suggest the presence of many risks. As orphans, children under five may be the least welcome foster children. They can contribute almost nothing to household work or income and require the most intensive care. Being closer in time to a parent's death than older orphans, young children are more likely to be seen as part of the death, bringing with them contagion or the curse of witchcraft; they may also be seen as inevitably infected through birth and breastfeeding. Many young orphans are in the care of elderly grandparents or older siblings in child-headed households who have little knowledge of the nutritional and medical needs

of young children. Children under five in all circumstances are more vulnerable to potentially fatal malnutrition, diarrhoea, and pneumonia; in the context of AIDS, children are less likely to receive any treatment which requires extra travel time, time, and medical fees. How do caregivers invest the time, energy, emotion, and money in the care of young children they see as both dangerous and likely to die?

Children who do not receive good care are likely to be impaired in multiple ways. Malnutrition during the first few years of life causes irreversible stunting and impaired cognitive functioning well into late childhood (Mendez and Adair 1999). Immunisations and treatment for basic infections in the early years can make a life-and-death—or damage—difference. Young children deprived of consistent caregivers and simple interpersonal and environmental stimulation suffer long-term cognitive and psychosocial consequences. This, in turn, will have long-range, multiple effects on society. Studies show higher levels of physical, cognitive, and emotional well-being, as well as increased lifetime learning and earning, are associated with good early childhood care. Children without quality care in the early years are more likely in the future to fail out of school, turn to a life of crime, and perpetuate the cycle of poverty as adults (Deutsch 1999).

Community members in AIDS-affected societies understand to some extent that orphans require care and planning: "if we don't care for them, they will be thieves" (personal communication, Sudan); "we don't want a generation of street children here" (personal

## TOOLS FOR ASSESSING THE CARE OF CHILDREN UNDER FIVE IN AIDS-AFFECTED AREAS

■ Assessing the care of young children is not only a natural prelude to mitigation work, but it has great potential for linking mitigation and prevention efforts. Planning for the future care of young children brings acknowledgement of AIDS to the fore; knowledge about HIV transmission is an important part of allaying fears and encouraging foster care for young children.

■ In preparation for fieldwork in Western Kenya, the staff at Ready to Learn Center in the Academy for Educational Development searched for tools to assess the status and caring situation of young children that could be used in AIDS-affected areas. Very little was found. (See "Assessment and improvement of care for AIDS-affected children under age 5" on our website at: [www.aed.org/readytolearn/RTLActivities\\_publications1.html](http://www.aed.org/readytolearn/RTLActivities_publications1.html) for a review of tools examined.)

■ Assessment tools for orphan care in general range from the very simple, designed primarily to identify appropriate beneficiaries or to acquire basic enumeration data, to multi-stage studies involving stakeholders from household to national levels. Basic demographic information is common to all; the range of topics addressed beyond this depends partly on the degree to which the process was participatory and partly on the focus of the group conducting the survey.

■ Procedures for collecting data have included household visits, Participatory Learning Activity (PLA) mapping exercises, questionnaires, semi-structured interviews, focus

group discussions, workshops, and participant observation. Most studies reviewed used a combination of tools, and there was little uniformity on what information was collected beyond the number of orphans, the identity of caretakers, and orphan school attendance.

■ Some major surveys have elicited data about characteristics of households that do affect under-five children such as the number of meals typical for a day, the occurrence of visits by health workers, and household income. The most specific child-oriented questions involve children over five: attendance at school, participation in recreational activities, knowledge of agricultural skills, and knowledge of HIV/AIDS transmission and prevention.

■ Questions addressed specifically to the whole care situation of children under five years of age were largely missing from the tools. Some relatively lengthy and sophisticated tools for assessing breast-feeding practices, dietary practices for children under five, and community health systems were found, but nothing more comprehensive or easier to use. Since that time, the ECD team at the World Bank has launched a Child Needs Assessment Toolkit. Designed by the Task Force for Child Survival's Center for Child Well-Being and U.S. Center for Disease Control and Prevention, the toolkit is designed as a survey (see page 62 for more details).

It is an epidemiological instrument to assist organisations (at the district or city level) in assessing (through the use of a survey of households) the scope and needs of young children and families living in communities affected by AIDS. It has been pilot tested in Zimbabwe, however, full field testing using cluster sampling has not been done.

■ Most children under five in AIDS-affected areas are most likely to be reached by local community volunteers: community health workers or home-visitors from church and community groups. They will need tools that touch on the key aspects of good care for young children—nutrition, health, stimulation, and affection—that are simple to understand and use as a basis for future visits or community planning. Ready to Learn has designed prototype tools with these goals in mind and is currently field-testing them in Western Kenya.



Peru: PAHO/3-33/Carlos Gaggero

**Children under 5 in AIDS-affected areas are most likely to be reached by local community volunteers, community health workers, or home visitors from church or community groups.**

communication, Kenya). Communities need more information about the kinds of care most crucial to keeping children, and communities, safe.

## Special Vulnerabilities of Children under Five

### Nutrition

The prevalent feeding patterns in much of Africa and Asia are particularly dangerous for the welfare of HIV-affected children. These patterns are characterised by

premature (before six months of age) introduction of foods that have little nutritional value, that often are vehicles for infections, and that reduce the nutritional and disease-preventive properties of breastfeeding. Beliefs and practices about foods and feeding of young children makes good nutrition for healthy children relatively rare, and even more rare for children who are ill or thought to be ill.

Several studies have reported that orphans under five are more likely to be stunted or malnourished than non-orphans (Tembo and Kakungu 1999; Semali et al. 1995; Poulter 1997; Nduati et al. 1993). Foster

(1993) found no difference. Cultural beliefs concerning the importance of good treatment for orphans will impact results, along with careful controls for HIV infection and mortality in the age group. Rates of malnutrition, which mostly affects under-fives, are expected to increase sharply in AIDS-affected communities as medical costs, loss of labour, and the selling or dispersal of assets due to medical and funeral costs reduce households' ability to buy and produce food.

A researcher of breastfeeding practices in a heavily AIDS-affected region of Zambia reports the special difficulties faced by the under-five age group: "Nutritionally, the under-fives are very, very vulnerable... families can't afford to feed them... Everyone is assuming that the younger kids are being taken care of... This is Africa and Africans take care of kids," but, "Little kids fall through the cracks" (Piwoz 2000). Households fostering orphans do have reduced ability to provide food. Kraak and other (1999) found that when families care for orphans they lost time working at income-producing and food-producing activities. Food consumption has been found to drop by as much as forty percent in families and communities affected by AIDS (UNICEF and UNAIDS 1999). Traditions that require the sacrificing of livestock and other assets for male funerals further deplete the financial resources available for orphan care. Among the Luo in Kenya "one cannot attend to farm work or other income generating activities after a death within the close relative circle until all the rituals are completed." When this requires waiting for travelling relatives to arrive, the lack of labour "only worsens the already threatened food security of the bereaved" (Ayieko 1998).

The nutritional needs of every age group under five are threatened in unique ways by the epidemic:

**Children ages 0-6 months of age: breastfeeding** Breastfeeding provides optimum energy, protein, and micronutrients for young infants and toddlers; its anti-infective properties help prevent or reduce the severity of common illnesses, including the diarrhoea and pneumonia that are major causes of death in developing countries. Maternal orphans, children of mothers who are too sick to breastfeed, and children of mothers who know they are HIV-positive and choose not to breastfeed, are deprived of the essential nutrition in breast milk, its protection against common diseases, and the physical and psychosocial interaction that accompany breastfeeding.

Because of the high costs of special milk or formula to replace breast milk, it is difficult for families to provide them in sufficient amounts for infant feeding. Likewise, ensuring that replacement milk is fed to children under hygienic conditions is extremely difficult in most developing countries. The fuel, utensils, water and soap needed for hygienic preparation add monetary, time, and energy costs beyond the means of impoverished and over-stretched caregivers.

Caregivers in child-headed households or elder-headed households of AIDS affected children often lack knowledge, as well as funds and time, to provide adequate replacement feeding.

Burkina-Faso caregivers believe that the breast milk of infected mothers automatically infects children. Wet-nursing is not seen as an option because this group also believes, correctly, that healthy women can become infected by wet-nursing infants born to infected mothers (Taverne 1999). Changing wet-nursing practices are reported in rural Kenya (O'Gara 2001) and Zambia (Piwoz 2000).

Similar beliefs were recorded in the Ndola district of Zambia. Researchers reported that "The risks due to breastfeeding are believed to be very high, and most men, women, and traditional birth attendants had the impression that all HIV-positive mothers pass the virus through breast milk." At the same time, babies who are not breastfed are "thought to be at high risk of dying."

The alternatives to breastfeeding are also ruled virtually impossible: "All providers felt that it would be very difficult or impossible for women in their communities to safely offer replacement food to newborn



Suriname: PAHO/2-077/Julio Vizcarro

**Breastfeeding offers essential nutrition, protection against common diseases, and the physical and psychosocial interaction that accompany breastfeeding.**

babies. Most felt that people could not afford infant formula, and the time needed to boil water and clean utensils would be too great" (National Food and Nutrition Commission Ndola District Health Management Team 1999).

In Rwanda a traditional good wish after the birth of a baby is "May you breastfeed well." Not breastfeeding signals incomplete motherhood, and, now, may signal HIV infection. In Zambia, women in a recent study (Piwoz 2000) told researchers that refraining from breastfeeding was almost not an option—to do so would make family and community members suspect HIV infection and could result in spousal violence or ejection from the home.

The unhappy compromise is most often mixed feeding, a combination of breastfeeding with substitute feeding. This, the most prevalent pattern, is the most dangerous and the most likely to facilitate transmission of HIV from mother to child.

**Children ages six to thirty-six months of age: complementary feeding** Because most infants and toddlers are normally breastfed, there is often little understanding of the nutritional needs of a non-breastfed child over six months of age, who needs additional foods beyond milk substitutes as well as frequent feeding suited to child-sized stomachs. Child- and elder-headed households in particular may lack knowledge of appropriate foods, or because of time and financial constraints, shift children in their care too quickly to adult foods and eating patterns.

In some African countries, feeding follows a hierarchy, with adults eating the good food first and the remains passed from the oldest to the youngest child (Evans 1997). Once toddlers walk stably and especially once a younger child joins the family, the "lap child" is often left to fend for itself at mealtime. These traditional patterns have always meant that conditions of scarcity are hardest on young children. Fostered orphans may fare worse yet.

Beliefs about what food is good for young children also affect their nutrition. In Zambia it is thought that the sauce rather than the solids in the family meal is best for young children, and families need encouragement to feed some of the most nourishing solids to young children (Piwoz 2000). In many cultures, food, and even fluids, are withdrawn from children who are ill. Active feeding when anorexia sets in is not practiced in these cultures or not initiated soon enough.

**Children ages three–four: family foods** High rates of anaemia and other nutrient deficiencies such as vitamin A and zinc have been observed among many children under age five; few affordable foods contain sufficient iron and zinc (meat is a particularly good source) to meet their needs. The increased poverty associated with AIDS makes anaemia and nutrient deficiencies more likely because high quality foods become less available. Studies in Cote d'Ivoire

showed that when a family member has AIDS, average income falls by fifty-two to sixty-seven percent, while expenditures on health care quadruple (UNICEF and UNAIDS 1999).

Children aged three to four eat best when supervised during meals, and when they are given snacks during the day in order to meet their energy requirements. Caregivers in AIDS-affected households are more likely to lack time and resources to procure and prepare energy dense, micronutrient rich foods, to offer food at sufficiently frequent intervals for small stomachs, to monitor eating, and to responsively feed young children.

Even in the best of circumstances children under five can be fussy, disorganised, slow, and erratic eaters, easily thrown off track by colds, distractions, and minor discomforts. Giving young children time and attention around eating when time is scarce and food scarcer presents tremendous challenges to caregivers.

**Food discrimination** Orphans in focus groups have reported that what food is available in the household is often not shared with them. One orphan reported: "When my relatives cooked food they used to hide it from us." Another orphan told how he was sent to collect firewood and in his absence the food there was given out to the non-orphan children. One orphan summarised the situation in the following words: "We [orphans] do not mind not having enough food or clothing. After all everybody else is in this situation because of poverty. What we mind is being regarded different by the rest of the family" (Ayieko 1998).

### Health concerns

As Foster (1998) points out, children under five who are maternal orphans are extremely vulnerable to serious illness "since elderly and juvenile caregivers are frequently uninformed about nutrition, oral rehydration, immunisation, and diagnosing serious illness." Kamenga et al. found higher rates of missed clinic visits among infants born to HIV-positive mothers due to "premature maternal death from HIV infection and lack of a suitable guardian" (1990). These same issues may apply to all AIDS-affected children under five, not just maternal orphans, as many mothers transfer care concerns to older children and grandparents while they attend to or work to replace lost income from very sick family members.

Improved survival rates in an orphan hospice in Nairobi suggest that malnutrition and lack of attention to health issues plays a significant role in under-five orphan mortality. The hospice cares for abandoned children born to HIV-positive mothers, ordinarily a high-mortality group in Kenya. The feeding and prompt treatment for opportunistic infections offered at the hospice makes a difference: fifty-six out of sixty children admitted in the first year and half remained alive and well (Mwangi 1994).



### **Common infections**

Diarrhoea and acute respiratory infections are the major causes of death for young children in developing countries. Maternal orphans and children whose mothers are too sick to breastfeed or choose not to because of HIV concerns will be at much greater risk of contracting these illnesses. A recent meta-analysis was conducted to assess the risk of mortality among non-breastfed infants compared to breastfed infants in developing countries. This study illustrated that when all deaths occurring after the first week were included, the pooled odds ratios of risk of dying from diarrhoea and acute respiratory infections were four to six times as high for infants ages birth to three months who were not breastfed compared to those receiving any breast milk. The benefits of breastfeeding remained throughout the first year of life. Severity of diarrhoea has been shown to be less among breastfed children even into the third year of life. Non-breastfed children may be at extra risk of death during each episode because caregivers may believe that these illnesses are the first signs of AIDS and therefore may be even less likely to seek treatment.

### **Immunisable diseases**

In AIDS affected areas, the demands placed on health services may mean that fewer resources are available to provide immunisations. In addition, when young children are stigmatised because they have lost a parent to illness and are themselves considered to be at risk of having AIDS as well, some health services are unwilling to vaccinate them.

The greater susceptibility to common infections by orphans and other vulnerable children may also lead to a lower immunisation rate. Mast et al. (1966) found that fewer than half of the caretakers surveyed believed a child with any symptoms of illness should not be immunised. Since coughs, fevers, and diarrhoea are common among African children, especially in poorer families, it seems all too likely that many orphans are not receiving full immunisations.

Field staff in Kenya report that it is difficult to get information about the immunisation status of many orphans because records have been lost during children's relocations after the death of a parent. Records are also lost due to maternal deaths as it is mothers who deal with children's immunisations.

Health concerns may be likely to get little attention in orphan households in general. Child heads of household may not know what to do or where to go, nor to be able to determine when, action is seriously required. When the location of health clinics require transportation and waiting time as well as fees for services from already over-stretched caregivers, the direct and opportunity costs of health care mitigate against any action. Where caregivers believe that symptoms are early signs of AIDS, they are forced

to ask themselves: why invest in a dying child? Unfortunately such attitudes can lead to care which make the threat of disease more likely to become a reality.

### **Psychosocial concerns**

Psychosocial issues for orphans older than five involve grief over the loss of parents, as well as over separation from siblings, stigmatisation, and isolation. Issues of physical, mental, and sexual abuse are also prevalent in foster households. In a situation analysis conducted in Zambia, the Participatory Assessment Group (1999) reported that orphan focus groups identified the following as significant problems for the children: lack of love, being victims of discrimination, and exclusion. In problem-ranking exercises this lack of love/discrimination was ranked higher in importance than either lack of clothing or shelter. In a study by Bochow (1999) in Tanzania, older orphans expressed the need for someone who could be trusted and relied upon and who was capable of understanding the children after the loss of their parents.

Children under five have even more urgent needs for love and trust from consistent caregivers, and are less able than older children to manage or satisfy those needs in other ways. Very young children are less able to be helped by the kinds of counselling and group supports useful to older children. The primary, addressable psychosocial issues for children under five involve consistency of caregivers in addition to basic stimulation of all kinds.

**Consistency of caregiver** As noted in a recent report on supporting orphan care in Kenya, "Infants and young children... need to establish secure attachments to an adult care provider and develop a sense of trust, self-worth, and autonomy. Accomplishing these developmental tasks helps shape the child into the person he or she will become" (Donahue et al. 1999). Orphans by definition have lost at least one primary attachment to an adult caregiver, and their situation is usually worsened by having to leave their homes after a parental death. In Zimbabwe, seventeen percent of orphans were moved to the homes of relatives after the death of a parent (Foster et al. 1995). Thirty-three percent of children in child-headed households, mostly double orphans, were relocated within the two years prior to the study (Foster 1998). A study of 1,100 orphans in Kenya found that forty-eight percent of orphans moved at least once upon the death of parents (Ayieko 1998).

As orphans are frequently distributed among several households in order to ease the burden of care, during the move, young orphans often lose not only parents, but the older siblings and cousins who have spent the most time caring for them, and who were objects of attachments as well. Foster et al. (1997) reports that children under five are especially likely to



Guatemala: PAH0/4-018/Carlos Gaggero

**Opportunities for play positively affect the physical and mental health of orphans and vulnerable children.**

be fostered out while older siblings are left to live by themselves. Although understandable, these practices result in a maximum disruption of attachments.

Children who are paternal orphans may be forced to move, with or without their mothers, because of witchcraft fears. Young widows among the Luo of western Kenya are encouraged to remarry within the extended family, regardless of the cause of the first husband's death. If their new husbands die, however, the widows are labelled "husband killers," accused of witchcraft, mistreated, and "encouraged" to leave their marital homes. Child-headed households in this same community may also be forced to move because of traditional beliefs: among the Luo, when both parents die the roof of a house may not be repaired unless the wife was inherited by customary laws and this "causes many children to move into different houses for shelter" (Ayieko 1998).

The lack of prior arrangements mean that children can experience a long period of uncertainty about who will care for them and where. Many parents fail to make any preparation for their deaths in terms of wills, child care arrangements, or transfer of agricultural and other production knowledge because of the belief that talking about death hastens it (Ayieko 1998). Drew et al. (1996) found that only two percent of families in northeast Zimbabwe wrote a will prior to death. Fears of witchcraft make planning for death difficult in many areas of Africa because a person who talks to another about their impending death can be charged with witchcraft (Foster et al. 2000).

The grandmothers, widows and widowers, or older siblings of newly orphaned households have such greatly increased responsibilities that a crushing workload prevents much consistency in care. This workload may disrupt caregivers' availability for their own young children. Caregivers in Zimbabwe

frequently complained of the lack of time to attend to young children (O'Gara 2001). Piwoz reports that young orphans in Zambia are frequently cared for by rotating teenagers taking shifts—not a prescription for secure attachments (Piwoz 2000).

**Stimulation** Maternal orphans under two years of age are inevitably deprived of the natural stimulation provided by breastfeeding since wet-nursing, especially of infants born to mothers suspected of having died of AIDS, is no longer thought safe in most regions. Breastfeeding gives infants and toddlers the tactile stimulation of being held, the auditory stimulation of mothers'

voices: they feel their mother's warmth and learn basic patterns of communication. For both older infants and toddlers, breastfeeding promotes normal cognitive and social development through stimulation and through ensuring that the child gets individualised attention and affection. Maternal orphans and children whose mothers are too ill to breastfeed miss out on this support for normal development. What will replace it?

Children old enough to talk in Africa have a variety of caregivers to stimulate and nurture their growth. In households *not* overburdened with grief and unusual workloads, caregivers have time and energy to tell young children stories, challenge them with riddles, make them toys, sing and dance with them, and show them how to do simple tasks that stimulate their mental capacities. In AIDS-affected households, this time and energy may be missing altogether.

Nursery school, an important alternative source of stimulation for young children, is not an option for most young orphans. Even the minimal fees are beyond the reach of fostering families with suddenly many more mouths to feed and many more older children to educate. Stigma and witchcraft fears also play a role. Even when AIDS is not attributed strictly to promiscuity or prostitution, it is still a cause for shame, and for shunning of entire families. A community-based survey conducted in 1989 in the Mpigi District of Uganda revealed that seventy-one percent of the respondents regarded AIDS as shameful, partly because traditional beliefs held that wronged relatives may seek revenge by inflicting illness (Konde-Lule and Rwakaikare 1989).

Ayieko (1998) tells the story of an orphan boy in Kenya who no longer attends school. The boy believes that his educated parents died of AIDS because members of their extended family, envying

them this education, used witchcraft to sicken them. He does not want to be bewitched because of attending classes himself.

#### **Psychosocial impacts on health and survival**

Children's psychosocial environments affect their survival as well as their development. In a study of nutritional resilience in a hostile environment, Zeitlin (1991) found greater weight gain and development among children who had received more physical interaction, affection, and praise from their mothers and relatives, as well as among those who received more verbal and environmental stimulation. More recently, Long and others (1998) found that caring practices at the Kisangani Therapeutic Feeding Centres, which included "conversing with the children" and "play and exercise," increased the speed and quality of recovery among severely malnourished orphans. Disruption of attachments, lack of stimulation, and lack of the humanising patterns of talk, play, and learning all represent serious physical health dangers for young orphans.

**General aspects of care** Some traditional beliefs protect orphans. The Luyha of western Kenya believe that mistreatment of children angers the spirits of dead parents and brings bad luck. The neighbouring Luo, however, believe that orphans, especially boys, are likely to thrive and crowd out other sons; this belief has led many to mistreat orphans or to accept only girls as foster children. Girl orphans not only become household helpers, but are likely to marry and move away and thus "do not pose long term competition for family resources with caregivers' own children" (Ayieko 1998).

The belief that children are the shared responsibility of a whole network of adults is widespread in Africa, and a positive factor for young children. Hunter and Williamson note in *Children on the Brink* that "In Africa, despite their poverty, children benefit from... a stronger safety net than in other regions. These include multigenerational families, single mothers living in sub-households, customs for exchanging children among kin, and the sharing of child support and child rearing. Many of these patterns and customs differ in Asia or Latin America" (Hunter and Williamson 1997). The AIDS epidemic and increasing orphan crisis, however, continues to deplete extended families' resources. The extended family "is not a social sponge with an infinite capacity to soak up orphans" (Foster et al. 2000).

**Coping with grief** The symptoms of grief-related distress in children under five depend significantly on their experience of death and on how they are being cared for in general, as well as on their personality.

Children aged birth–three demonstrate their grief physically through:

- crying
- regressive behaviour in the areas of language, mobility, and self-help
- fearful and clinging behaviour
- difficulties eating, toileting, and sleeping
- development of comfort habits such as thumb-sucking and hair-pulling

Strategies include the need for consistent caregivers who will comfort children physically by holding and rocking them and who will give attention to them through games, stories, music and play opportunities (Ramsden 2001).

Children aged three-five may express their grief physically (outbursts, tantrums, aggression) or through withdrawal (nightmares, apathy, anxiety). It is important to provide opportunities for the expression of their grief through play, music, drawing, role playing and the creation of memory books and boxes (see box) (Ramsden 2001).

Information to caregivers about young children's grief should include:

- Acknowledging a death to children
- Explaining caregivers/adults own grief
- Explaining that parent's death was due to illness, not child
- Talking honestly and briefly about what is and isn't known about the child's own future at least once, and then in response to questions

The "egocentrism" of this age group means they cannot imagine that everything is not about them, so a special burden is *guilt*—they are often very sure that everything (which may extend specifically to individual bouts of adult crying, or to the departure of the parent) is their fault. The *anxiety* is hard to dispel unless you can get a child to talk to you about it but this will be exceedingly hard to do in rural Africa because taboos about talking about death are strong in many places, and children are not likely to confide in



Zambia: UNICEF/HQ95-1046/Pirozzi

**It is a widespread belief in Africa that children are the shared responsibility of a whole network of adults—a positive factor for young children.**

strangers. The guilt is hard to dispel in rural Africa because so many adults believe that illness and death ARE caused by the social actions of others and may not be able to bring themselves to completely excuse the child from guilt (Lusk 2001).

It would be very important for anyone attempting grief work with caregivers around young children to learn what the specific beliefs in each area are in terms of what is appropriate to say when talking about death; what do people ordinarily believe children should be told; how much of illness and death tends to be credited to witchcraft or failed social obligations or bad behaviour; and what funerals look like in that area and how adults are expected to behave at them. (Lusk 2001).

### Programmes for AIDS affected children under five

Many communities, donors, governments, religious groups, and NGOs are attempting to meet the needs of orphans and other vulnerable children through community mobilisation, micro-enterprise development, community-based support, material assistance, payment of school fees, counselling, and residential care. Communities are organising, but they cast a wide net, and children under five can too easily slip through.

While most HIV/AIDS programmes have at least the potential for benefiting children under five, programmes specifically designed to meet the needs of this age group are rare. An Internet and document search for programmes that provide care *primarily* for AIDS-affected children under five yielded few examples. These few certainly do not comprise the entire universe of programmes in operation; during project work in Western Kenya, several small community-based programmes were discovered, and there is no reason to doubt that such programmes are not common in many other communities in many other countries. Some documented programmes are outlined below by country.

#### Kenya

**Nyumbani Orphanage and Hospice** Founded as a response to the growing number of abandoned and neglected HIV-positive children in Nairobi, Nyumbani provides children with a home and nutritional, medical, and psychosocial care. Children live in a simulated village with seventy children living in ten family-style units; house "mothers" and "fathers" live and stay with the children twenty-four hours a day. Elementary and preschool teachers hold school on site. A nursing team provides medications and medical care. Nurses are always on duty; physicians visit on a regular schedule. Children with one or both parents living but ill at the time of admission are cared for temporarily as parents recover. The orphanage is



Photo: PAHO/3-039

### MEMORY BOOKS AND BOXES

Memory books and boxes are effective tools for helping children deal with grief, especially those under the age of 5. Originally developed by the Ugandan National Community of Women Living with HIV/AIDS (Nacwola), the 'Memory Project' enabled HIV+ mothers to discuss HIV/AIDS and death openly with their children, make plans for the children's future, and save family histories and childhood memories by writing them down in a book. These family records are especially vital for children who lose their parents when they are very young, providing insight into the parents they never knew. Memory boxes include items special to the dying adult that are kept for children—photos of parents, special jewellery, a baseball glove.

funded solely by donations. A study of 104 children cared for at Nyumbani (fifty-four current and fifty prior to the study) reported a mean age of 42.3 months at admission, or just over three-and-a-half years of age (Swartzendruber 1999). See their website: <http://www.nyumbani.com>.

#### Lea Toto Community-Based Programme

The kind of care offered by Nyumbani is too expensive to be widely replicated. Lea Toto was established in 1998 by the Nyumbani Orphanage as a more affordable model. Lea Toto supports HIV-positive orphans living with their caregivers in communities in and near Nairobi. Nyumbani provides professional oversight, free medical care, some material support (used clothing and blankets), and facilities for monthly educational workshops for caregivers. Social workers and counsellors visit families in their homes to offer social support and encouragement; some of the most destitute families also receive a small monetary sum monthly. Lea Toto social workers and counsellors help HIV-positive parents make arrangements for their children in the event of their deaths. Twenty-five children from twenty-two households were enrolled during June-August 1998; the mean age of the children at admission was 57.3 months, or almost five years (Swartzendruber 1999).



## Malawi

**Open Arms Infant Home** This home, run by the Davona Church in Blantyre, Malawi, provides twenty-four hour volunteer care for about twenty-five infants diagnosed as HIV-positive. Children are put up for adoption when they are older.

**The Poverelly Sisters Orphanage** This orphanage, run by the Poverelly Sisters in Balaka, Malawi, provides a home for birth to four-year-old HIV infected children from local communities. Relatives of the children are identified and asked to visit them once a month. Relatives are expected to bring ten Kwacha in cash or an equivalent in-kind contribution to the running of the orphanage.

## Zambia

**Kaoma Cheshire Home** Kaoma provides care for infants left when mothers die during or shortly after giving birth. The district social welfare office, health institutions, community members, and traditional leaders refer infants to the home. A letter of verification from the local traditional leader must support referrals from villages. A relative living within the vicinity must be identified to take responsibility for the infant by visiting weekly, by giving in kind or monetary payments for care at the centre, and by looking after the child if he or she is admitted to the hospital. Children are discharged between two and three years of age. No information on numbers of children or cost per child is currently available. To help fund daily operations, the home has six rental properties, a small herd of cattle, and a kitchen garden. Funding is available to purchase land for a commercial farming venture, and a guesthouse is being considered.

**The Muslim Care Orphanage** A private initiative carried out by a business family in Lusaka for the children of their employees who died from AIDS, the orphanage cares for twelve children from the age of six months to seventeen years. A school teacher teaches preschool and nursery school children at the orphanage. Children live at the home and spend weekend day visits with their families.

**Sisters of the Sacred Heart** A day care centre for young orphans and other vulnerable children in Mbala. They are supported by NORAD.

**The Bethany Home and Study Centre** This centre runs a preschool for young orphans and provides health care, shelter, food, and clothing as part of a programme for orphans of all ages and widows; older children and widows are provided basic education and practical skills in farming, tailoring, carpentry, welding, and bricklaying.

**The Livingstone Street Children Association** Runs a child development centre for street children and orphans. Basic education, skills training, counselling, health education, family life and HIV/AIDS

education, alcohol and drug abuse education, sports, drama, and poetry are provided for older children.

**The People Act Foundation** Provides a preschool for orphaned children, along with basic education and literacy programmes; food security activities, such as crop production, food processing, preservation, and storage; and water and sanitation health education to women and older children in rural communities.

**The Senanga Home-Based Care/Smart programme** Provides care through visits to homes and hospitals. It also runs a day care centre for young orphans, a feeding centre, and a community school, as well as providing uniforms and school fees for double orphans.

## Zimbabwe

**Ethandweni, the White Water Said Children's Home** Ethandweni is home to sixteen boys and girls ranging from infants to teenagers who have become orphans because of HIV/AIDS. All are from the Matopo district in the South Province of Zimbabwe.

**Home of Hope Home of Hope, at the Nyadire Mission Centre in Harare, Zimbabwe** Cares for infants who lose their parents until relatives are able to take them. Mother and father figures care for the infants; children are gradually introduced to relatives with the goal of eventually returning to the family. A child who is not adopted by age two or three goes on to an orphanage.

### Concerns about orphanages

Most of these documented programmes for under fives are orphanages. Two facts are of special interest here: 1) the current capacity of the four orphanages with available enrolment numbers is approximately 120 children; and 2) almost all orphanages make a great effort to keep strong ties with relatives. One of the many concerns about orphanages (see below) is that they separate children from the ties to relatives and communities that provide the basis for a productive future in developing societies: through a network of relatives and schoolmates, young adults will later find housing, jobs, and marriage partners. Orphans raised completely in orphanages lack this social network. Temporary care until age two or three is an important innovation, with promise. Caution is necessary, however; some transit home staff report that many children died within a year of returning to relatives; malnutrition and contaminated water supplies were suspected, but the exact cause of death was unknown.

Institutional placement is considered "at best a last resort, to be used only until more appropriate placement can be arranged...because it generally fails to meet children's developmental needs, including opportunities for attachment and normal socialization. The younger the child, the more likely it is that place-

ment in an institution will impair his or her psychological development" (Hunter and Williamson 1998).

Orphanages are not only very risky for children but are the most expensive option for orphan care. In the Tororo District of Uganda, the ratio of costs to support a child in an orphanage was fourteen times higher than support in a community care programme (Germann 1996). Other studies have found ratios of 1:20 or 1:100 (HOCIC 1999). In 1992 the annual cost of residential care in Kagera, Tanzania was 5.7 times the cost of supporting a child in a foster home (World Bank 1997).

Despite the limitation of orphanages, they remain an option for overstressed communities. A study in Zambia (Participatory Assessment Group 1999) focused on perceptions of the present and ideas for the future in an open-ended approach. It is distressing, if understandable that the community's solutions to shelter and education problems for orphans were orphanages. Ready to Learn's participatory learning and action (PLA) exercises in Western Kenya, (November 2000) revealed the same thinking: community members thought the best solution to orphan care was an orphanage.

There remains a great deal we do not know about orphanages. Many questions remain to be answered: How different are the developmental outcomes for orphans in orphanages and foster homes? How can it be determined that orphanage care is a child's most viable option? What arrangements between children, staff, relatives, and communities can make orphanage care more viable?

### Programming options

In the United States there has been a strong effort to avoid targeting funds and programmes specifically to "AIDS orphans" and, instead, to direct efforts towards

all vulnerable children in communities affected by AIDS. This has been done both for the sake of justice and to avoid local backlash. Children often begin to suffer the effects of their parents' illnesses long before a parent dies, and children whose parents have died from other causes—or children whose circumstances are desperate for other reasons—all deserve any available help. The scale and longevity of the crisis means that programmes for young children must be primarily supported by local efforts. However, communities are more likely to be divided than mobilised by pre-determined external targeting criteria. Given that mere mention of AIDS is still taboo in many societies and that children of parents with AIDS-like symptoms find themselves shunned by entire neighbourhoods and schools, it would be inhumane to stigmatise families with any visible association with AIDS; such stigmatisation could also cause those who desperately needed help to forego treatment or support. Clearly, programming should be done for all vulnerable children under five. Some examples follow:

#### *Through existing AIDS sensitisation programmes*

- Organise information campaigns to communicate the risks of mother-to-child-transmission and other needed messages about HIV to help prevent abandonment of children by mothers known to be HIV-positive.
- Organise campaigns to increase awareness of the special needs of children under five among caregivers, health providers, teachers, and community leaders.

#### *Through existing Home-Based Care (HBC) programmes*

- Assist HBC trainers and caregivers to monitor the condition of young children in their patients' households.
- Train HBC trainers and caregivers to identify and respond to children's needs.
- Link HBC caregivers with local community resources for children.
- Support HBC trainers and caregivers with information, proposal writing assistance, and funds.
- Assist HBC trainers and caregivers to encourage parents to write wills, to make arrangements for their children's care once they become too sick to care for their children, and to talk to their children about the future.

#### *Through existing Home-Visiting programmes*

- Assist home visitors to monitor the condition of vulnerable children in the households they visit.
- Train home visitors to identify and counsel caregivers about young children's needs.
- Facilitate home visitor/caregiver/children/local services connections.



Northern Pakistan: Aga Khan Foundation/2001-064/Jean-Luc Ray

**Programme options need to include ways to increase awareness of the special needs of all vulnerable children under 5 among caregivers, health providers, teachers, and community leaders.**



Ivory Coast/0981-084/Jean-Luc Ray

**Caregiver support groups provide practical and spiritual assistance.**

- Support home visitors and caregivers with information and funds.

*Through existing services for children*

- Work to change health services fees for children under five to minimise the burden on vulnerable families and children—and make sure this provision is known to all.
- Arrange transportation to community nurses, local health posts, and clinics for vulnerable children.
- Increase awareness of treatment for diarrhoea and acute respiratory illness and stress importance of immunisations for sick children throughout the community through child-to-child programmes in schools, through public workshops and posters, and through special training for community health volunteers.
- Advocate with administrators to change community requirements and fees for nursery school or day care centres to make them accessible to vulnerable children.
- Advocate with administrators and community members to combat stigma which may influence provision of services to AIDS-affected children.
- Advocate for legal and economic support to child-headed households to enable children to maintain their closest remaining sibling relationships as well as ownership of land.

*Develop alternative child care services*

- Mobilise community labour for cooperative day care in crèches with linkages to nutrition and health services which are located near concentrations of AIDS-affected children under five.

- Coordinate rotating neighbour care or volunteer babysitting to free single parents or child heads of households to work, give elderly caregivers respite, or provide emergency care when necessary.
- Mobilise foster care by neighbours.
- Support of small group homes within children's own communities through a religious body, NGO, or CBO.

*Develop caregiver supports*

- Link caregivers with AIDS clubs or sports clubs in local schools and get older children involved in assisting caregivers and children with household challenges.
- Create caregiver support groups that include counselling and training in parenting skills.
- Support local committees and religious groups to provide practical and spiritual assistance to caregivers of vulnerable children.

*Regional, national, and district advocacy*

- Advocate for debt relief targeted to social services, especially for young children.
- Advocate for low-cost drugs to mothers. Studies show that one dose of nevirapine for the mother at the onset of labour and a second dose for the by immediately after birth can cut the incidence of mother-to-child transmission in half (from CNN report "FUTURE Africa likely a land of the elderly and orphaned", 10 July 2000).
- Advocate to prolong the life of parents through increased access to antiretroviral drugs, treatment of opportunistic infections

## POLICY ISSUES

### Building political will

- Outspoken acknowledgement of the AIDS and orphan crisis at the highest level of government
- Capacity building, management training, and investments in data collection can all help to show that HIV/AIDS is as much of a threat to political stability as any outside enemy
- Involvement of NGOs, INGOs, CBOs, and religious groups in planning and strategy phases
- Use of all popular media to promote prevention, mitigation, and care efforts
- Include all orphans and vulnerable children in policies, not "AIDS orphans"

### Supporting the development of national action plans

- A single, powerful national AIDS plan (UNAIDS has concluded this as among the vital elements of successful response, based on 15 years of action against the AIDS epidemic)
- All stakeholders should be part of national planning
- Activities should be monitored and evaluated
- A comprehensive orphan policy should be developed

### Rededicating, renewing, or creating policies and laws to:

- Reflect comprehensive orphan policy
- Protect adults and children against discrimination based on confirmed or suspected HIV/AIDS infection
- Protect and promote children's rights
- Protect women's rights in education and employment opportunities
- Protect women's rights in property and inheritance
- Encourage men to take financial responsibility for their families

### Advocate for measures to prolong the life of parents including:

- Affordable and accessible drugs during delivery for mother and

post-delivery for child to reduce mother-to-child transmission

- Affordable and accessible life-prolonging medicines made a priority for caregivers of young children
- Prioritisation of treatment for opportunistic infections for caregivers of young children
- Counselling and support group centres for caregivers of young children

### Expand protective services to children

- Information campaigns to inform all citizens of the rights and protective services, welfare services, and judicial recourse available
- Advocate for expansion of current child welfare and protective services
- Child support grant systems should develop alternatives to birth certificates as proof of identity and citizenship since most children do not have birth certificates
- Application processes for child support grants should be speeded; some applicants in South Africa filed when children were young and by the time grants were processed, children were too old to receive them (over 7 years of age)

### Support the development of sustainable, community-owned initiatives in preference to orphanages or children's homes

- Orphanages are too expensive and not able to provide the secure attachments young children need or the social network older orphans will need to make it in later life
- Short-term care for very young orphans may be a needed last resort; such homes should insist on regular contact with relatives where at all possible, and return children as soon as possible to their communities
- Children's homes within natural communities of relatives may be a good option
- Community homes and community care should not excuse the state from providing services to orphans, and should not be a convenient cover for neglect by the state

### Invest in poor communities

- Allocate health resources to basic services in poor areas rather than advanced medicine
- Allocate educational resources to basic education rather than secondary and tertiary education
- Invest in nutrition activities, and low-cost water and sanitation for hardest hit areas

### Debt relief targeted to poverty reduction

- Make AIDS a priority in poverty reduction through debt relief. A 1998 UNICEF-UNDP study of 12 countries in sub-Saharan Africa showed that 7 of them spent more than 30% of national budgets on debt-servicing but only between 4 and 20% of budgets on basic social services
- Of the \$1 billion to 2.3 billion needed annually to mount an effective prevention campaign in Sub-Saharan Africa, only 160 million was available in 1997; needs for mitigation and care are even greater, and increase as the epidemic continues to grow
- Increase flow of resources to most AIDS-affected regions: keep Africa high on the development assistance agenda
- Link debt relief to social assistance programmes



Egypt: UNICEF/96-1057/Toutounji

**Policies and laws should protect and promote children's rights.**



like tuberculosis and pneumonia, counselling for positive living approaches, and food.

- Advocate programming designed to combat stigma so children have equal access to health, social, and educational services.
- Advocate and mobilise communities to encourage local leaders to protect the property and inheritance rights of widows and orphans, to organise cooperative children care, to organise orphan visitation programmes, and to provide financial support.

## Conclusion and Recommendations

Action in almost any sphere can have a significant impact on young children in AIDS-affected communities. Since ninety percent of those infected with HIV/AIDS currently live in Sub-Saharan Africa where so many countries have been wracked by wars, disease, drought, floods, famine, and structural adjustments resulting in social service cutbacks, most AIDS-affected children live in circumstances where *everything* is needed: income-generating activities and the expertise to manage them, clean water, improved knowledge and practices in nutrition and health and caring for young children, better access to health and educational services, improved knowledge and practices in all areas that touch the rights of women and children, among many, many other things.

Readers of *Coordinators' Notebook* already have young children on their agendas. Our challenge has always been getting children on national agendas with significant resources, technical and monetary, to make a difference for their lives. Now we need to do that same work, at global, national, and local levels and with special urgency, for young children in AIDS-affected areas.

Every nation must be concerned with preserving a living, healthy generation to take it forward to the future. Adult deaths from AIDS are already draining the work force of power and talent. The financial and labour demands of households devastated by AIDS are forcing the next generation out of school. If the survivors of the next generation are wasted physically and mentally, then it is truly difficult to see how countries themselves will survive. As Hunter and Williamson wrote in 1997, "With orphans eventually comprising up to a third of the population under age 15 in some countries, this outgrowth of the HIV/AIDS pandemic may create a lost generation—a large cohort of disadvantaged, undereducated, and less-than-healthy youths. The threat to the prospects for economic growth and development in the most seriously affected areas is considerable" (2).

Attention and resources to the needs of children under five and their caretakers can provide a pivot to

turn these trends around. Unless under-fives are cared for in the present, no amount of later intervention is likely to be effective or efficient. Better use of food and health services can liberate already grieving households from the grief of sick and dying children. Better use of time resources can free adults to work and farm; it can also free older children to attend school. And it will preserve a generation of survivors much better able to meet the challenges of the post-epidemic years.

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**We need to respond urgently at all levels: unless under-fives are given attention and provided with resources in the present, no amount of later intervention is likely to be effective or efficient.**

# Infant Feeding Practices in Africa in the Context of HIV/AIDS

*Comments and Excerpts from  
“Early Breastfeeding Cessation as an  
Option for Reducing Postnatal  
Transmission of HIV in Africa”*

S. L. HUFFMAN ET AL.

*Early Breastfeeding Cessation as an Option for Reducing Postnatal Transmission of HIV in Africa* (Huffman et al. 2001) examines the implications and risks of recent World Health Organization recommendations for modifying breastfeeding practices to reduce postnatal transmission of HIV in Africa. Sections of the article are excerpted below to update *Coordinators’ Notebook* readers on some of the current research and issues surrounding mother-to-child transmission of HIV/AIDS.

Most of the half-million children who died from acquired immunodeficiency syndrome (AIDS) in 1999 were infected with human immunodeficiency virus (HIV) by their mothers during pregnancy, delivery, or breastfeeding (UNAIDS 2000). In seven countries in Sub-Saharan Africa, HIV prevalence rates exceed twenty percent. Most women currently infected by HIV are of childbearing age and may live up to ten years past the date of infection; therefore, the number of young children infected with HIV will continue to grow. In the absence of interventions to prevent mother-to-child transmission (MTCT) of HIV, an estimated twenty-five to forty-five percent of HIV-infected, untreated mothers will pass the virus to their infants. What can be done to reduce the rate of transmission?

## Interventions

**Anti-retroviral drugs** The risk of HIV infection from partial breastfeeding (i.e., nonexclusive breastfeeding) by untreated mothers ranges from ten to twenty percent, and about half of all postnatal transmission occurs after the first six months of life (de Cock et al. 2000; Piwoz 2000a). Recent studies show that providing HIV-infected mothers with short-course anti-retroviral drugs can reduce MTCT by



Namibia/1552-013/Jean-Luc Ray

**Efforts to modify breastfeeding to reduce mother-to-child transmission must be addressed in culturally sensitive and appropriate ways.**

forty to fifty percent by six weeks post-delivery. However, even with this treatment, about eight to ten percent of mothers pass the virus to their babies through continued breastfeeding up to twenty-four months (Wiktor et al. 2000; Owur et al. 2000).

**No breastfeeding** In industrialised countries, HIV-positive women are often advised not to breastfeed as a means of preventing postnatal transmission of HIV. In Africa, however, alternatives to breastfeeding are frequently unavailable, unaffordable, or culturally unacceptable. Because breastfeeding offers the greatest protection against infection, malnutrition, and premature death among infants living in resource-poor settings (WHO Collaborative Study Team 2000), discontinuation of breastfeeding by HIV-positive mothers who lack access to safe replacement feeding methods would create a very serious health crisis.

**Replacement feeding** Breast milk would need to be replaced by other foods. Breast milk substitutes, however, are not commonly accessible, affordable, or, in many places, safe due to lack of safe water. Studies suggest that first foods given to young infants in Africa are nutritionally inadequate (particularly thin porridges), lacking vitamin A, iron, zinc, and other

essential nutrients (Bentley et al. 1991; Hung 1992; Gibson et al. 1998; WHO 1998b). Furthermore, infrequent feeding and small portion sizes contribute to low consumption of complementary foods by young children (Caulfield et al. 1999; Huffman et al. 2001). In Sub-Saharan Africa, only fifty percent of the population has access to safe water, and only forty-five percent has access adequate sanitation (UNICEF 2000). Hygienic replacement feeding is difficult under such circumstances (Humphrey and Iliff 2001), and most of these populations are reliant on breast milk to nourish young children into the second year of life and beyond. For most women in Africa, breast milk substitutes are costly and seldom used for infant feeding.

For early weaning, the most common breast milk substitute in Africa is cows' or goats' milk, both of which are lower in most micronutrients than breast milk. Vitamin A deficiency is a major concern in weaned infants because most vitamin A comes from breast milk during the first two years of life and vitamin A stores in infants are low (Humphrey and Rice 2000; West et al. 1986; Cohen et al. 1983). Vitamin A deficiency is associated with higher rates of diarrhoeal and respiratory infection in children. High-dose vitamin A supplements need to be provided to infants near the time of breastfeeding cessation.

Scurvy occurred in the United States in the early twentieth century among some children whose mothers boiled cows' milk and thus destroyed the vitamin C content (Carpenter 1999). A similar problem with scurvy and other micronutrient deficiencies may develop among African infants whose mothers boil their milk, if the infants do not consume enough vitamins from foods. There is also a risk that feeding cows' milk to infants and small children can result in blood loss from the gastrointestinal tract. In some children, such gastrointestinal blood loss appears to be nutritionally significant and may contribute to the development of iron deficiency anaemia (Sullivan 1993).

The challenges of finding safe replacement feeding strategies will face families regardless of whether mothers choose not to breastfeed at all, or stop breastfeeding early, but more serious consequences may arise the earlier replacement feeding is begun. Replacement feeding recommendations based on locally available nutrients must be included in breastfeeding counselling to prevent MTCT.

**Exclusive breastfeeding** A study conducted in Durban, South Africa (Coutsoudis et al. 1999) suggested that exclusive breastfeeding reduced infants' risk of postnatal HIV infection. The study observed that infants who were exclusively breastfed for at least three months had no excess risk of HIV infection at six months of age compared to infants who were not breastfed. In fact, the exclusively breastfed babies had significantly lower rates of HIV transmission at six

months and at fifteen months compared to infants who were partially breastfed and who also received other liquids or food in early infancy (Coutsoudis et al. 2001). The hypothesised explanations for the reduction in HIV transmission risk were based on the observation that exclusively breastfed infants are exposed to fewer bacterial contaminants and food antigens, which can damage the gut lining and cause inflammation. Other liquids and foods may compromise intestinal integrity, resulting in small lesions in the immature gut through which HIV can pass to infect the infant.

**Early cessation of breastfeeding with exclusive breastfeeding** Several studies have used mathematical models to examine the impact of breastfeeding duration on the risks of infant HIV infection and mortality (e.g., Ross and Labbok 2001; Krasovec et al. 2000; Kuhn and Stein 1997; Nagelkerke et al. 1995). Initiation of exclusive breastfeeding followed by early breastfeeding cessation for women who know they are infected with HIV has been suggested as one means to reduce postnatal HIV transmission, and one feeding option offered by WHO, UNAIDS, and UNICEF (1998). The important and positive aspect of this recommendation is the added weight it lends to the argument for exclusive breastfeeding, a powerful preventative for many of the leading causes of infant mortality, but one which has not been widely adopted in Africa.

Early and rapid cessation of breastfeeding, however, can cause physical and emotional trauma both for young infants and for mothers. Infants may experience dehydration, refusal to eat, malnutrition, cognitive and social deficits associated with disruption of the mother-child bond, and a higher risk of abuse and neglect. For mothers, the effects may include painful engorgement, mastitis, pregnancy, and depression. Counsellors who support HIV-positive mothers in implementing this modified breastfeeding option should be aware of the possible consequences for both mothers and children and be prepared to help mitigate them.

**Three-step approach** These risks of early and rapid cessation of breastfeeding could be reduced by a three-pronged approach to modified breastfeeding for HIV-positive women:

- Exclusive breastfeeding—no other liquids or food—for six months or until the decision is made to stop breastfeeding, if that occurs before six months of age.
- Transition feeding with expressed breast milk fed by cup.
- Exclusive replacement feeding with breast milk substitutes and family foods (i.e., no breast milk).

The intermediate step of expressing breast milk is recommended by WHO as a method of reducing the many risks posed by abrupt cessation.



## Current Infant Feeding Practices

Implementing the WHO recommendations—or the three-step process outlined above, will require significant change in most aspects of current African infant feeding practices. Understanding current feeding patterns helps illustrate why implementation of early breastfeeding cessation may prove difficult, and it also points out behavioural issues that must be addressed within programmes aimed at supporting the behaviour in culturally sensitive and appropriate ways for HIV-positive mothers. Below is an outline of some of the most common feeding patterns observed in Africa, with their implications for efforts to modify breastfeeding to reduce MTCT. These patterns often vary among countries and ethnic groups, and between urban and rural areas.

**Long Duration of Breastfeeding** In most African countries, breastfeeding is universally initiated, with the average duration of breastfeeding ranging from eighteen to twenty-five months. Few infants less than twelve months of age are not breastfed. Implications of this practice are threefold: 1) experience with breast milk substitutes is extremely limited; 2) any woman with a child under eighteen months of age who is not breastfeeding is likely to be suspected of being HIV positive; and 3) increased pregnancies and increased number of orphans may result.

Women who rapidly stop breastfeeding when their children are very young may quickly be identified by the community as being HIV-positive and may face the added stress of having to deal with the prejudice and stigma that often accompany HIV infection, including ejection from home and spousal violence.

The risk of pregnancy is very low among women who exclusively breastfeed during the first six months postpartum. Exclusive breastfeeding extends the duration of amenorrhoea (non-ovulation); less than two percent of women who fully breastfeed day and night and are amenorrheic risk pregnancy during the first six months postpartum. However, women can quickly become pregnant once they resume menses or stop breastfeeding, a fact that may be unknown to African women, who are used to being protected from pregnancy by breastfeeding. Closely timed pregnancies can be detrimental to the health of the mother, her infant, and her fetus.

**High Frequency of Breastfeeding** Infants are breastfed on demand and are fed frequently during the first year of life. Ghanaian infants between one and six months of age are fed as often as twenty-one times per twenty-four hours (Lartey et al. 1999). Reports suggest that many infants are breastfed whenever they cry or are in need of comfort. Infants in Africa seldom use pacifiers. There are several implications for switching from breastfeeding to breast milk substitutes: 1) because replacement feeding requires fuel, heating,

and hand-feeding—all time and energy expensive activities—women will have to change centuries-old practices about feeding frequency to make replacement feeding feasible; and 2) mothers will need to find or learn about alternative methods of comforting infants.

**Frequent Night Breastfeeds** Most infants sleep with their mothers during the night and are given free access to the breast. They continue to breastfeed at night well into their second year of life. Implication: because heating breast milk substitutes in the middle of the night is not feasible for most African mothers, the practice of ready accessibility of night feeds, and perhaps traditional sleeping arrangements, will require change.

**Introduction of Other Liquids and Foods** Liquids are introduced into infants' diets quite early. By three months of age, nearly three-quarters of infants have received supplements, primarily water or thin porridge (few receive milk other than breast milk). This means that the compromise of intestinal integrity with bacterial contaminants and food antigens, which increase the likelihood of the HIV virus passing to infants, happens early and is widespread.

**Infant Feeding Logistics** Infant feeding in most traditional African cultures centers around near-constant contact between infants and their mothers or other caregivers. Rural mothers often keep their infants with them as they work in their fields during the day—for example, tying them to their backs and shifting them to the front for breastfeeding. Once children are no longer breastfed, they are often left at home with other caregivers such as grandmothers or older siblings. The implications for using alternative feeding methods are, among others, that normal patterns of attachment and bonding between mother and child may be seriously disrupted, and that the quality of infant care may be impaired as infants are left with grandmothers unready for the more intensive demands of very young children than older weanlings.

For infants, breastfeeding confers a special claim to their mothers' care and attention, which cannot be assigned to others (Bohler and Ingstad 1996; Harrison et al. 1993). When breastfeeding stops, infants lose this special claim, and they can be and often are, by tradition, handed-off to grandmothers or siblings.

Proximity, physical contact (Lowinger et al. 1995; Feldman et al. 1999; Lvoff et al. 2000), and responsive care-giving (Valenzuela 1997) all play a major role in attachment formation. All three would be threatened by physical or emotional separation at early cessation of breastfeeding.

In Africa, as noted, this transition from breast to food commonly occurs around age two, and, though this may be difficult even for a two-year-old, the traditional timing does not disrupt the fundamental process of attachment, or mother-child bond, which

is usually complete by eighteen months (Lier et al. 1995). On the other hand, for young infants, if rapid cessation of breastfeeding results in consistent physical or emotional distance from the mother, the attachment process will be drastically interrupted, and the impact can be severe, pervasive, and long lasting. Insecure, ambivalent, or disorganised attachments are associated with multiple, negative effects on children, including increased stress reactivity (Gunnar et al. 1996; Gunnar 1998; Joseph 1999), anorexia (Chatoor et al. 1998), non-organic failure to thrive (Klein 1990), limited exploratory competence (Cassidy and Berlin 1994), behaviour problems in preschool, elementary school, and high school, and psychopathology in adolescence (Carlson 1998). Attachment problems are also associated with limited competence in the domains of peer relations, conduct, school, work, and activities (Masten and Coatsworth 1998).

Sucking helps regulate an infant's emotional and physical state, and it reduces stress. Sucking induces calm, reduces heart and metabolic rates, and elevates the pain threshold in rats and humans (Blass 1994). Even non-nutritive sucking (on a pacifier or fingers) improves heart rate, oxygenation, and pain response behaviour (Bo and Callaghan 2000; Shiao et al. 1997), the frequency of sleep and calm alert states (Gill et al. 1992), and nutrition and growth (Kimble 1992).

Unless replaced, the loss of sucking caused by an abrupt cessation of breastfeeding may leave the infant less able to cope with everyday stresses and cause prolonged crying, which, in turn, may add to the mother's stress and cause a deterioration in the mother-child relationship.

**Passive Feeding Practices** Most available reports suggest that active feeding ceases once mothers introduce other foods and children are eating a family diet. Mothers do not typically encourage their children to eat, nor do they talk to their children during feeding sessions (Engle et al. 2000). Implications: The intensive interaction needed to assist a six-month-old in eating the necessary amount of replacement foods may be absent, resulting in significant consequences in malnutrition, morbidity, and mortality.

Few African women are at risk of pregnancy in the first postpartum year because of current breastfeeding patterns and the associated postpartum amenorrhoea (i.e., non-ovulation). Given the low contraceptive prevalence in Africa, postpartum amenorrhoea is especially important and many women rely on breastfeeding to protect them from pregnancy. At twelve months postpartum, many more women are amenorrheic than are using contraception. Implication: In the absence of family planning counselling and interventions, more infants subject to HIV infection and orphaning will be born.

**Abrupt weaning** Rapid cessation of breastfeeding is not unknown in Africa, but it more commonly occurs with older toddlers, around eighteen months of

age (Almedom and de Waal 1990; Dettwyler 1987; Harrison et al. 1993; Rwanda Ministry of Health 1994; Mokwena 1988; Nydegger and Nydegger 1966). Women generally stop breastfeeding abruptly when they become pregnant or when a child has reached a particular age.

These techniques do not always work, however, as evidenced by studies in Sudan, Ethiopia, Uganda, and Peru that found that many mothers who try to stop breastfeeding quickly begin breastfeeding again to comfort their children (Almedom and de Waal 1990; Bohler and Ingstad 1996; Marquis et al. 1998). Implication: Such failure among HIV-positive mothers may increase the risks of postnatal HIV transmission since a return to breast milk after the introduction of replacement foods may increase infants' vulnerability.

In summary, early breastfeeding cessation may present a viable approach for some HIV-infected mothers to reduce postnatal transmission of HIV, but it runs counter to traditional practices, which include the gradual introduction of liquids and foods, with breastfeeding cessation seldom occurring before the second year of life. It is important, therefore, to distinguish this modified breastfeeding practice from traditional practices by pointing out the relatively rapid transition in the infant's diet, by providing caregivers with alternative methods of comforting infants, and by helping mothers ease their infants into new feeding patterns early in life.

Difficulties will be encountered and changes will be required regardless of how the shift from exclusive breast milk to exclusive non-breast milk foods is made. The middle step of breast milk expression is suggested as a means of making the above changes easier by allowing for more flexibility before breast milk is entirely excluded, and of preventing other consequences likely to be much more severe with abrupt weaning. These consequences are outlined below.

## The Risks of Early and Rapid Breastfeeding Cessation

Infants of HIV-positive mothers need to make an abrupt switch from breast milk as a food to non-breast milk foods in order to maximise prevention of MTCT. Exclusively breastfed infants are exposed to fewer bacterial contaminants and food antigens, which can damage the gut lining and cause inflammation; when non-breast milk foods are introduced infants can be exposed to other liquids and foods which may compromise intestinal integrity, resulting in small lesions in the immature gut through which HIV can pass to infect the infant. The intermediate step of breast milk expression may facilitate the switch to foods without the many dangers inherent in abrupt cessation of breastfeeding without intermediary measures.

Early and rapid cessation of breastfeeding can cause physical and emotional trauma both for young infants and for mothers. Infants may experience dehydration, refusal to eat, malnutrition, and trauma. For mothers, the effects may include painful engorgement and mastitis. Counsellors who support HIV-positive mothers in implementing this modified breastfeeding option should be aware of the possible consequences for both mothers and children and be prepared to help mitigate them. Some of these issues are outlined below.

### Risks for the Infant

#### *Nutritional and Health Risks*

- **Dehydration:** Many infants refuse to drink from cups or bottles when deprived of the breast, and this can quickly lead to dehydration.
- **Refusal to eat:** The stress of cessation of breastfeeding and unfamiliarity with feeding from a cup or bottle can lead infants to refuse to eat. This can cause lethargy and crying, which in turn can cause or exacerbate dehydration.
- **Weight loss and malnutrition:** Young infants who are not accustomed to eating other foods can quickly lose weight and become severely malnourished when taken off the breast. Infants who stopped breastfeeding too early have developed marasmus, an extreme form of malnutrition (Jelliffe 1968).

#### *Psychological Risks*

- **Trauma:** Rapid cessation of breastfeeding causes trauma for the infant, manifested by intense crying (Nydegger and Nydegger 1966; Harrison et al. 1993; Shostak 1983), although some infants may also become silent and withdrawn, especially if becoming malnourished. Marquis et al. (1998) report that weaning after twelve months has been associated with short-term negative consequences, including a reversal in motor and language development, emotional disturbances (intense sorrow, resentment, crying, temper tantrums), learning difficulties, and physical problems (illness, weight loss, loss of appetite, and loss of sleep).

Gray (1996) notes that among the Turkana in Kenya, mothers abruptly stop breastfeeding when they become pregnant, and that this is a “traumatic event for both mothers and children.” Children were observed to respond with “frequent tantrums, loss of appetite and refusal to eat.”

### Risks for the Mother

#### *Health Risks*

- **Engorgement:** Breastfeeding women may produce 750 ml of milk or more every twenty-four hours. Missing a feeding at the breast may cause engorgement, plugging of ducts, and mastitis (Lawrence 1994; Riordan and

Auerbach 1993). Engorgement involves congestion, increased vascularity, and accumulation of milk, and may cause considerable pain. Engorgement afflicts one-third to two-thirds of postpartum women who decide not to breastfeed. Anthropological studies report that even mothers of toddlers frequently suffer swollen and painful breasts during abrupt cessation of breastfeeding (Nydegger and Nydegger 1966).

- **Mastitis:** Women who rapidly stop breastfeeding experience sudden, poor drainage of the breast. This can be reduced, but not eliminated, if they express their milk. Poor breast drainage can result in plugging of the ducts and, eventually, mastitis (swelling and inflammation of the breast, often accompanied by fever). For example, one study of sixty-five cases of mastitis found that nine of the women had missed feedings or had abruptly stopped breastfeeding prior to the onset of illness (Marshall et al. 1975).

Studies show a higher incidence of clinical mastitis in industrialised countries than in Africa, which may be explained by the fact that African women breastfeed more frequently. Reducing the frequency of breastfeeding to accommodate early cessation of breastfeeding therefore may increase rates of mastitis, even if the process is not rapid or abrupt. Mastitis can be especially dangerous for immune-compromised women, such as those infected with HIV, because it may lead to systemic infection and breast abscesses. Elevated breast milk sodium (due to inflammation or reduced breast milk production) and mastitis are associated with higher breast milk viral load and greater risks of HIV transmission during breastfeeding (Semba 1999; Semba et al 1999; Willemsen et al. 1999).

The intermediate step of expressing breast milk may help mothers to prevent infant dehydration, mitigate a child's refusal to eat, and decrease malnutrition and trauma, as well as help mothers themselves to prevent engorgement and mastitis. The effectiveness of this step or any programme to promote it is unknown.

It is also important to recognise that the impact of early and rapid breastfeeding cessation on maternal and infant health in general remains unknown. Mathematical models suggest that the number of HIV-infections that would be averted by early breastfeeding cessation is not likely to be great. If the modified breastfeeding practice described in this paper is included among the several infant feeding options available to HIV-positive mothers, it will be important to balance the unsubstantiated potential benefit of the practice against the “also unknown health affects and other costs of achieving it” (Ross and Labbok 2001).

In addition to the issues raised in this paper, the success of programmes to change feeding practices

among HIV-positive women will depend on several other factors. First among them is the strong stigmatisation associated with HIV/AIDS and the difficulties this poses for targeted education, promotion, and counselling programs. Transforming the infant feeding practices of HIV-positive mothers who do not wish to be identified or singled out for behaviour change will require careful planning, community outreach, and social support, as well as financial commitment. Such resources are currently scarce in the areas most affected by HIV. Without public education to build awareness and social support for new patterns of infant feeding, and without adequate counselling, mothers may be subjected to a difficult and isolating experience. They may be able to follow through only partially and end up with mixed feeding patterns that could increase rather than reduce HIV transmission.

The WHO recommendation that early cessation of breastfeeding be included in the list of options discussed with HIV-positive mothers is problematic on many fronts. The three-step process described in this paper is intended to make adopting this recommendation more feasible and less dangerous for mothers and infants, but its actual benefits—as well as those of other feeding options, has yet to be evaluated in the full context of consequences.

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Kopanamang, South Africa: The Kopanamang Consortium

**The Foundation's priority is to fund work which increases the organisational capacity of communities to support families and children affected by HIV/AIDS.**

## BERNARD VAN LEER FOUNDATION:

# Foundation-supported Initiatives on HIV/AIDS, Africa Region

Since the mid 1990s, the Foundation support to HIV/AIDS initiatives has been mainly focused on prevention, increasing community and parental awareness of the virus, how the disease is transmitted, and how transmission can be prevented. Projects have focused on education, awareness, advice to women, promoting changes in behaviour concerning protection during intercourse, and access to support services. While the main thrust of our support continued to emphasise education and prevention, we acknowledged that, in the face of the unfolding epidemic, there was a need to look beyond awareness programmes. The Foundation could no longer afford to concentrate on prevention alone given the escalation of HIV/AIDS and the increase in the number of orphans. This realisation was a turning point in the Foundation's programme, which began to fund work to increase the organisational capacity of communities to support families and children affected by HIV/AIDS.

So far the epidemic has orphaned more than ten million children—children who before the age of fifteen have lost either their mother or both parents to AIDS. In many of the countries in the region, AIDS is

leaving so many children orphaned so quickly that family structures have difficulty coping. The deep-rooted kinship system of extended family networks made up of aunts, cousins, and grandparents that has thus far proved itself resilient to major social changes is now rapidly unravelling. At the same time, governments are withdrawing support from social and welfare services as a result of structural adjustment. Institutional care is both costly and not suitable for the long-term care and support of children, and in any case, institutions alone would not be able to cope with the large number of orphans in need of care.

In the context of limited social support systems outside of families, and where basic social services are largely inadequate, orphans are particularly vulnerable. As traditional safety nets become unravelled, and more young adults die, HIV/AIDS orphans are at greater risk of malnutrition, illness, abuse, and sexual exploitation than children orphaned by other causes. These orphans must grapple with the stigma and discrimination so often associated with AIDS, stigmas which can deprive them of basic services and education.

The vulnerability of children is made worse by geographic concentration—vulnerable children are cared for by vulnerable families and live in vulnerable communities. The Foundation's strategy in the region is to work with marginalised or disadvantaged groups who are in danger and yet have no access to service provision and assistance. Following our philosophy of building on people's strengths, the strategy acknowledges that, however critical and devastating the crisis may be, countries and communities across the region are rallying to respond to the damage and to counter some of the most dire effects of the disease. Many communities are already caring for large numbers of orphans, and are providing appropriate solutions to their immediate needs.

The Foundation currently supports sixteen projects in South Africa, Kenya, Namibia, and Zimbabwe designed to address care, education, and prevention, but also to strengthen the coping mechanisms of communities and families to care for children who are already orphans or who the potential to become orphans. Although some projects were not originally specifically designed to address HIV/AIDS-affected children, the environment in which they work has necessitated re-thinking and reformulating approaches to reach out to these most vulnerable of children.

### **The regional picture (eastern and southern Africa)**

Sub-Saharan Africa is currently the epicentre of HIV and AIDS, being home to nearly seventy percent of the world's HIV-positive people. In 2000, an estimated 3.8 million adults and children became infected with HIV/AIDS, bringing the total number by the end of the year to 25.3 million. The epidemic is not uniform; in many west African countries, the spread of HIV seems to be slow and in some cases even contained. It is not clear whether this situation will continue, especially as there are signs of a significant epidemic emerging in Nigeria. But the worst situation is in the eastern and southern sub-regions.

In 2000, AIDS deaths in Africa totalled 2.4 million, compared to 2.2 million in 1999. In Botswana, Namibia, Kenya, Zimbabwe, and South Africa, the epidemic is expected to climax before 2010, and the orphan population is expected to peak seven to ten years later. This means that orphan numbers will probably increase through at least to 2010.

### **Logical programme choices**

The Foundation recognises the need for urgent action in supporting children, families, and communities who are affected by HIV/AIDS. Our mandate and philosophy, coupled with our programme choices and target

beneficiaries, have prepared us well to learn how best to increase family and community capacities to care for orphaned children. Community and family needs cannot be separated from the general care of children, and responses need to be developed as part of broader based community care initiatives. However small, family-based solutions are some of the most realistic options for children and need to be expanded within and beyond the boundaries of communities.

For family and community care to work, resources must be injected into communities, and the care initiatives need state welfare and education subsidies. The initiatives need to liaise with other family and community counselling services and look for direct funding from private sponsorship, industry, and commerce, which can apply for tax incentive schemes. There are some examples of this in private sponsorship, such as that of large-scale commercial farmers involved in informal fostering initiatives, for example the Farm Orphan Support Trust (FOST).

Given the magnitude of the problem, even relatively low-cost interventions require significant resources to become sustainable and go to scale, while the support structures necessary to sustain the interventions require interdisciplinary cooperation. While most projects are working towards this end, the process needs political will and guidelines on collaboration, particularly between the welfare, health, and education sectors.

Acknowledging the different alternatives that communities support in a context of limited resources is equally important. While we are aware that institutional and family or community based care need not be mutually exclusive, they should both be developed as potential choices in a range of care options. Our partners are working simultaneously in several models of care which include: informal fostering by the extended family or non-relatives; substitute or foster care families; family type groups; child headed households; and orphanages.

Some of the projects began by looking at the needs of AIDS orphans but gradually reformulated their criteria and became more inclusive to other vulnerable children. Similarly, projects working to improve the well being of children in general are gradually embracing strategies to incorporate children affected by HIV/AIDS. In a context of general marginalisation of families and communities there is an increasing awareness and concern to avoid stigmatising these children. In this respect, projects embrace a wide range of approaches to cater to children and provide quality outreach. For example, women volunteers in Zimbabwe, also called child rights monitors, make home visits to support and advise parents in childcare matters. They also check that children's needs and rights are met. Projects are increasingly adopting child participation methods to address sibling support and

give an active voice to children. This has proven most relevant in addressing child abuse and neglect.

Most of our supported projects identify strategic intermediary organisations to work with on increasing their organisational and programmatic capacity and those of their partners at the community level to cope with the scale of HIV infection. As the projects focus on partnerships for capacity building, resource provision, networking and influencing policy, they indirectly help communities to identify and explore ways to support vulnerable children and families; to develop databases to assess the scale of the problem and to trace families; to encourage leaders to protect the property and rights of children; to train community members to identify and protect children at risk of being abused; to make ECD centres more inclusive; and to provide emotional, material and financial support to families.

Collaboration between NGOs and governments is essential to improve the quality of response and ensure that the basic welfare of children is safeguarded. Several mechanisms have been put in place to simplify procedures and improve coordination with key agencies, and increase partnerships with them. Foundation support has been at the heart of statutory

agencies' efforts to address welfare reform and coordination. However it is not a task that can be taken single-handedly by one organisation—stronger commitment and political will is needed to improve children's access to integrated service provision and improve their quality of life. This problem is further complicated by the fact that governments in Kenya, Zimbabwe, and South Africa do not yet have a clearly defined role, and that responsibility for children's welfare, health, and education often belongs to the most inefficient and under-resourced government agencies. Like NGOs, governments also rely on funding, and assistance from international donors is not coordinated.

Though our support does not directly target prevention of mother to child HIV/AIDS transmission, the Foundation is part of two large regional networks which combine information on prevention, testing and anti-retroviral drugs for HIV positive mothers, with organising home-care for children. Both networks—the Children's Rights in an HIV positive World and the ABA (Aiding Babies Fight AIDS) Trust<sup>1</sup>—use the extensive knowledge that exists in these areas to lobby governments to provide expanded free services to poor women.

## What have we learned?

### On children's vulnerability

Of the many vulnerable members of society, children who have lost one or both parents are among the most exposed of all. They face greater risks of suffering psychological distress, increased malnutrition, loss of access to services, and reduced opportunities for schooling and education than most of their peers. In most cases, the children's predicament begins long before their parents die, as households become stressed by dwindling resources. Preliminary data from our supported programme identified the following most common areas of vulnerability:

- Children orphaned by AIDS are just one of many competing urgent priorities of governments which are under intense pressure to cut back on social and health services under structural adjustment programmes.

<sup>1</sup> The ABA Trust in the Eastern Cape, South Africa, has 16 clinics, several of which are located in poor communities to provide services (testing and administering anti-retroviral drugs) to pregnant mothers. The Trust does this through a large volunteer network. Tests for HIV can be obtained for USD 1. Drugs cost USD 6. One tablet given to the mother at the start of labour, and three drops to the baby in the first three days after birth is all that is needed to stop transmission. The Trust hopes that the Government will eventually take over these services.



Grahamstown, South Africa: Bernard van Leer Foundation

**Recognition of child-headed households acknowledges that acceptable standards of care should be based on what is actually possible within the community in which the child lives.**





Zimbabwe: Bernard van Leer Foundation

**The need to respect and keep the children’s best interests in mind in situations where the welfare of the whole community is weakened must be maintained.**

- In traditional societies, the extended family usually takes care of orphans. But siblings are often separated in order to share the economic burden between different members of an extended family. This brings further stress to children who have lost their parents.
- When absorbed into their extended families or cared for by non-relatives, orphaned children may be the first to be denied education if families cannot afford to educate all the children of the household.
- Children orphaned by the epidemic are unlikely to have access to ECD services, school, and health services. Because of their situation they are often forced to migrate and are likely to take on adult responsibilities.
- As the rights of the children are inextricably linked to those of their surviving parent, laws and practices that deny widows their rights and property have devastating consequences for children after their father’s death. Children can be pushed off family property and lose their inheritance.
- Orphans tend to migrate to urban centres in search of jobs, thus swelling the ranks of the urban poor.
- Often emotionally vulnerable and financially desperate, orphaned children, especially girls, are more likely to be sexually abused and forced into exploitative situations, such as prostitution, as a means of survival.
- Pregnant women are not routinely screened for HIV and very few know their seropositive status or the kind of risks their babies face. Few

have the means to have the test and obtain anti-retroviral drugs.

**On families and communities**

- Family-based care is at the heart of HIV/AIDS care, and in communities worst hit by the disease, more than one member of a family is often affected. The extended family network, still found in many of the countries in which we work, is a national strength—especially where health care is not available and resources to pay for hospitalisation are limited. But the extended family can be easily exploited.
- In the rural areas where women produce most of the food, households lose their source of income when they spend long hours caring for sick family members, or when they themselves are infected and ill. This severely affects the well being of children. The requirements for day care services and nutrition at the community level is fundamental.
- Scarce resources and a lack of income, plus the stress of HIV/AIDS itself, negatively impact on the effectiveness of programmes that are based on voluntarism. Programmes need to become economically sustainable and able to pay workers for their model of care and service provision to be effective.
- The need to respect and keep the children’s best interests in mind in situations where the welfare of the whole community is weakened must be maintained. This is especially important as there is increasing evidence of child abuse and neglect.

### On programme and policy challenges

A key challenge is to develop a system that links community mechanisms with accessible and appropriate legal, psychosocial, and material resources. While every attempt should be made to provide the child with the best possible care, a review of existing legislation needs to be realistic. Acceptable standards of care should be based on what is actually possible within the community in which the child lives. This would mean, for example, the recognition of child headed households and other alternative models.

One such alternative model might be to encourage micro credit initiatives to meet the immediate needs of households and children. But projects will have to broaden their donor base and seek support from other sources for this. However, as both the social and the economic activities need equal attention, a careful balance between the two must be maintained.

Collaboration with governments and international agencies on the part of projects is essential to ensure that resources are mobilised and directed at the most cost effective interventions in a coordinated way. Special efforts are needed to ensure that government funds and tax levies collected for addressing the HIV/AIDS situation (in the case of Zimbabwe) are channelled in a transparent manner to support community interventions. This is the best way to value the contributions of communities as partners.

### What next...

There are two important new developments in international and regional programming in Africa. One is the high international public profile that the issue of HIV/AIDS in Africa has gained in the past year, and as a consequence there is a massive influx of money from governments and private sources, some of it pledged and some of it real. The second development is the increasing call by international organisations for local responses to AIDS to be scaled up. The Foundation should observe these developments with care. The high level of attention and commitment to

respond to HIV/AIDS on the continent is most appropriate and welcome. But more money and more attention do not always mean new ideas.

Equally we should be aware that international attention on scaling up community based responses, which often goes with large sums of money does not distort the balance of content and scale. Doing more in terms of scale does not always mean bigger. Sometimes better coverage of community initiatives can be achieved through replicating functional responses rather than through inflating these responses to a level where they lose their anchor in community life.

Being aware of these developments, the Foundation aims to:

- continue to review and evaluate its experiences and strengthen networks for mutual learning including more systematic documentation of experiences;
- commission research to help identify and analyse the cost benefits of household and community responses to HIV/AIDS, their impact and further explore the absorption capacity of families to foster children informally
- create opportunities to learn more about programming and policy formulation. The urgency of addressing the crisis gives us the added responsibility of focusing our strategies and sharing what we know.

To this end, the Foundation will commission a review process in the Africa region in 2002 to inform our learning agenda during the next strategic planning phase. This will entail commissioning country and regional programme reviews, documenting good practice through publications and CD-ROM, and widely sharing our findings with our partners and the development community at large.

For more information on Project Descriptions in Zimbabwe, South Africa, Kenya and Namibia, please see: [www.bernardvanleer.org](http://www.bernardvanleer.org)

## Speak for the Child: A Program for AIDS-affected under-fives in Kenya

DIANE LUSK

The most common forms of AIDS-related orphan assistance programmes have been aimed at school-aged children and their respective households through assistance to caregivers. However there is a pressing need to identify and address the needs of orphans too young to be in school. What of the children too young to be in school? What are their needs? How are caregivers managing the more intensive demands presented by small foster children? What can be done that will most directly affect these children and improve their lives?

The Ready to Learn Center in the Academy for Educational Development secured funding from the Displaced Children and Orphans Fund to pursue these questions, and visited Kenya in the fall of 2000 to learn about the current state of programming for AIDS orphans there as well as to explore possible partnerships. The thirty international NGOs contacted were engaged in the planning phases for a shift from a nearly exclusive focus on AIDS prevention to one focused on mitigation and care. One, the Community-based Programme on HIV/AIDS Care Support and Prevention (COPHIA), had progressed to include community mobilization for Home-based Care (HBC) training.

Small local community-based organisations (CBO) in Western Kenya—for long the area hardest hit by AIDS—had sprung up to address some orphan care needs. One programme, in an area nearly stripped of healthy adults, mainly provided a daytime gathering place for 700 orphans, aged five to fifteen, who gathered on lent land. Four adult volunteers struggled to provide some education and occasional food. This alone, however, was a great help to the orphans: "Just having a place to be together keeps them going," said the coordinator. The children's actions endorsed this observation, voting with their feet: some walked seven kilometres every day to attend. In another hard-hit area, a local committeewoman started a small childcare centre for forty-five orphans in a government-owned abandoned hut, which the local chief had permitted them to use. Just \$500 from Catholic Relief Services bought windows and doors, eating utensils, and a water pump and a bicycle to assist a tomato-growing Income Generating Activity (IGA) to support volunteer

teachers and to buy food. In a third programme, preschool- through grade four-aged children were taught and fed in community-constructed buildings on land donated by the community; the preschool class, conducted on rough-hewn benches in the sun, held a *barambee* (a social event with speeches and food to raise funds) for a palm-leaf roof. However, only half the funds needed were raised. As one observer noted: "People in Kenya are *barambeed-out*."

These examples of community efforts to reach the youngest orphans have become part of the dialogue with the Community Based Program for HIV/AIDS Prevention, Care, and Support (COPHIA) about a partnership in Western Kenya. COPHIA had conducted quantitative studies and Participatory Rural Appraisals (PRA) around HIV/AIDS issues in six locations in Kenya. One of these was South Kabras, a rural sub-district not far from Kakamega, the provincial capital of Western Kenya, where reported HIV prevalence is at sixteen percent. The district is a heavily populated rural area with about 600 people per square km. The dependency ratio is high, with just fifty percent of the population being under the age of fifteen and sixty-three percent under the age of twenty. The main economic activity is farming and wage employment revolves around two sugar factories. Of the six divisions covered in the COPHIA needs assessment, those in western Kenya had the highest incidence of vulnerable households.

COPHIA's two-week-long community mobilising exercises in South Kabras included problem listing, ranking, prioritising, and solution brainstorming. The community action plan included training of the community in general on AIDS issues, and training of Community Health Worker (CHW) volunteers in home-based care (HBC) for AIDS patients being attended at home. The community hoped as well to build a counselling resource centre, which could be a base for volunteers, for information and counselling, and for condom distribution.

Orphans were mentioned only briefly during the PRA exercises; the primary concerns were prevention and care for adults. Leaders in COPHIA thought that perhaps the community might be interested in devoting a corner of the counselling

centre to a day-care centre for orphans and vulnerable children, similar to other small volunteer efforts seen in western Kenya, but the whole community would need to be consulted before making this kind of decision.

Active community participation and involvement has been, in other countries, a critical “success” factor in local projects. The Ready to Learn project team wanted to use the Participatory

Learning and Action exercises both to create the space for community design of the programme and to learn about their views and practices for care of young children. Building on COPHIA’s work in South Kabras allowed for a shorter, more affordable, “mini-PRA” focussed on vulnerable children to be commissioned. The design of these exercises is in the box below.

## A “SPEAK FOR THE CHILDREN” PLA

### Preparation

A trained team of Participatory Learning and Action (PLA) experts spends some time in the community and trains local leaders as facilitators. The team meets with local leaders in the community—both chiefs and representatives from community institutions such as NGOs, churches, and women’s groups—and they discuss project responsibilities and the logistics of group composition and feeding. The group takes a walk around the community to observe sites and possible relevant resources for the PLA work. The PLA team and local facilitators meet to select exercises best suited to the topic and the community, and to prepare material (paper charts or natural materials) for the selected exercises.

### Focus Group Types

Several different focus groups can contribute to a community’s assessment and planning for young children. Usually at least two groups are created for any PLA exercise—one for women and one for men—since perspectives tend to vary widely by gender. A separate youth group may also be desirable, for similar reasons, and with the hope that by participating in the problem analysis, youth will be motivated to be part of the solution action plan.

Since 6–10-year-old children in families in the developing world often have the most direct responsibility for the care of children under 5, at least one separate meeting with them as a group is recommended as well (see daily calendar exercise below). In some communities a

meeting for grandmothers may also be recommended.

### Day One: Focus Groups and Mapping

#### Focus Group Topics

These initial topics can be discussed with all groups meeting together:

- Defining vulnerable households (see poverty assessment below)
- Views on the problems of young children in such households
- The role of the community in caring for vulnerable children

#### Mapping

The focus groups meet separately to draw a map (on the ground or on a big sheet of paper spread out so people can gather around it) of their community and locate vulnerable households with young children and areas of land and structures which are potential resources for children’s programmes (e.g., abandoned houses on public trust land, churches, local institutions for children, water resources). This map can be used to indicate the number and aggregation of vulnerable child households and to inform the final action plan as possible programmes and logistics are discussed.

### Day Two: Problem Listing and Ranking for Children and Caregivers

Focus group members are then asked first to imagine that they are children of different ages and then they are asked to speak for the children; they then imagine that they are caregivers for children of different ages. For children and for caregivers, problems are free-listed—every suggestion is recorded—and then

ranked according to importance by the group.

**Children** For infants (<1 yr.), toddlers (1–2 yrs.) and 3–5-year-old children, separately, answer the following questions:

- What are my problems?
- Which ones are most important?

**Caregivers** For caregivers of each age group, ask:

- What are my problems?
- Which ones are most important?

### Day Three: Child Daily Calendars

Focus groups are asked to construct a daily calendar from a child’s point of view. For each time period in a typical day, people are asked to answer the following questions, separately for infants, toddlers, and 3–5-year-olds:

- What is the child doing?
- Who is in charge of the child?
- What is the person in charge doing?

### Day Four: Forming the Community Action Plan

At the end of these exercises, all groups gather to synthesise all the information that has been discussed, to identify at least thirty to thirty-five needy children, and to develop an action plan for improving their caring situation. Community action plans (CAPs) may be made separately in women’s and men’s groups, then merged into one plan by the PLA team and local facilitators for presentation to the group. After discussion, the group solicits volunteers for an implementation committee to launch the CAP.



Forty-five women, forty men, and thirty-nine youth attended the “Speak for the Child” PRA held at a secondary school in South Kabras from 27–30 November 2000. The team leader also held discussions with fourteen children aged six–ten years who were caregivers of children under five themselves.

## PRA Results

**Defining vulnerable households** People in the community did not come up with a list of vulnerability factors for *households*, but of vulnerability factors for *children* in households. They were:

- Children from very poor families who could not afford food, i.e., went without food for a whole day
- Children whose parents have died from disease such as HIV/AIDS
- Children from single parents who cannot afford to care for them
- Children abandoned by parents
- Children born out of wedlock and neglected by care providers
- Children born of incest (which is a taboo) are rejected by the community
- Children from child-headed households

In COPHIA’s HIV/AIDS PRA in South Kabras, the community looked at the list and then chose two factors/criteria they thought were most practical in terms of defining a vulnerable household: fostering orphans and caring for sick people. They agreed that poor households, single-parent households, and child-headed households were obvious criteria in determining vulnerable households, but also commented that they had not expected there to be so many additional factors that increase the stigma and subsequently impact on the household, such as abandonment, illegitimacy, and incest.

**Problems of young children in vulnerable households** Diseases ranked first in the prioritised problem list for young children in vulnerable households. The diseases listed included HIV/AIDS, malaria, measles, diarrhoea, cold, flu, malnutrition, and polio. Lack of adequate food ranked second, orphanhood ranked third. These were followed (in ranked order) by lack of education/information awareness, lack of guidance and counselling, lack of school fees, lack of care and love for children, and lack of clothing.

**The role of the community in caring for vulnerable children** Participants in the PRA discussed how the community could contribute to the care of vulnerable children. They raised many general possibilities: spiritual guidance; guidance and counselling in families; assistance in food

preparation; helping with land preparation, seed provision and cultivation; fundraising to assist with food, clothing, and education; and taking care of children at homes to avoid “de-linking” them from loved ones and relatives.

**Problem listing and ranking for children and caregivers** The project hoped for separate rankings of problems facing infants, toddlers, and preschool-aged children. The men’s group did not undertake this exercise in any form. The women’s group listed the following problems as crucial for children under five: lack of food; lack of immunisations; community ostracism of orphans; lack of love and care; poverty; diseases—especially HIV/AIDS; lack of school fees for orphans; lack of clean water; lack of unity in homes and in community; alcoholism; and negative attitudes toward education. The youth group listing included inadequate child care, poor child spacing, and lack of recreational activities in their rankings of problems for children under five.

**Daily Calendars** The project had hoped to get a picture of a typical day from the group, partly to serve as a context for later individual interviews with caregivers in vulnerable households. Of particular interest was how many people typically had charge of young children. Researchers in Zambia had indicated that young orphans were often cared for in “rotating shifts of teenagers”; what kinds of shifts took place in Western Kenya?

The PRA participants did not undertake the daily calendar task as envisioned. Instead, both men’s and women’s groups discussed the many people who served as caregivers in households and their typical roles. Seven different types of caregivers were identified: mother, father, youth, household helpers, grandparents, neighbours, and siblings. Mothers’ roles include feeding and washing children, cooking for the family, fetching water and firewood and vegetables, washing and ironing clothes, cleaning house, taking sick children to hospital, milking, working in the garden, and entertaining visitors. Fathers’ caregiver activities include providing cash for purchasing food, clothing, school fees, and medicine, as well as providing security and discipline to the children. Youth (a group that includes all unmarried people between fifteen and fifty years of age) activities included cooking for children, fetching water and firewood, washing utensils, and playing with children. Neighbours assist with baby-sitting of children under five and assist in watching over cattle. Household helpers’ roles were said to be a blend of mothers’ and youth roles. Grandparents babysit, which includes playing with children, singing for the children, and telling them stories; the women’s

group also described them as teaching children how to cook, to sweep, and to look after cattle. Older siblings, like mothers, feed and wash children and fetch water and firewood. Daily activities for all children under five were listed together: baby-sitting, playing with other children, running errands within the home, attending nursery schools, and washing utensils. The youth group alone did attempt a typical daily calendar for birth to two-and-a-half-year-old children, and one covering children two-and-a-half-years old to five years of age, but no mention was made of who was in charge during any of these activities.

**Community Action Plan** Many options were considered. The final outcome called for the formation of "Speak for the Child" committees, which would identify vulnerable children under five; promote good childcare in the community, especially the sensitisation of nursery school administrators to the need of vulnerable children and an exploration of their willingness to help; and identify a central plot of land as a site for a future child development centre that, with some project support and community fundraising and volunteer labour, could be built to help address the problems of orphans and vulnerable children.

## The Next Step

Encouraged by these results, the Ready to Learn team from Washington hired a three-person Kenyan team to undertake work in South Kabras. With all on board as of 1 March 2001, Washington staff joined the new Kenyan staff in meeting with the "Speak for the Child Committees" in South Kabras. The committees all expressed their desire to begin right away. Since the original proposal promised tools tested first in one community, then replicated in four others, a rolling plan of implementation was agreed on, and representatives from subcommittees drew lots for the order of implementation. Shianda sub-location, which comprises fifteen villages, drew lot #1.

## The Survey

The Shianda subcommittee was asked to provide one volunteer and one elder for each village to be surveyed. Elders were needed to introduce volunteers to households, and to help them locate households that were likely to have children under five. Elders tended not to be literate, however, and could not conduct the survey themselves. The survey was conducted over the course of a week, with day one providing an introduction to the project and the questionnaire, some pilot interviewing, and debriefing. Over the course of the next four days, 837 households took part in the survey.

Our goal of this initial survey was to lay the groundwork for an easy-to-use targeting tool to pass on to communities: How can the most vulnerable households with children under five be identified? The two-page questionnaire solicited information about the name, birth date, sex, health status, and immunization status of children under five; about the identity of other people in the household, their relationships, schooling, contribution to the household, and health (number of illnesses in past six months); about the identity of caregivers for children under five, their typical caring tasks, and the identity of those who took over for them if they had to leave the child. A second page asked about household assets—land, animals, sources of income, source of water and distance from water, source of heating and lighting—and brief descriptions of typical meals; the second page also called for volunteer observations about housing and hygiene.

There were two major surprises in the survey results: 1) many more children under five were living without any parent in their household than would be officially recognised as having lost both parents; and 2) household assets did not differ significantly for households fostering orphans and other households with children under five.

In every fifth household surveyed (only houses with children under five were surveyed) lived at least one child under five whose parent had died. Both parents of twenty-seven young children had died; sixty children's mothers had died; 187 children's fathers had died. Many children who have officially lost only one parent to disease or accident, however, have effectively lost both parents as the surviving parent is no longer a member of the household. For over forty percent of children whose mothers have died, the father is also absent; for half of these children, household adults do not know if the father actually is alive somewhere or not. Of children under five whose fathers are known to be dead, the mothers of twenty-two percent are absent from the household. In seven cases, no one knows whether either parent is alive. Although twenty-seven children had parents both known to be dead, 169 children had no parent at all living with them.

Vulnerability indicators did not cluster in this community, making it impossible to target "vulnerable children" in a general way. Eating only one meal per day, not sending school-aged children to school, having no land, having chronically ill members, not having immunised children—none of these factors correlated significantly with each other.

Looking at the differences between households sheltering orphans and those who were not, the

team also found very few differences in asset indicators, such as number of acres owned, lack of pit latrines, number and diversity of crops planted, distance to water sources, number of rooms in the household structure—even quality and cleanliness of clothing. Orphans *were* more than twice as likely to live in households where only one meal a day is eaten. Most of the differences between households with orphans and those without were more personal: households with more than one mother were more likely to have orphans; the greater the number of children under five in a household, the more likely it was to have orphans. At the other extreme, households with only one adult member were more than two-and-a-half times as likely to have orphans than households having more adults; perhaps related to this, the adult identified as “caregiver while primary caregiver is away” was much more likely to be “nobody” or “whoever is left” in households with orphans, rather than a family adult or named sibling or neighbour as in other households. The answer to “How do you get food?” in households with orphans was much more likely to be “begging” or “from sympathisers” than in other households. Fifty percent of households sheltering orphans had more than one chronically ill household member; among all households surveyed, the proportion was only twenty percent.

### Home-visiting

These survey results, along with community expectations, led the team to work first with the eighteen households where both parents were known to have died, and four others where serious illness or disability, in addition to a death, afflicted a household with young children. Five assessment tools were designed, each with three components: questions for caregivers, caregiver observations, and child observations. The tools addressed different aspects of care: 1) a love tool looked at the caregiver-orphan relationship, 2) nutrition and health 3) psychosocial issues 4) cognitive development, and 5) language development. Home-visitors brought a multi-grain, high-nutrient flour to give as the traditional gift of guest to host in these sessions.

The data from the first eight weeks of home visiting is just being analysed. These are some preliminary results:

- Many young children are abandoned before a parent’s death, and elderly caregivers speak of this as abandonment not placement. They say: “After the father died, mother left the child and went to an unknown place”; “The mother brought the baby when he was three months old and abandoned him”; “The father had already died and mother married elsewhere. So the child just continued to stay here. Child not wanted by step-father”; “Child’s mother died when he was very young. The father took off to the coast and does not communicate”; “Child abandoned by father when mother was ailing.”
- Children under five are relatively abandoned even within their households. The local staff reports: “Most times we go to a household we find children without a caregiver... Most children are left unattended for about four to six hours... The five- to six-year-olds are left alone, but the two- to four-year-olds are left along only if there is a group of at least two or more children around.”
- Grandparents described themselves as having no choice, as the caregivers as the place of last resort: “No one wanted to take him”; “There was nobody to take the responsibility”; “When the mother died, nobody was willing to take care of the child.”
- When asked “What do you enjoy about this child?” as part of exploring the caregiving relationship, more than half the caregivers noted “obedient” or “sendable” as their first or main response: “goes to the river and the mill”; “she is a child who can be sent”; “nobody can take something from the house when (she) is there”; “listens and obedient”; “she’s sendable and does not become sick”; “does not touch food until served.” There were, also, many touching answers: “when the children are happy playing they make the home lively”; “when the child is satisfied she is playful and smiles a lot”; “child is talkative”; “the child loves her”; “he keeps her company.”
- Lack of immunisations is a concern. Many caregivers say that they have lost the child’s health card, or that when they took up the care of the child there was nobody to inquire about the health or immunisation status; in situations where fathers have left children with caregivers, they are not able to pass on information about health cards or immunisations because that is a woman’s affair in Kenya. Some orphans were brought from totally different places and caregivers don’t know where these children were attending clinic previously.
- Adequate food is not a problem in every household; in many, children under five were given something, if only tea with milk

or cold porridge, four or five times during a twenty-four hour period. Where food was not given, caregivers say that it is because there was truly nothing to eat: "Yesterday the caregiver slept hungry; the child ate at the neighbours." On too many data sheets, field staff had to write: "It is difficult to advise a family on the need to have a balanced diet when they have no food."

- The most common problems related to feeding were lack of protein in twenty-four hour recalls, stomach aches after meals, diarrhoea, dirty utensils, complete lack of adult assistance with eating, and scrambling for food with older children.
- Of the approximately thirty young orphans in households visited, some never knew their parents or had been separated from them for many years, and most had been living in their current households for at least a year. No obvious psychosocial issues were observed. Some were shy, withdrawn, afraid of anything new, clingy; others were aggressive, had problems sharing, were uncooperative during play with others. Only two children impressed home visitors as unusually withdrawn or aggressive. Their fears were not uncommon for under fives: dogs, cats, darkness, caterpillars. Only one fear was related to the orphaning experience by a caregiver: one child feared

crowds and the caregiver believed the child remembered the crowd at her mother's funeral.

- Children who have been recently orphaned and are old enough to ask about their parents are not being told their parents are dead, but rather that they have gone away and will return. Caregivers may feel constrained by the general taboo about discussing death, but it is difficult for some of the children who may not understand the reason for their parents absence.

Throughout their visits, project staff have been offering caregivers ideas for enhancing their care-taking skills, including adding food resources, accessing health services, selecting low-cost protein and vitamin-rich foods, increasing hygiene in selected areas, and trying alternative methods of discipline. Some ideas have been received with pleasure and implemented. These experiences will be culled for use in volunteer training programmes.

### **The future**

In the coming months, the Ready to Learn project team will analyse the full results and refine a set of tools for use in home visiting by local community health workers trained in home-based patient care. After meetings with community health workers to learn of their own experiences and constraints, a training will be offered in the use of the tools for home visits to improve the care of young orphans.



## Early Childhood Education and Care and the AIDS Epidemic in Brazil

ALESSANDRA SCHNEIDER AND CRISTINA RAPOSO



Belo Horizonte, Brazil: Puelitio/Diane Alexopoulos

*Democracy?  
It means offering  
everyone the same  
starting point...*

—MÁRIO QUINTANA

Over the last decade science has illustrated how the experiences of a child's first few years impact the rest of his/her life. These first years are characterised by fast physical and mental development: the human brain grows four-times in volume and the connections among its brain cells multiply by six. Huge changes take place within the architecture of the brain in response to environmental stimulus during this period, and the processes that solidify the basis for cognitive and emotional capacities are developed. After the first ten years of life, brain flexibility is reduced and it is more difficult to promote adequate integral development. Thus, the first years of life are both extraordinary and critical.

Children's early development is a combination of physical, mental, and social growth; therefore, it is important to consider not only what happens to the child, but also how the child relates to the world, and how the world relates to the child. How the child is cared for, how its basic needs, such as food, health, security, stimulation, and learning are responded to are critical to the child's development. A family's access to services and support in caring for young children can significantly impact the child's development and overall quality of life, especially for those children who are considered at risk.

In Brazil, providing children with the proper care during these first crucial years, especially those children whose lives have been touched by AIDS, is a challenge. Brazil is a country with huge geographic dimensions and visible social inequalities, and only a small fraction of children and their

families have access to services such as education and early childhood development programmes, be they formal (institutional) or community-centered. When no public or community programmes exist to compensate for these pre-existing inequalities, children from poor communities tend to be doubly disadvantaged, and they experience greater difficulties in learning and socialisation. Such stigmas follow them into their adult years, thereby perpetuating the cycle of poverty in their families. In Brazil, another segment of the infant population continues to be marginalised due to poverty, and these infants suffer from the difficulties inherent to the environment, such as a lack of adequate stimulus, and which besides being materially poor, may also be stressful and aggressive.

HIV negatively impacts a child's development, in much the same way that development is affected by poverty. Similarly, the HIV epidemic can hamper a country's attempts to prioritise human development. AIDS is the most cruel inequality index in the world, as UNICEF's *Report on the Situation of Children in the World 2002* points out. Poverty, malnutrition, lack of water, and dearth of knowledge have grown in face of this pandemic. Neither words nor statistics are capable of capturing to the full extent the situation that orphaned, poor, and socially stigmatised children face every day.

Brazil's experience in the struggle against AIDS has been praised as a success story by many international organisations. Over the past twenty years, the Brazilian national response to HIV/AIDS has brought together a highly diverse

group of national and international bodies in a joint effort to contain and reverse the spread of the epidemic. The United Nations predicted that by the year 2000 Brazil would have 1,200,000 infected people. However, the control of the epidemic in the country over the last twenty years has exceeded all expectations, and Brazil has begun the 21st century with a total of approximately 597,000 HIV-infected people. This means around 600,000 new infections have been avoided.

The Brazilian national response against AIDS is being led by the Ministry of Health. Its National STD/AIDS Programme Office (NAP) is responsible for assembling, financing, and disseminating information about best practices, civil society projects, evaluating programmes, and developing a broad strategy of partnerships in order to strengthen the impact of federal government policy initiatives. The main goals of Brazilian public policies in the area of promotion and prevention of HIV/AIDS are the improvement in the quality of life of people affected by the epidemic, citizens' rights, participation in programmes, and social control.

The first recorded AIDS case in the country was in 1982. There have been 215,805 registered cases in Brazil from 1980 to March 2001. The ratio between HIV-infected men and women dropped from 9:1 in 1987 to 3:1 in 1996. HIV has infected mainly low income women of reproductive age,

with children and/or with plans for future pregnancies. In addition to the feminisation of the illness, the pauperization of the illness has been a concern for governmental and non-governmental institutions alike.

When we speak of children with AIDS in Brazil, we refer to 7,335 Brazilians that acquired the HIV virus when they were less than thirteen. According to the AIDS Epidemiological Bulletin of the Ministry of Health (2001), 5,924 children (or approximately 80%) acquired the illness when they were born. It is known that 2,909 have already died, representing forty percent of the total of infected children between 1983 to 2000. Perhaps even more alarming is the fact that almost thirty thousand boys and girls younger than fifteen became AIDS orphans between 1987 to 1999.

As a result of the increasing number of infections among the female population, prevention of mother-to-child transmission of the disease has been made a top priority in Brazil. The Ministry of Health and its partners are now paying close attention to this particular population. The main instrument that is currently being used to reduce the impact of the epidemic among women is the incorporation of STD/HIV/AIDS prevention (especially vertical transmission) activities into basic health care for women, with special emphasis placed on HIV testing at prenatal sessions, as well as during delivery and post-delivery. Women today can count on specific interventions and have guaranteed access to appropriate therapies along with improved access to prevention information.

The national campaign to foster HIV testing and to promote access to antiretroviral drugs for HIV-positive women and their recently born babies has proved to be particularly effective. Through a prenatal programme, it has been possible to encourage pregnant women to seek medical care before the fourth month of their pregnancy along with visits to the testing services. Another goal is to reduce the incidence of vertical transmission by means of interventions carried out during the period of pre-natal care, during labor and delivery, and during the first weeks of the baby's life.

It was noted that sixty-five percent of vertical transmission cases occur during labor and delivery. The remaining thirty-five percent of the infections occur in the womb during the last weeks of pregnancy. According to the recommendation text of the Ministry of Health on maternal-infant transmission prophylaxis of HIV/2001, breast-feeding carries an additional risk of HIV transmission of seven to twenty-two percent. Currently, thanks to



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the anti-retroviral therapies, more than sixty percent of children whose mothers have AIDS are not HIV-positive (in the year 2000, 5,129 pregnant Brazilian women infected with HIV received injected zidovudine during delivery to reduce risk of transmission). This percentage increases with early treatment, starting in the fourteenth week of pregnancy, and when the delivery is made through previously scheduled surgery. In these cases, HIV-transmission rate from mother to child may be less than eight percent.

In Brazil, the number of newborns infected with HIV dropped from 843 in 1997 to 263 in 2000, according to the 2001 *Epidemiological Bulletin of AIDS*. This is an important and encouraging reduction in AIDS control in the country. However, both the children born with the infection and those without are impacted by the disease in various ways: by the probability that they will become orphans; by social prejudice regarding HIV/AIDS. If we add to this the fact that infection rates are higher in poor areas and among women, we can see that even by reducing the number of infected people, we will still find a proportionately higher rate of directly or indirectly infected children, making them twice as vulnerable.

### **The Necessity for an Early Differentiated Intervention**

The AIDS epidemic presents challenges that are as important to overcome as the discovery of its medical cure. Due to the complexity of the disease, a

multidisciplinary approach in programming is fundamental for achieving effective results. As noted by the Interdisciplinary Brazilian Association on AIDS (ABIA), "it is necessary to focus not only on AIDS, but also on a wider social context in which AIDS is inserted and in more comprehensive responses that create an atmosphere for behavioral change for risk reduction."

Unfortunately, stigmatisation toward those directly or indirectly affected by AIDS is present in most countries, taking place in schools or health services. Although researchers show that the population is aware of HIV-transmission methods, social prejudice often directly interferes with the way affected people seek out and follow their treatment. In this regard, the adoption of intervention approaches is indispensable, with a more holistic view of the affected population, particularly children. It is necessary to see them as integral beings, and not only as people with specific needs, in this case needs already stigmatised by AIDS.

The institutionalisation of orphans has been a commonly employed strategy for the care of this population, causing, on many occasions, the loss of family and community. Institutionalisation can have a mitigating effect: as children are segregated from and lose their family and cultural identity, they may feel more vulnerable and discriminated against, and subsequently face future difficulties with social integration. Some solutions to more compassionately caring for orphans would be through the use of community support networks, through widening the debate on the necessary

attention that should be given to HIV-positive children, and through guaranteeing their effective participation in the community and thus helping to diminish the discrimination against HIV-positive/infected people.

Poverty and the lack of information contribute to the increase in new AIDS cases. It is important that intervention programmes consider components such as the generation of labor and income opportunities, in partnership with those that promote an improvement in nutrition, living conditions, and school and preschool attendance. The efficiency of health programmes such as the Familiar Health Programme and Community Health Agents are and will continue to be instrumental in the prevention and treatment of the epidemic.

Additionally, preventive education should be seen as an integral part of an educational policy for all, with the possibility of being viewed as a mobilising resource for changes in attitude, knowledge and practices as stated by Mr. Koichiro Matsuura, UNESCO General Director: "the main cause for the dramatic dissemination of HIV and AIDS is the lack of knowledge. Since treatment does not completely cure and the treatment that can help is still very costly for the majority of the world population, prevention through education, followed by action, is the best remedy. Preventive education should be a part of the objective of Education for All. The loss for not implementing a preventive education will in fact mark the entire world for the rest of this century."

As stated by Dr. Robert Myers of the Consultative Group on Early Childhood Care and Development, "the battle for saving the lives of children should always be followed by an effort to make sense out of their existence." Therefore, this means to advance a new manner of viewing and stimulating the full development of children, starting in the context of their relationships and the understanding of their basic needs.

The United Nations General Assembly Special Session on HIV/AIDS held this past June in New York was a turning point for people living with HIV/AIDS. The Declaration of Commitment document recognises that the protection of human rights for people living with AIDS is an essential element to a global response to the epidemic.

Recognising the right to prevention, treatment, and care will make it possible to eradicate the damage that AIDS has caused among the child population, and will make hope possible for the future.

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Vietnam: UNICEF/HQ99-0916/Lemoyne

# Network Notes

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## Activities of the CG Secretariat



### **Education for All: Main Issues and Lessons Learned in Developing and Using ECCD Indicators**

As we described in the last issue of the *Coordinators' Notebook* (No. 25, 2001), indicators serve a wide range of purposes and are approached with different disciplinary or sectoral interests. The main purposes guiding CG efforts in the area of indicators have been to promote: 1) debate on and adoption of relevant ECD public policies; and 2) quality, effective programming for young children and families. To this end, we hope to ensure policymakers and programmers are informed and held publicly accountable. Achieving this implies the availability and effective use of systems for periodic data collection in order to monitor the condition of children as well as the various programmes underway intended to enhance children's well-being. In turn, the resulting analysis and information can aid further actions towards improving the status of children when governments lag in their efforts.

In our view, an "indicator" is more than a descriptive statistic and should be accompanied by some sort of standard or norm that allows a judgement to be made about how we are improving (even if that is simply to say that we should eliminate all disease or we should have 100% coverage). Child development is seen in an integral way—including physical, intellectual, social, and emotional development—and resulting from the interaction of a changing child interacting with changing environments (family, community, cultural and physical environments as well as those created to promote development, i.e., preschools).

Over the past twelve years, the Consultative Group consortium of regional ECD networks, donor agencies, and international NGOs and foundations has organised a series of activities related to the theme of ECCD indicators, such as a review of child development instruments and measures, a cluster of efforts to construct a child profile, and country studies aimed at defining and operationalising indicators at a national level in four countries. A key reason for undertaking the latter was dissatisfaction with the two ECCD indicators defined in and used as a part of the Year 2000 Assessment of Education for All. Both were quantitative indicators of access or enrolment; no indicators were included that measured child development and learning or that assessed the quality of programmes. In addition, countries used different definitions and age ranges in their reporting, making comparisons difficult.

Although we realise that the EFA assessment continued to help place ECCD on national and international agendas and demonstrated the potential value of ECCD indicators, we were led to ask how we might create better indicators for monitoring and help incorporate them into

standard reporting systems at both national and international levels. Accordingly, the Consultative Group carried out five country case studies (Nepal, Jamaica, Colombia, Namibia and the Philippines) whose main task was to describe the state of ECCD and to develop a process in each country that would lead to the identification, development, and, in some cases, piloting of agreed-upon, country-specific early childhood indicators. In the case of Colombia and Jamaica, the intention was also to give additional stimulus to the previous child profile work by drawing upon, where relevant, the results of this earlier effort.

The CG's various partners, members and friends continue to debate and work on ECCD indicators. Please see [www.ecdgroup.com/initiatives](http://www.ecdgroup.com/initiatives) for ongoing updates on our work in the area of ECCD indicators, including 1) *follow-up work* building on the initial case studies (i.e., in Jamaica, see detailed accounts of the implications of the indicators work for policy and an overall analysis of the experience) and 2) *new efforts* to bring together those working in this area of indicators, including developing a core set of indicators that can be used internationally for advocacy purposes in addition to national indicators developed in-country.

The Consultative Group on Early Childhood Care and Development (CGECCD) remains interested in knowing more about and promoting debate on the level, nature, and impact of ECCD programmes on children and their families, and the ability of policymakers to adequately assess the situation of young children (their well-being, level of risk, readiness to learn etc.). In particular, the CG continues to encourage coordination and communication among its different members and participating ECD networks, as well as others involved in this area of work. Preliminary email discussions and exchanges have begun with twenty or so individuals and are expected to continue; joint meetings are also to be planned as a way to coordinate the growing number of initiatives now underway or in the planning stages on developing ECCD indicators. To this end, the CGECCD is very keen to hear from others involved in similar work with a view to compiling an accessible information system around indicators related to the physical and psychosocial development of young children; we are also interested to receive information on the instruments created for these purposes. For more information, please contact the Consultative Group through its international Secretariat at [info@ecdgroup.com](mailto:info@ecdgroup.com).

### **EFA Flagship Initiative for Early Childhood Development**

As the lead organisation for the EFA Flagship Initiative for Early Childhood Development, our main goals are to 1) highlight attention to the importance of Integrated Early Childhood Care and Development, 2) to monitor the progress since Dakar of the first goal, "To expand and improve comprehensive early childhood care and education, especially for the most vulnerable and disadvantaged children" and 3) to demonstrate the positive linkage between ECD and broader EFA goals, for example, in preparing children for school, increasing achievement and retention in primary school, and as a way of improving girls' education.

Our three main objectives this year include:

**1. Collecting case studies of countries who have developed ECD strategies as part of their national EFA plans** especially for children under three who are invisible in many EFA plans at country level. For example, three case studies soon to be submitted look at:

- Jordan's national strategy on Early Childhood Development—their experiences and achievements

## **Activities of the CG Secretariat**

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- Pakistan and the work of an emerging ECD Working Group in Pakistan who are providing input and policy recommendations to the ECE section of the draft National Plan of Action for Pakistan
- Tanzania and the work of an ECD Advocacy and Networking Group that among other activities produces an ECD/EFA newsletter and is currently preparing to ensure that ECD is seen as a priority at the MINEDAF VIII—Eighth Conference for Ministers of Education of African Member States in December 2002

**2. Compiling and analysing research studies that demonstrate the positive impact of ECD on broader EFA goals**, i.e., school readiness, retention, and achievement in primary grades, especially for girls, i.e., ongoing impact assessment studies (both quantitative and qualitative) in Nepal which demonstrate the positive impact of ECD on achievement and retention in the lower primary grades as well as other studies in the Caribbean, Colombia, Cuba, Laos, Turkey, South Africa, Guatemala, India, Jordan etc.

**3. Coordinating, communicating and disseminating further work of the Consultative Group and others on improving existing and developing better ECCD Indicators** (see [www.ecdgroup.com/indicators](http://www.ecdgroup.com/indicators) for more information). This is being done in collaboration with the UNESCO Institute of Statistics and others.

Progress on these three objectives will be disseminated widely, including through the development and ongoing updating of the ECD Flagship Website, which the Consultative Group is responsible for developing and updating. The main objective of the site is to bring users up to date on goals/information related to ECD in the Dakar framework, the purpose of the flagship initiative, to provide updated information on those countries including ECD into their national plans (what are they talking about) and which countries are already underway with their plans, and to provide resources and contacts for those who have not yet included ECD in their national plans.

It is hoped that the Website could also provide information to help those working on their EFA Plans (or not as the case may be) to move beyond what the two EFA indicators are including and link to the CG Website on developing and using ECD Indicators.

For more information and to *send in material related to progress and updates* on ECD/EFA, please contact the Consultative Group through its international Secretariat at [info@ecdgroup.com](mailto:info@ecdgroup.com).

### United Nations General Assembly Special Session on Children

As reported in *Coordinators' Notebook 25* (2001), the United Nations General Assembly Special Session on Children, held in New York, May 8–11, 2002, was an unprecedented meeting of the UN General Assembly to review the progress made for children in the decade since the 1990 World Summit for Children and the Declaration and Plan of Action. Three Substantive Sessions of the Preparatory Committee were held prior to the special session, with a draft outcome document, "A World Fit for Children," presented by the UNGASS Bureau at the second preparatory meeting. The final document presented at the Special Session in May 2002 can be found at [www.unicef/special-session/documentation](http://www.unicef/special-session/documentation).

CG advocacy efforts at the both the preparatory meetings and Special Session included presenting a statement at the UN General Assembly on the importance of ECCD, developing an ECCD



advocacy package for delegates attending the Special Session, organising side events on the impact of early childhood experiences on the brain, stressing the importance of early childhood care and its role in the development of national action plans, and working on the development and use of ECCD Indicators (at a global and especially at a national level), as well as working through the Child Rights Caucus (CRC) to lobby for the inclusion of stronger ECCD language in the alternative NGO outcome document. This alternative document prepared by the CRC, outlined more specific goals, actions, and issues not addressed in the draft outcome document.

The CG lobbied to have ECCD stated as a goal in the outcome document and that reference should be made to programme activities that were not solely health-related goals. Specifically the CG recommended the following:

- improved access to quality early child and family programmes aimed at promoting the physical, emotional, social, cognitive, and spiritual development of children aged birth to six years, particularly for the disadvantaged and those with special needs
- a focus on the improvement in the development of children measured at ages three and five according to national standards
- assurance that all young people, parents, and caregivers have acquired the knowledge deemed appropriate to support the care and education of children in the earliest years. In addition, by 2010, all countries would have developed, implemented, and monitored national comprehensive ECD policies including nationally defined goals and indicators related to child survival, growth, and development

The final text of the outcome document related to ECD eventually did have one non-health target (located in the Education section) as compared to earlier versions of the document. Although at the time this was seen as an achievement, in reality we merely regained what was originally in the World Summit Document.

ECD was included in two of the outcome document's four major goals:

### 1. Promoting Healthy Lives

Article 36. (e) Development and implementation of national early childhood development policies and programmes to ensure the

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Honduras: PAHO/1-086/Armando Waak

## Activities of the CG Secretariat

enhancement of children's physical, social, emotional, spiritual, and cognitive development;

Strategy (10) Strengthen early childhood development by providing appropriate services and support to parents, including parents with disabilities, families, legal guardians and caregivers, especially during pregnancy, birth, infancy and early childhood, so as to ensure children's physical, psychological, social, spiritual and cognitive development.

### 2. Providing Quality Education

Article 39 (a) Expand and improve comprehensive early childhood care and education, for girls and boys, especially for the most vulnerable and disadvantaged children;

Strategy (8) Strengthen early childhood care and education by providing services, developing and supporting programmes directed to families, legal guardians, caregivers, and communities.

Although the above articles represent some progress for ECD, those of us working and advocating for young children believe there remain significant and un-addressed challenges in the document:

- The above goals are without reference to nationally defined goals and indicators.

Although we wanted an outcome on children—not on policies and programmes—we were met with the argument that developmental outcomes for children (or disabilities and delays) are not measurable (compared to mortality and malnutrition). This gives us a further challenge to continue to do further work on developing global, and especially, national, indicators and to keep at the forefront the fact that increased investment in early childhood development requires increased evidence of outcomes.

- There continues to be a lack of recognition that learning begins at birth, articulated in both the Jomtien and Dakar Education For All Declarations.

This is evidenced by the fact that basic education is defined as primary schooling. There is also a lack of specific reference to ECD in the ten principles of the Global Movement for Children, despite announcing to the world in the State of the World's Children how important ECD is. We strongly believe that much more could be stated to recognise and build upon families' achievements in supporting their children's overall development and learning, most of which occurs in and around a child's home and community during the earliest years.

- The Convention on Child Rights (CRC) is seen as *a* framework, not *the* framework for meeting the needs of children, families, and communities.

Despite ratification of the CRC by most countries of the world, child development has not yet become a natural and important part of the national development plans and monitoring the developmental progress of nations. In the absence of a more holistic human development/social justice framework, agencies often over-emphasise the physical status of children because, by its very nature, progress in the areas of children's psychosocial development is more complex to assess, whereas weight or completion of immunisation schedules are easier to measure.

The rights to affection, interaction, security, stimulation, and opportunities for learning have been accepted and recognised as being as fundamental as the basic needs for food, healthcare, and protection—and not just as needs but rights, (implying duties and obligations). Children's rights are about the obligations of all adults to protect the best interests of children, and to create

the conditions under which they can develop and thrive. For more information, see *Early Childhood Matters* No. 98, 2001 at [www.bernardvanleer.nl](http://www.bernardvanleer.nl).

**Follow-up and proposed further action:**

1. See following list of useful links:

- For a report on NGO activities during the Special Session, see: [www.ngosatunicef.org/docs/SSC\\_final\\_report.doc](http://www.ngosatunicef.org/docs/SSC_final_report.doc)
- To view a list of concrete commitments made by governments, UN Agencies, NGOs and other official participants, see: [www.ngosatunicef.org/Commitments/index.html](http://www.ngosatunicef.org/Commitments/index.html)
- For a summary and analysis of the Country Statements prepared by Canadian Senator Landon Pearson's office (including national priorities, achievements, and unresolved challenges) presented at the Special Session visit: [www.sen.parl.gc.ca/lpearson/htmlfiles/hill/17\\_htm\\_files/Committee-e/1-Country%20statements.pdf](http://www.sen.parl.gc.ca/lpearson/htmlfiles/hill/17_htm_files/Committee-e/1-Country%20statements.pdf) or [www.crin.org/resources/infoDetail.asp?ID=2919&flag=report](http://www.crin.org/resources/infoDetail.asp?ID=2919&flag=report)

2. We are currently reviewing the summary and analysis of country statements prepared by Canadian Senator Landon's office and the list of concrete commitments made by governments, UN Agencies, NGOs, and other official participants. This may also include further work to: determine how many countries referred to ECD; track whether and how ECD will be included in National Plans (similar to what we are doing for EFA); and to see how we can use the information to highlight those countries that are moving ahead and provide resources/contacts/case studies for those countries where ECCD not a significant priority. As a possible link for the next CN issue on Advocacy, we might also conduct an overall analysis on the various early versions and later final version of the Outcome Document (which was considerably watered down on the ECD front). This analysis may help highlight concerns and ways to move forward in ensuring ECD is more prominent and better understood.

3. *Work of the Child Rights Caucus*. Please email: [childrightscaucus-subscribe@domeus.co.uk](mailto:childrightscaucus-subscribe@domeus.co.uk) for a copy of the final alternative text and position statement. In addition, a series of resources are available to assist NGOs in following up on to the Special Session, including guidelines for NGOs on developing National Plans of Action. The briefing provides practical advice on how you can:

- find out about your government's previous plans of action
- build networks with other NGOs
- approach your government to get involved in preparation of its NPA
- involve children and young people
- ensure that the follow-up process is integrated into, and does not in any way undermine, national implementation of the CRC
- ensure that National Plans of Action (NPAs) and/or other planning processes use the Convention as their framework and are rights-based, and that monitoring and follow-up are integrated as far as possible with the reporting process under the CRC

As is evidenced by the final outcome document, there remains much to be done in terms of advocating for the needs and rights of young children. This remains a key ongoing priority of the Consultative Group. The next issue of the *Coordinators' Notebook* (due out in late Spring 2003) will explore ECCD advocacy at local, national, regional, and international levels, and will include case studies and describe tools for advocacy.

## Activities of the CG Secretariat

# News from the International Secretariat

## Caribbean

The Child Focus Project II, initiated in October 2001 and funded by the Inter-American Development Bank (IADB), is providing technical assistance to IADB member countries to strengthen early childhood development and bridge the gaps in communication and coordination among associations within the region. Major activities of the project include drafting and sharing child-centred legislation; developing a fiscal planning model for the ECD sector based on standards; developing a social marketing process to educate parents and inform the general public to be delivered through ECD associations; identifying expected learning outcomes for children ages 0–8, including best practices curricula and methodologies; developing a web-based Master's degree program in ECD Development Leadership; and strengthening regional and local associations for ECD.

Through the Child Focus Project II, the newly designed and improved Caribbean Early Childhood Website, [www.caribecd.org.jm](http://www.caribecd.org.jm), was launched earlier this year. The site provides information on and links to resources dedicated to child development, parenting, and family issues, as well as professional staff development in the Caribbean from a Caribbean perspective. It also serves as a major communication link for national early childhood associations and their membership throughout English speaking Caribbean and seeks to capture and share research, experience, and regional intervention in the early childhood sector. Visit the site for outcomes of the 4th ECD Conference, including an update on implementation of the Caribbean Plan of Action.

For more information on the Child Focus Project II, contact:

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## Latin America: The Consultative Group on ECCD-LA

The principle activities of the CG-LA in the past year included:

- The third encounter of the Network of ECCD Networks in Latin America held in Cartagena, Colombia (November 2001) focused on leadership and capacity building. An interdisciplinary and intersectoral group of fifty-five professionals from eighteen countries belonging to more than forty-seven organisations and institutions participated. The health sector was broadly represented, and it was the first time in which a research network (Childwatch) and a representative of mass media (*El Tiempo*, a Colombian newspaper) attended. Many of the activities of the CG-LA in 2002 have also been part of the action plan for the region which includes:
  - active ECCD advocacy as a critical part of the national development plans
  - active information exchange between different stakeholders
  - promotion of innovative training models of human resources at different levels to develop strong leadership in ECCD across the region
  - work with parents and families
- The work of the newly named ECCD network in Colombia, *Grupo de Desarrollo Infantil* contributed to a major advocacy process—The Colombian Alliance for Public Policy on Children and Youth—which includes activities to promote ECCD in the country and to advocate for the new government of Colombia to recognise ECCD as a priority. CINDE prepared the framework document of the alliance.
- Support by the CG-LA to Paraguay in the development of a national ECCD plan as well as other country networks.
- CG-LA ECCD advocacy work with other networks including *Pronunciamiento Latinoamericano*, a civil society network created to promote coherence in the EFA plans; the Latin American Child Rights Caucus working with the Caucus at the UN Special Session, including follow-up on action plans.
- Initiatives looking at violence in early childhood and adolescence (Brazil, Venezuela, Colombia) and child welfare indicators (CG-LA is participating as part of the regional team).
- Organisation of a regional meeting on families, indicators (UNESCO regional office), translating the *Coordinators' Notebook* on Indicators into Spanish (UNICEF), as well as support from Save UK, PLAN International, OEI, and the Pan American Health Organization.

Plans for 2002–2003 include strengthening the Network of Networks, further work on the Website, participating in the study of the impact of crisis, adjustment, and reform on children, women, and families (case studies in Argentina, Ecuador, Colombia, Venezuela, and/or Chile), and, in collaboration with the Organization of American States, to organise the First Hemispherical Interagency on Higher Education related to ECD.

For information contact:

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## News from the International Secretariat

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### Central Asia: MOCEF

#### “Will you play with me?”: MOCEF’S New Television Project

The Mother Child Education Foundation in Turkey has been working in the field of adult and early childhood education since its establishment in 1993. Its mission is to empower people by means of education and enable them to improve the quality of their lives. By providing free education services to children and adults of low socio-economic background, MOCEF’s programs target the most needy populations and communities. All of MOCEF’s programs are based on scientific premises and developed in partnership with academics from reputable universities. Over 150,000 participants have benefited from MOCEF programs and over 2,000 teachers and volunteers have been trained. In addition, through its research and publications MOCEF is actively involved in advocacy efforts to develop policies in the areas of early childhood and adult education.

MOCEF’s first and most widely implemented program, the *Mother Child Education Program*, aims to empower mothers of pre-school aged children by supporting them in their parenting roles while also equipping them with the knowledge and tools to necessary to help foster the

cognitive development of their children. Another one of MOCEF’s important programs is the *Father Support Program* which aims to encourage and support fathers to take a more positive and active role in their child’s development. MOCEF works in collaboration with government organisations, multilateral organizations and national and international NGOs in order to create sustainable training models and deliver its programs across Turkey, Europe, and most recently Bahrain.

In 2001, in an attempt to significantly multiply the number of beneficiaries reached and diversify its models of implementation, MOCEF has developed a television program based on its Mother Child Education Program and Father Support Program. Working in collaboration with the public broadcasting service TRT (Turkish Radio Television), MOCEF developed “Will you play with me?” (“Benimle Oynar mısın?” in Turkish), an innovative sixty-five part television series targeting both pre-school aged children and their parents. This move to include parents in the target audience is actually



Colombia: P/MH0/2-009/Armando Waak

what "sets this television program apart from other children's programs" argues Prof. Bekman, academic consultant to MOCEF. As such, this program was developed not only in order to reach a larger group of people, but was also developed as an alternative to existing children's programs.

The program's academic content, structure, and specific aims were carefully designed by a team of academicians and practitioners from MOCEF. The entire program, from conception to broadcast, took over a year of collaborative team work. MOCEF's team of consultants worked very closely with the writing team, as well as TRT's production team throughout the entire process. The end result is a program which is educational yet entertaining, full of important messages and yet fun to watch.

In general, the program aims not only to support the cognitive, physical, social, and emotional development of pre-schoolers, but also to support parents in their parenting roles by providing them with information on child rearing, child development and positive parenting attitudes. In order to reach these general objectives, over 300 specific objectives were formulated based primarily on the content of The Mother Child Education Program and The Father Support Program and also on the input of academicians from related fields, pediatricians, and other educators.

The content is delivered in several forms: studio drama, puppetry, animation, live action and film footage of various topics. All 65 segments of the program are comprised of 30 minutes of unrelated short sequences in which various messages are delivered through these various forms. Approximately 50% of the program is aimed at fostering the cognitive development of the child, 20% at social and emotional development, 18% at child rearing attitudes and approximately 2% aims to promote environmental awareness. The cognitive development component of the program specifically aims to improve eye hand coordination, pre-numeracy and pre-literacy skills, concept recognition and while also focussing on the importance of reading books and play.

After months of research, collaboration, and actual realisation of the various components, "Will you play with me?" began airing in February of this year. Due to widespread interest from the media and viewers, MOCEF and TRT have started working on a second sixty-five segments. "Will you play with me," because of its colorful characters, high quality 3-D animations, catchy songs and most of all, because it has filled an important void in the area preschooler and parent education, has been very well received by both the target audience and experts in these field. Both MOCEF's and TRT's ultimate aim is to make a sustainable and widespread contribution to preschool and parent education via this program. The medium has opened a new door for MOCEF and allowed its expertise to reach mothers, fathers, and children in much need of education and support.

For information contact:

Central Asia

Mother Child Education Foundation

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Fax: 90-212-234-0106

Email: [acevist@turk.net](mailto:acevist@turk.net)

Website: [www.acev.org](http://www.acev.org)

## News from the International Secretariat

# Other Regional Initiatives

## Young Children Affected and Infected with HIV-AIDS in Sub-Saharan Africa

### Another tragedy!

In the state of The World's Children 2001 published late last year by UNICEF, we can read about the effects of HIV/AIDS on children. The following excerpt from the Report on the global HIV/AIDS epidemic, June 2000, UNAIDS, Geneva, appears on page 39:

"The firestorm rages most ferociously in sub-Saharan Africa, the home of 10 per cent of the world's population, 70 per cent of the world's HIV-infected people, 80 per cent of AIDS death and 90 per cent of AIDS orphans."

UNICEF's report goes on to state that "...with 5.4 million new HIV infections in the world in 1999 alone, the worst is yet to come."

### Looking for a response

In response to this situation, several members of the Early Childhood Development Network in Africa (ECDNA) who attended the 10th Conference on Quality in Early Childhood Education in London last year met with Professor Helen Penn, one of the Conference sponsors, and shared their views on the impact of HIV-AIDS on the young child. We all agreed that it would be most important to take a closer look at how the HIV-pandemic is actually impacting on the development and education of young children in sub-Saharan Africa. We also need to take into consideration the "firestorm" reported by UNICEF, and see what more we should do to soften its impact on the young child population, the most vulnerable victims of the pandemic, with a special focus on young orphans and vulnerable children (YOVC's).

### An Initiative

An Initiative is being launched by members of the ECDNA to review strategies and programmes being implemented in sub-Saharan Africa for pre-schoolers in the context of the HIV/AIDS epidemic. The aims are:

- To provide a forum for action research in sub-Saharan Africa about young children affected by HIV-AIDS by understanding action-research on key issues and interventions and developing methods for investigating key issues and evaluating interventions.
- To disseminate the information gained by liaising closely with other agencies in the field to share and exchange information, and by providing a systematic research base which uses local work as well as international information and developing a website to disseminate research.
- To build the capacity of ECDNA as an organisation as a resource for early childhood in sub-Saharan Africa.

### Actions to be implemented

This Initiative will spread over a period of eighteen to twenty-four months and will cover the following aspects:

- Liaison with relevant agencies already involved with young children and HIV/AIDS;
- Literature review that focuses on policies and programmes supporting young children affected by HIV/AIDS;
- Systematic dissemination of information gathered;



- Research of the best strategies being implemented in several countries in Asia, Europe, and the Americas, and contrasting these with those being developed in countries in sub-Saharan Africa;
- Action Research Projects, which will be carried out in five countries in sub-Saharan Africa;
- Overview and dissemination of information at local, national, and regional levels with the support of a core team within the ECDNA.

#### **Countries to be involved initially**

The Action Research program will be initiated in the following countries and should last for a year:

**Kenya:** building on existing projects; mothers' views on the transmission of HIV/AIDS from mother to child will be investigated further. The outcomes of different kinds of interventions on children will be evaluated, and the monitoring and evaluation processes updated in the light of the findings.

**Namibia:** the impact of HIV on teacher deployment in standard one and two of the school system will be investigated and its impact on children's learning evaluated.

**South Africa:** the concept of a Safety Net for young children affected by HIV/AIDS, how the Safety Net works, and for whom, will be looked at in the light of several attempts already undertaken in deep rural, semi-rural, and township in RSA.

**Swaziland:** information and dissemination strategies in local communities will be looked at. What local communities really want will help redirect a media campaign within Swaziland.

**Uganda:** models of community interventions, especially psychosocial interventions, for young children affected by the pandemic in both rural and urban areas will be compared, their coordination studied, and the evaluation shared with a range of agencies for children affected by HIV/AIDS in both rural and urban areas with a view to improving their on-going practices.

Information generated and gathered from this Initiative will be shared at several forums being organised over the next few months. Other interested countries will be invited to join the Initiative. The information and data gathered will be entered on a Website for wider distribution.

– J. Cyril Dalais, Convener  
*jacdalais@intnet.ma*

**For further information on all regional network activities and profiles, please visit our expanded regional network section on the CG website: [www.ecdgroup.com](http://www.ecdgroup.com)**

## Other Regional Initiatives

# Activities of the Partners

## Early Childhood Development (ECD): An Overview of the Aga Khan Foundation's Investment

The Foundation has developed approaches that support children's growth and holistic development, thereby building their capacity to learn throughout life, in South Asia and East Africa, as well as Portugal, the UK, and the USA, since the mid-1980s. It has expanded its area of operations over the last decade leading to work in Tajikistan and, most recently, in Mozambique. Initial discussions are now underway to expand programmes to Syria and Afghanistan.

Support to and work with young children, caregivers, and their families occurs through the Foundation's *Young Children and the Family Programme* (YCF), which falls within its broader Education Programme. The main aim of this investment has been to increase access to, and the quality of, formal and non-formal early childhood care and development programmes, especially for girls and other disadvantaged groups. Through its *Health Programme*, efforts that improve the health and nutritional status of children and mothers contribute significantly to and are increasingly an interlocking piece of the Foundation's work in ECD.

Across programmes AKF has sought to explore interventions that would be, at the same time, appropriate to the cultural context of the family and community and affordable to poor communities, yet also use the most up-to-date knowledge on early childhood development. The focus therefore has been on the development of locally relevant curricula, experimentation with different types of training for caregivers or preschool teachers, and identification of successful and sustainable ways of community mobilisation and involvement. The Foundation has increasingly supported action-oriented research linked to projects, in order to assess the feasibility, cost-effectiveness, efficacy, and impact of different approaches.

A cornerstone of the Foundation's YCF programme has been to address the need for *wider institutional infrastructures to support ECD initiatives*: Local leadership and institutions that serve to catalyse and nurture efforts to support young children and their families are essential for achieving quality programmes. The Foundation has promoted the establishment of local Resource Centres (governmental or non-governmental), which operate at small, medium, or larger scales and, over time, can evolve into independent, sustainable institutions that meet the needs of young children and their families through community-led interventions. This includes a strong focus on developing human resource capacity and leadership skills, especially of girls and women, as well as the testing of different types of partnerships and alliances between communities, civil society organisations, the private sector, and government.

Below is an overview of programmes and initiatives currently supported by the Foundation starting with new initiatives, many of which build on previous programme experiences.

## The Human Development Programme of the Aga Khan University

The *Aga Khan University* and *Aga Khan Development Network* partners are now developing the *Human Development Programme (HDP)*. HDP's main components related to ECD services, research, education, and communication will be integrated, both inter-dependently and multidisciplinary. The years 2002–04 are the main planning, development, and preparation phases, with the programme coming on-board for implementation from 2004 onwards. The HDP will have four core areas of work: First, it hopes to act as a catalyst and facilitator of the development of sustainable community-based ECD models that combine health, nutrition, nurturing, and early education activities, and to monitor their processes and outcomes. This will be done through work with a range of NGOs and other service providers. Second, research related to integrated ECD will be designed to support and document community-based education and communication components. Longitudinal studies addressing the consequences of early caring practices for development throughout the life cycle will be undertaken; new mapping and charting tools will be used to document changes in maternal and child status over time and space; and the findings of research disseminated widely for different audiences. Third, the HDP education component will include modular, problem-focused areas of knowledge for a variety of educational and advocacy purposes, and for accredited ECD qualifications, including distance education approaches. And, fourth, HDP hopes to organise regular communication and advocacy related activities to improve broader understanding around the importance of ECD at all levels in Pakistan (and the region).

### Mozambique

AKF is currently developing health, education, and ECD interventions that will be integrated into a rural development programme in Cabo Delgado Province. The aim will be to support communities to organise themselves around expanding opportunities for their economic and social development, while at the same time encouraging relevant social service providers from local and provincial government to reach out and expand their work into the communities. ECD efforts are likely to include, for example, parenting programmes within local health centres during immunization campaigns or growth monitoring and awareness

## Activities of the Partners



Pakistan: Aga Khan Foundation/1518-030/Jean-Luc Ray

## Activities of the Partners

raising around HIV/AIDS in the community and childcare provision during female literacy classes.

### East Africa

AKF is supporting two major initiatives in the region: first, the Madrasa Resource Centres in Uganda, Kenya and Zanzibar and, second, it is involved, with the Bernard van Leer Foundation, in the Government of Kenya's ECD project financed by the World Bank.

The Madrasa Programme started in East Africa in the mid-1980s in Kenya and spread to Uganda and Zanzibar in the early 1990s. It seeks to provide access to high quality, culturally relevant, and affordable early childhood education and development in order to increase the chances of children from deprived communities to access to and success in later education. Over the last five years, the Madrasa Resource Centres enabled over 180 poor communities in the three countries to establish and manage their own preschools. Over 9,000 young children benefited and over 900 young women were trained as teachers, enhancing their status and confidence within the communities. The general organisational capacity and confidence of communities to manage their preschools and other affairs was considerably strengthened through the training of hundreds of community members in financial and organisational skills. The programme is actively involved in key ECD networks and government working groups in the region as well as in carrying out regional research on the impact and effectiveness of the Madrasa community preschool approach.

While the Madrasa Programme has worked through organising communities around preschool education, the AKF sub-programme within the Government of Kenya/World Bank ECD project is focusing on families and communities setting up ECD village committees in communities that oversee and monitor different ECD services operating within their area. These include the piloting of home-based and centre-based day-care services, parent education around HIV/AIDS awareness and prevention, and the enabling of local health mobile clinics to visit the villages, etc. Some 900 children benefit directly from these community ECD services.

### South Asia

Early Childhood programming is an expanding area for the Aga Khan Foundation's work in Pakistan with efforts based in and around Karachi, Sindh, Balochistan, Northern Areas, and Chitral. The different programmes focus on improving pre-primary and primary education, mothers' and other female education levels and parenting skills, and developing local institutional capacity. For example, AKF has supported the Teacher's Resource Centre pioneering work in early childhood education in the country which recently led to the Government's approving TRC's curriculum guidelines for the *katchi* (kindergarten). The new ECD programme *Releasing Confidence and Creativity* (funded by USAID) aims to test approaches for improving access and quality in the *katchi* classes and Grades 1 and 2 (where most drop-out occurs), while also creating stronger links to families in order to promote their active and continued involvement as the children's first teachers. Teacher training, curriculum, and materials development; access for females; and community participation in education are all core components.

These ECD programmes have been successful in capacity development, particularly for girls, and have been instrumental in reducing poverty through basic education and building the capacity of communities to make their own decisions. For the AKES, Pakistan project in rural Sindh, which has set up sixteen community-based schools to



increase girls' access to and success in school; community development has been key to its success. Together, these ECD efforts have benefited over 5,400 children, some 400 parents and 600 predominantly female teachers/heads over the last 4–5 years.

India was a critical testing ground for most of AKF's work in the field of ECD in the 80s and early 1990s. This included support for the establishment and strengthening of NGOs working in early childhood education and care, such as CHETNA's Child Resource Centre, the Centre for Learning Resources, and SEWA's childcare programme. Over the last 6–8 years, AKF's support has focused on NGOs working to improve the quality of primary education. Through some of these efforts, preschool interventions and the issue of children's transition from pre-to primary school have been addressed in both formal and non-formal settings. AKF hopes to move forward on joint Health and YCF efforts in India in the coming years. In Bangladesh, AKF has supported, with other donor agencies, BRAC's efforts to increase education opportunities for females. More recently, as BRAC began to pilot preschool classes within its broader programme, the Foundation facilitated visits by BRAC staff to the above preschool efforts in India and Pakistan to encourage the sharing of lessons, materials, and strategies.

### Europe

The Childhood Association works through a range of selected existing educational institutions with the aim to improve the quality of their interventions with young and primary age children in and around Braga in Northern Portugal. The Integrated Educare Project seeks to provide a holistic child development model through the promotion of integrated centres for children and their families, which could be extended to other areas of Portugal. The project is demonstrating a broader role for local universities and their teacher training programme through applying these in nearby communities. The Association's work is furthered through a series of publications that have emerged out of the ongoing action research by the team and through their links with other early childhood professionals and academics across Europe. AKF Portugal is currently working to update and revise its strategy for ECD and, among other areas, is considering future work that would address the social and economic development of women and children from different ethnic minority communities.

### USA

The Learning Center for Parents and Children (PIAR LCPC), initiated in the mid 1990s, aims to improve immigrant children's readiness and their chances of success in later formal schooling by encouraging parent-child groups to work jointly through a series of pre-school type activities two to three evenings a week. The programme has a strong focus on helping mothers to develop the skills and confidence necessary to begin operating in the new cultural context of the USA, including effectively interacting with the social services and schools. It is linked to other initiatives that help these new immigrant mothers enter the work place or develop home businesses through special training and mentoring initiatives. The LCPC programme began as a grassroots effort in Houston and then was replicated in Dallas and Chicago. There are now plans to extend the work to Atlanta where there are a significant number of young immigrant families (mainly from South Asia). Overall, project beneficiaries total some 400 families in Dallas, Houston, and Chicago.

## Activities of the Partners

## Activities of the Partners

### UNESCO

The Early Childhood and Family Education Section at UNESCO Headquarters is launching three new initiatives related to policy development in early childhood for information purposes and possible use of the available services and resources.

The first initiative is the UNESCO Policy Briefs on Early Childhood series. It is a monthly flash note for policy makers, responding to their need for information on policy options and strategies for early childhood. The Briefs are prepared by the Section or invited experts, reviewed by a peer review group and circulated both in print and through UNESCO web site and emails. Further information will be available shortly on the UNESCO web site at <http://www.unesco.org/education/educprog/ecf/index.htm>. Please help circulate widely including to the concerned government ministries.

Second, in order to assist the Member States' preparation of national policy and action plans on early childhood, we are establishing a UNESCO Early Childhood Policy Hotline in our web site. The Hotline is a communication mechanism through which the Member States can forward their policy questions and issues and obtain answers and responses, in written form. Requests for the review of national policy framework are welcome. Until the Internet version of Hotline is completed, requests can be forwarded to the Section through either email ([sh.choi@unesco.org](mailto:sh.choi@unesco.org)) or fax (33 1 45 68 56 26) or regular mail.

Finally, we are undertaking a series of case studies on integrated early childhood systems and co-ordination mechanisms for early childhood, in both developed and developing countries, to be printed as part of the UNESCO Early Childhood and Family Policy Series. The reports are available in both print and Internet versions (<http://www.unesco.org/education/educprog/ecf/index.htm>). The first issue is on the New Zealand's reform for integrated early childhood system. For information on other reports being prepared, future topics and cases being considered or if you know of a case to be considered for the series, please send your inquiries and comments to [sh.choi@unesco.org](mailto:sh.choi@unesco.org)

We hope that these initiatives are found useful for your continuing efforts to support and promote early childhood programmes.

In addition, UNESCO's Early Childhood section is initiating some activities in the area of young children and HIV/AIDS. These activities concentrate on: 1) information sharing and contribution to discussions through online email dialogue and development of a Young Child and HIV/AIDS website; 2) in cooperation with other partners, development of materials/modules to use for working with young children affected and infected by AIDS, 3) support through networking and partnerships for meetings around the issues of HIV/AIDS. The workshop "Protecting the rights of young children affected and infected by HIV/AIDS in Africa: Updating strategies and reinforcing existing networks" took place in UNESCO Headquarters earlier this year and was organized in cooperation with the Early Childhood Development Network for Africa (ECDNA). The meeting brought together representatives of early childhood development NGOs, institutions and UN organizations to identify strategies, lines of action and innovative approaches to respond to the needs of young children. A concrete result of the workshop was the development of "Guiding principles for care of young orphans and vulnerable children under 8 years of age" and of a draft Action Plan.

# ECCD Resources

The CNA Tool Kit provides organisations working in communities impacted by the HIV/AIDS epidemic with a methodology, questionnaire, and software for assessing the child care, health, and development needs of young children. The results will help to inform the design of projects to assist children and families by assessing the well being of young children and their families, their needs for care and educational services, and ECD-related priorities in the identified community. The assessment will also provide information on caregiving aspects and attitudes, as well as on the obstacles and trends of entering primary school. Using the furnished survey, interviewers gather information about the family and the main caregiver of young children from sample households, as well as facts regarding the basic and unmet needs of each child under eight years of age.

The survey is designed to collect information on the following domains related to the needs of young children:

- Health care quality and access of both the children and primary caregiver
- Health status of both the children and primary caregiver
- Main caregiver's ability to care for an ill child
- Availability of support for the primary caregiver
- Basic needs such as clothing and bedding
- Nutrition
- Education
- Child care (other than by primary caregiver)
- Legal needs such as loss of property upon death of parent, guardianship
- Discrimination and stigma due to HIV in the family
- Family income and resources
- Living conditions such as housing, sanitation
- Psychosocial needs such as consistency in caregiver, stimulating daily activities, and behavioural, emotional and developmental problem

After entering survey information using pre-programmed data entry screens, organisations can use a furnished software program to analyse the data and generate reports. These reports can be used to help design service programmes, secure funding, and monitor and evaluate programmes specifically targeting the needs of young children and their families in AIDS-impacted areas.

The ECD Team will provide training and technical assistance to accompany this assessment tool.

The CNA Toolkit is available free of charge. If you are interested in participating in field testing efforts, please review the Protocol for Evaluation of the Child Needs Assessment Toolkit and contact: [ecd@worldbank.org](mailto:ecd@worldbank.org)

For more information contact:

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Email: [asurrency@worldbank.org](mailto:asurrency@worldbank.org)

[www.worldbank.org/children/aids.html](http://www.worldbank.org/children/aids.html)

*The Child Needs Assessment (CNA) Tool Kit: An Epidemiological Tool to Assess the Needs of Young Children (0-8 years) in AIDS-affected Communities*

EARLY CHILD DEVELOPMENT TEAM, EDUCATION SECTOR OF THE WORLD BANK, AND THE TASK FORCE FOR CHILD SURVIVAL AND DEVELOPMENT

*Through Children's Eyes* is a collection of drawings and stories from the World Health Organization Global School Contest on Mental Health held in 2001 as part of World Health Day. This booklet was produced as part of global effort to reduce the stigma associated with mental disorders. The booklet contains brief descriptions about mental health and mental illness in terms youth should be able to understand. A teacher guide for classroom discussion and a brief description of the WHO child and adolescent mental health program is included. The booklet may be obtained in English or French from the Department of Mental Health and Substance Dependence, WHO, 27 Geneva 1211, Switzerland or as a pdf file on the WHO Web page: [www.who.int/mental\\_health/publications](http://www.who.int/mental_health/publications).



Brazil: PAHO/3-100/Carlos Gaggero

*Children with HIV/AIDS...  
Our Response*  
CENTRE FOR HIV/AIDS  
RESEARCH, EDUCATION  
AND SERVICES,  
JAMAICA

*Children with HIV/AIDS... Our Response* is a Trainers Manual produced by the Centre for HIV/AIDS Research, Education and Services (CHARES), is funded by UNICEF, and is for use in training caregivers of children living with HIV/AIDS at home and within community settings. The topics covered include:

- the role of the caregiver
- basic information related to HIV/AIDS in children
- medical problems related to HIV/AIDS
- breaking the news about being HIV positive
- nursing care of children with HIV/AIDS in the home setting
- basic psychological needs of children with HIV/AIDS
- relationships and quality of life – interpersonal relationships
- nutrition in HIV/AIDS
- preparing children for hospitalisation
- disciplining the sick child
- needs of the child in a hospice or children's home
- needs of the child in school and in the community
- dying and death
- the caregiver-support network
- the caregiver-taking care of me
- time management
- occupational and recreational activities

For more information and/or to order a copy, please contact Mrs. Hope Ramsay directly by e-mail ([ramsayhope@hotmail.com](mailto:ramsayhope@hotmail.com)) or by phone 876-977-6921. The cost of the manual is \$USD 25.00.



# Electronic Resources



Lesotho: UNICEF/HQ00-0789/Pirozzi

Please send us your additional resources at: [info@ecdgroup.com](mailto:info@ecdgroup.com). These will be posted to our website.

**[www.aegis.org](http://www.aegis.org)**

AIDS EDUCATION GLOBAL INFORMATION SYSTEM

**[www.crin.org/theme](http://www.crin.org/theme)** *Click on HIV/AIDS*

CHILD RIGHTS INFORMATION NETWORK

**[www.icad-cisd.com](http://www.icad-cisd.com)**

INTERNATIONAL COALITION FOR AIDS AND DEVELOPMENT

**[www.icad-cisd.com/content/factsheet\\_detail.cfm?id=12&lang=e](http://www.icad-cisd.com/content/factsheet_detail.cfm?id=12&lang=e)**

PDF: HIV/AIDS and Education

**[www.icad-cisd.com/content/factsheet\\_detail.cfm?id=31&lang=e](http://www.icad-cisd.com/content/factsheet_detail.cfm?id=31&lang=e)**

PDF: Best Practices for Care of AIDS Orphans

**[www.icad-cisd.com/content/factsheet\\_detail.cfm?id=20&lang=e](http://www.icad-cisd.com/content/factsheet_detail.cfm?id=20&lang=e)**

PDF: HIV/AIDS and Policies Affecting Children

**[www.kidzpositive.org](http://www.kidzpositive.org)**

KIDZPOSITIVE

The Kidzpositive Family Fund, launched by a group of dedicated professionals working in healthcare, aid, and the media in South Africa. The goal of this organisation is to generate funds for the grassroots support of mothers and children affected by HIV/AIDS.

**[www.paho.org](http://www.paho.org)** *Click on HIV/AIDS*

PAN AMERICAN HEALTH ORGANIZATION

**[www.staying-alive.org](http://www.staying-alive.org)**

A joint effort of AFXB (Association Francois-Xavier Bagnoud) and the World Bank ECD Team, Education Sector of the World Bank, the database facilitates cooperation among organizations and individuals assisting children made vulnerable by HIV/AIDS and their caregivers.

**[www.portal.unesco.org/aids](http://www.portal.unesco.org/aids)****[www.unesco.org/culture/aids](http://www.unesco.org/culture/aids)**

UNESCO

**[www.un.org/ga/aids/coverage](http://www.un.org/ga/aids/coverage)**

UNITED NATIONS

United Nations General Assembly Special Session on HIV/AIDS

**[www.unaids.org/youngpeople/index.html](http://www.unaids.org/youngpeople/index.html)**

UNAIDS

- PDF: Children and Young People and HIV/AIDS
- PDF: Investing in Our Future: Psychosocial Support for Children Affected by HIV/AIDS
- A Case Study in Zimbabwe and the United Republic of Tanzania
- UNAIDS Bibliographic Database

**[www.unaids.org/barcelona/presskit/childrenonthebrink.html](http://www.unaids.org/barcelona/presskit/childrenonthebrink.html)**

PDF Report: Children on the Brink USAID, UNAID, UNICEF  
July 2002

**[www.unaids.org/whatsnew/conferences/UNGASSchildren/index.html](http://www.unaids.org/whatsnew/conferences/UNGASSchildren/index.html)**

PDF: Orphans and Other Children affected by AIDS

**[www.unicef.org/aids](http://www.unicef.org/aids)****[www.unicef.org/newsline/00breastfeeding.htm](http://www.unicef.org/newsline/00breastfeeding.htm)**

UNICEF

**<http://www.who.int/inf-fs/en/fact242.html>**

WOMEN AND HIV

**[www.who.org/](http://www.who.org/)**

WORLD HEALTH ORGANIZATION

**[www.worldbank.org/children/hiv.html](http://www.worldbank.org/children/hiv.html)**

WORLD BANK

**[www.worldbank.org/children/HelpingTheChildren.pdf](http://www.worldbank.org/children/HelpingTheChildren.pdf)**

PDF: Helping the Children: World Bank Directory of HIV/AIDS Interventions in Africa October 2001

**[www.orphans.fxb.org/db/index.html](http://www.orphans.fxb.org/db/index.html)**

AIDS ORPHAN ASSISTANCE DATABASE (AOAD)

A joint effort of AFXB (Association Francois-Xavier Bagnoud) and the World Bank ECD Team, Education Sector of the World Bank. The purpose of the AOAD is to facilitate cooperation among organizations and individuals assisting children made vulnerable by HIV/AIDS and their caregivers. It allows users to find, learn about, and contact each other. The database also aims to help donors identify potential project partners directly, thus eliminating costly intermediaries.

**[www.worldbank.org/children/cnashome.html](http://www.worldbank.org/children/cnashome.html)**

CNA TOOL KIT

Developed by the World Bank Early Child Development Team, Education Sector of the World Bank and the Task Force for Child

Survival and Development, the tool provides organizations working in communities impacted by the HIV/AIDS epidemic with a methodology, questionnaire, and software for assessing the needs of young children.

**[www.allafrica.com/aids/](http://www.allafrica.com/aids/)**

ALL AFRICA AIDS SITE

All Africa has an AIDS sub-site that collects breaking news on HIV/AIDS and profiles the top AIDS headlines from news sites around the Continent.

**[www.tac.org.za/](http://www.tac.org.za/)**

THE TREATMENT ACTION CAMPAIGN

The Treatment Action Campaign (TAC) is a well-known campaign group that address issues surrounding the rights of those living with HIV and AIDS including the right to accessible and low-cost drugs.

**[www.health-e.org.za/aids.php](http://www.health-e.org.za/aids.php)**

HEALTH-E

A well-researched online health news service, Health-e recently won an award at the Highway Africa 2001 conference for innovative use of new media. Health-e provides a comprehensive and streamlined service of email updates linked to their website.

CABA: CHILDREN AFFECTED BY AIDS

A USAID initiative hosted by the Synergy Project, CABA focuses on children affected by HIV/AIDS. To subscribe to the forum, please send an e-mail with "subscribe CABA" in the subject line to: caba-admin@synergyaids.com. Or enter your e-mail address at: [www.synergyaids.com/caba/register.php](http://www.synergyaids.com/caba/register.php)

**[www.nigeria-aids.org/](http://www.nigeria-aids.org/)**

JOURNALISTS AGAINST AIDS NIGERIA

JAAIDS is a media-based non-governmental HIV/AIDS advocacy organisation in Nigeria, started by four Nigerian journalists in 1997. This email-based discussion, replicated on the web, focuses on Nigeria, but also on the wider African debates surrounding HIV/AIDS and includes activists, medical practitioners, advocacy and, research personnel.

**[www.hdnet.org](http://www.hdnet.org)**

HEALTH AND DEVELOPMENT NETWORKS

A non-profit organisation whose mission it is to mobilise a more effective response to HIV/AIDS and other health-and-development-related issues by improving information, communication, and the quality of debate through electronic forums, i.e, Break-the-Silence.

**[www.childaidsservices.org](http://www.childaidsservices.org)**

CHILD AIDS SERVICES

The Child AIDS Services directory is a national, South African database-driven directory of services for children and youth infected/affected by HIV/AIDS in South Africa The database, which currently has 1052 registered organisations, facilitates collaboration, information sharing, and research.

**[www.sahealthinfo.org/Modules/HIV\\_AIDS/hiv\\_aids.htm](http://www.sahealthinfo.org/Modules/HIV_AIDS/hiv_aids.htm)**

SOUTH AFRICA AIDS DIRECTORY

## Discussion Lists

## Directories

# Upcoming Meetings and Conferences

## **Bridging the Gap Between Education, Health, and Crime Prevention**

**March 26-28, 2003**

Organized by the Crime Prevention Unit, Attorney General's Department

For more information, contact:

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To be placed on a mailing list for more information, contact the conference coordinator at: [underdown.judy@agd.sa.gov.au](mailto:underdown.judy@agd.sa.gov.au)

## **High/Scope International Conference**

**April 29–May 2, 2003**

Organized by the High/Scope Foundation:  
Ypsilanti, Michigan

For more information, see:

[www.highscope.org](http://www.highscope.org)

## **World Forum on Early Care and Education**

*Acapulco, Mexico*

**May 13–16, 2003**

For further information, see:

[www.childcareexchange.com/wf/index.cfm](http://www.childcareexchange.com/wf/index.cfm)

## **National Association for the Education of Young Children (NAEYC) Annual Conference**

*Chicago, Illinois, USA*

**November 5–8, 2003**

For more information, see: [www.naeyc.org](http://www.naeyc.org)

## **Zero-to-Three Annual Conference**

*New Orleans, Louisiana, USA*

**December 6–7, 2003**

For more information, see:

[www.zerotothree.org](http://www.zerotothree.org)

# Past Meetings

## **The 2nd International Conference on Early Childhood Development: Integrated Early Childhood Interventions: What Works and Experiences Learned**

*Asmara, Eritrea*

**October 28–31, 2002**

The conference theme of *Integrated Early Childhood Interventions: What works and experiences learned* sought to identify advances made in

Early Childhood Development (ECD) and addressed the challenges faced by developing nations in the struggle to realise the Rights of a Child to develop in a holistic manner. This theme and the motto, which as stated by the children themselves as "The Future is ours", fit into the Dakar EFA Declaration and the efforts at developing ECD in an African setting.

For further information see: [www.worldbank.org/children/africa/eritrea\\_conf.html](http://www.worldbank.org/children/africa/eritrea_conf.html).



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THE CONSULTATIVE GROUP ON EARLY CHILDHOOD CARE AND DEVELOPMENT (CG) is an international, inter-agency group dedicated to improving the condition of young children at risk. The CG grounds its work in a cross-disciplinary view of child care and development.

Launched in 1984, the CG has taken as its main purpose the fostering of communication among international donor agencies and their national counterparts, and among decision-makers, funders, researchers, programme providers, parents and communities with the goal of strengthening programmes benefitting young children and their families.

The Consultative Group includes a broad-based network of agencies and regional representatives who each represent (or are involved in developing) broader regional networks of early childhood planners, practitioners, researchers, and policy makers. The CG operates through an *International Secretariat*, which draws on the consortium and the regional representatives to actively identify gaps and emerging areas of need and interest related to ECD, and to seek out new partners. The Secretariat is housed at Ryerson University in the School of Early Childhood Education. Administrative support is provided by the Ryerson Office of International Affairs.

The *Coordinators' Notebook* is produced by the Secretariat in collaboration with partners and regional networks and with support from the Academy for Educational Development, Aga Khan Foundation, Bernard van Leer Foundation, Christian Children's Fund, Dutch Ministry of Foreign Affairs, Pueblito, Save the Children Alliance, UNESCO, and UNICEF. Additional support for this issue was provided by the Aga Khan Foundation, Canada and the Canadian International Development Agency (CIDA).

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## GOALS

**TO INCREASE THE KNOWLEDGE BASE** The CG gathers, synthesizes and disseminates information on children's development, drawing from field experiences, traditional wisdom and scientific research.

**TO SERVE AS A CATALYST** The CG works to increase awareness of issues affecting children, developing materials and strategies to help move communities, organisations and governments from rhetoric to practice, from policy to programming.

**TO BUILD BRIDGES** The CG fosters networking among those with common concerns and interests, working across sectoral divisions, putting people in touch with the work of others by organising meetings, by disseminating information through publications, and by serving as a communications point.

**TO SERVE AS A SOUNDING BOARD** The CG engages in dialogue with funders and decision-makers about developments in the field, providing the base for policy formulation, planning, programming and implementation.

Members of the Secretariat occasionally provide technical assistance to individual organisations in programme design, implementation and evaluation, and in the writing of technical papers and reports.

The *Coordinators' Notebook* is produced twice annually. It is one of our networking tools. Each issue focuses on a particular issue or topic, as well as offering network news. We try to provide information on the most appropriate research, field experience and practices to benefit individuals working with young children and their families. We encourage you to share this information with the other networks you take part in. Feel free to copy portions of this *Notebook* and disseminate the information to those who could benefit from it. Please let us know about any programmes or efforts benefitting young children and their families in which you may be involved.

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