ECD and the HIV/AIDS Pandemic in Africa

Lynette Jackson
Global Connect Services, Canada
Chloe O'Gara
Save the Children, United States
Margaret Akinware
UNICEF, Zambia
Olive Akomas
Ministry of Health, Umuahia, Abia State, Nigeria
Lydia Nyesigomwe
Action for Children, Uganda
Susan Sabaa
Ghana NGO Coalition on the Rights of the Child

Abstract: An unprecedented number of young children in Sub-Saharan Africa are being adversely affected by the HIV/AIDS pandemic, yet programs specifically designed to meet the developmental needs of orphaned and vulnerable children (OVC) from birth to age 8 are rare. This article summarizes the daunting array of challenges facing young OVC in Sub-Saharan Africa, and profiles research and action projects undertaken by four members of the inaugural graduate-level cohort of the ECDVU to promote high-quality developmentally appropriate ECD care for young OVC in their respective countries. The projects underscore the pressing need for community-based, national and international stakeholders to reach beyond the escalating immediate demands for survival-level support for these children—

Address all correspondence to: Lynette Jackson, ECDVU, School of Child & Youth Care, University of Victoria, Box 1700, STN CSC, Victoria, British Columbia, Canada V8W 2Y2. E-mail: jacksonl@uvic.ca

International Journal of Educational Policy, Research, & Practice, Volume 5, Number 3, Fall 2004. ISSN 1528-3534;

> culturally appropriate ECD training and resources for both overburdened extended family and institution-based caregivers of young OVC must also be promoted as essential priorities. Higher levels of physical, cognitive, and emotional well-being and increased lifetime learning and earning are associated with good early childhood care; timely provision of integrated quality ECD training and care is urgently needed if today's young OVC are to mature into productive and contributing members to Sub-Saharan African society in their adult years.

UNICEF has cited HIV/AIDS as one of the top five concerns currently facing children in developing nations (together with child survival, war, exploitation, and insufficient investment). In the UNICEF New Year 2004 press release, Executive Director Carol Bellamy made special note of the extraordinary number of children in Sub-Saharan Africa negatively impacted by the HIV/AIDS pandemic: "Some 14 million children have been orphaned by AIDS, 11 million of whom reside in Sub-Saharan Africa. By 2010, the number of children in that region who have lost parents to AIDS is expected to have risen to 20 million" (UNICEF, 2003). However, action to meet the needs of orphans—particularly young orphans from birth to age 8—is thus far falling far short of what is needed to ensure a healthy, capable cohort of adults 15 years into the future. Recognizing the gravity of this situation, several ECDVU participants elected to undertake projects relating ECD to HIV/AIDS. This section of this special issue provides an overview of the particular ways that the lives of children in their early childhood years (from birth to age 8) in Sub-Saharan Africa are affected by HIV/AIDS and profiles work undertaken by these ECDVU participants in various African countries to bolster the well-being and holistic development of young children orphaned by the pandemic.

Background

Following his official tour of Ethiopia in May 2004, Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa, made the following observations regarding the negative impact of HIV/AIDS on Ethiopia's children:

> I regret to say that Ethiopia is only now beginning to understand the vast extent of the growing orphan crisis. The country is simply unprepared, at this time, to cope with the avalanche of children orphaned by AIDS; it's estimated that there are already a million orphans in Ethiopia. The Prime Minister pointed out to me that there is still some capacity, in the rural areas, to absorb orphans into the community through the extended family system. But he acknowledged that in the urban centers, where the

> great majority of orphans are to be found, there was as yet little capacity to respond.
>
> Frankly, unless the country devises an almost instantaneous strategic plan for orphans, backed by massive resources and focused intervention, Ethiopia will soon be reeling from the onslaught of abandoned, rootless, bewildered and despairing kids of all ages. It will feel like a raging torrent of child trauma to which everyone responded too late. Tens of thousands of young lives will be lost and ruined. I cannot put it strongly enough. (Lewis, 2004, para. 10-11)

Sadly, similar crises are mounting in many Sub-Saharan countries at this time.

Terminology in Use in Sub-Saharan Africa: Young Orphaned, Vulnerable, and "AIDS-Affected" Children

Kathy Bartlett and Louise Zimanyi (2002) of the Consultative Group for Early Childhood Care and Development Secretariat identify *AIDS-affected children* as: "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" (p. 1). Sabaa (2004, p. 23) reports that a variety of terms are employed in different regions of Sub-Saharan Africa to denote children who are being adversely impacted by the HIV/AIDS pandemic, including *children and adolescents affected by AIDS* (CAA), *children affected by AIDS* (CABA), *children in distress* (CINDI), *children in extremely difficult circumstances* (CEDC), and *children in need of special protection* (CNSP); however, the predominant descriptor in the current global literature is *orphans and vulnerable children* (OVC). The term *vulnerable children* is variously applied to describe children who struggle to survive and mature under conditions that do not permit fulfillment of their fundamental rights for optimal development. Its usage includes, but is not limited to, children adversely affected by the HIV/AIDS pandemic. *Vulnerable children* may also be used to refer to street children; child labourers; children who are sexually exploited, trafficked, neglected or handicapped; children living in child-headed households, foster care or centers for reasons other than loss of parent(s); children in conflict with the law; children living in poverty; refugee and displaced children; infants with their mothers in prison; children of single parents; "unaccompanied" children; and children from Indigenous minorities who live in remote areas.

In this article we use the term *young orphans and vulnerable children* (OVC) to indicate children from birth to 8 years who are orphans and/or vulnerable. We assume that almost all AIDS-affected children are

vulnerable based on the evidence presented here and elsewhere. We have elected to use *young OVC* because it is less stigmatizing, more reliably verifiable, and more inclusive than the designation of *AIDS-affected*.[1]

Challenges Facing Young OVC

There are many specific challenges facing young OVC in Sub-Saharan Africa. Very few reports to date have focused on the specific challenges faced by OVC in the early childhood years, and programs specifically designed to meet the needs of this age group are rare. Some of the high risk challenges facing orphans and vulnerable children from birth to age 8 include (adapted from Lusk & O'Gara, 2002):

1. Survival risks. Approximately 30% of children born to mothers infected with HIV are likely to be infected with HIV in the absence of anti-retroviral therapy for the pregnant mother. Treatment to prevent transmission at birth and reduce the risk of transmission via breast milk is not yet widely available in Sub-Saharan Africa. A secondary survival threat is that young children whose mothers die – for any reason – are at greater risk of morbidity and mortality than children with living mothers.

2. Increased morbidity. Malnutrition, diarrhea, pneumonia, and malaria pose significant risks for children in Sub-Saharan Africa in their early childhood years. AIDS-affected children are bombarded with multiple stressors, are often malnourished, and may be HIV-infected themselves. Households impoverished by AIDS may lack money to provide even basic health care for young children. Ailing parents or foster caregivers may not have adequate resources to transport young children to health facilities, to pay their health service fees, to buy medicine for them, or to follow through on home-based care. Households that are headed by the elderly or by children often lack basic knowledge of the particular health care requirements of infants, toddlers, and preschool children. Immunizations and treatment for basic infections are often missed.

Repeated bouts of illness have long-term effects on children's cognitive and psychosocial development. Malaise impedes action and reduces verbal interaction. A sick child is unlikely to play or explore. Reduction of these activities impoverishes normal development in the early years.

3. Malnutrition. As parents and other adults stricken with HIV/AIDS in the child's family system sicken, the labour force required to produce or buy food is diminished or lost. Adult caregivers of young OVC are predominantly women living in impoverished circumstances with little or no access to property on which to produce food and with scarce employment opportunities to enable them to buy food (USAID, UNICEF, & SIDA, 1999, p. 48). Furthermore, with illness and depression, active

feeding declines or ceases while competition within the household for food resources increases, exacerbating undernutrition of younger children. Once a young child becomes ill or marasmic,[2] the family—and health care providers—may assume HIV infection and view the child as dangerous or likely to die, thus a low priority for time, energy, emotion, and money. Malnutrition in the early years can cause irreversible stunting, impair cognitive and social function, and alter brain development and other foundational aspects of lifelong health and well-being.

4. Psychosocial trauma. As HIV-positive parents pass through phases of the illness, families experience uncertainty, anxiety, and intermittent crises. Children too young to express their feelings verbally are deeply affected by the trauma of witnessing their parents' pain in countries where pain alleviation medicines are unavailable, by adult depression, and by the stigma of HIV/AIDS and associated shame, fear, and isolation. Guilt over their helplessness to save their parents or reduce parental suffering combines with the immense grief, anxiety, and depression of witnessing a parents' descent into illness and death (USAID et al., 1999, p. 48). A family's deteriorating economic position due to mounting costs of "treatments" and funerals, the reduction of income of associated with AIDS, the impending loss of the family home and land, the ongoing uncertainty regarding stability of shelter and care after parents' deaths, and the likelihood of separation from siblings and multiple relocations are heavy burdens for young children to bear.

Once orphaned, 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. Young children are more likely than older children to be linked to their parent's death, infected through birth or breastfeeding, or associated with contagion or the curse of witchcraft. Young AIDS-affected children are at high risk of abandonment, neglect, stigma, harsh treatment, and abuse.

Young children deprived of consistent caregivers and interpersonal and environmental stimulation suffer long-term cognitive and psychosocial consequences. This will have long-range, multiple effects on society. Studies show that 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, in Lusk & O'Gara, 2002, p. 8).

5. Abandonment. Abandonment represents the far end of the spectrum of inadequate care. Some 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.

6. Delay or lack of entry into formal primary education. Household poverty, isolation, and despair keep children out of school. Recent data assembled by UNICEF (cited in Lusk & O'Gara, 2002, p. 6) 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. In Tanzania, children in households with recent adult deaths delay primary enrolment. In Zambia, one study reported that 32% orphans vs. 25% non-orphans are not attending school in urban areas; in rural areas 68% orphans are out of school compared with 48% of non-orphans.

Child labour. AIDS-affected children often find themselves under great pressure to prematurely assume adult responsibilities, even during early childhood years—to care for ill and dying parents, to care for younger orphans and foster siblings, to contribute to farm and domestic labour, or to add income in other ways to their households. As the death toll of the HIV/AIDS pandemic continues to mount, the once extraordinary phenomenon of child-headed households is becoming more and more commonplace in Sub-Saharan Africa. There are now orphaned children as young as 6 or 7 attempting not only to negotiate the challenges of their own survival without adult care or supervision, but also to care for younger siblings, some of whom may be infected with HIV. Children in these circumstances are highly vulnerable to exploitation.

ECDVU Action Research Projects Related to Care of Young HIV/AIDS Orphan Children in Uganda, Nigeria, Zambia, and Ghana

The unprecedented numbers of young OVC in Sub-Saharan Africa prompted four members of the inaugural graduate-level cohort of the ECDVU to undertake a final project or thesis exploring aspects of care for young OVC which related to their ongoing professional work in their respective countries. Despite limitations to the scope of their undertakings imposed by financial and time constraints, their work provides insight into the current status of a variety of current care situations for young OVC and underlines the urgent need for ongoing quality ECD training and pragmatic support for both over-burdened extended family caregivers and institutional staff members to ensure that the cognitive and psychosocial as well as the basic survival needs of young OVC in their charge are met.

Community-Based Assistance for Grandparents Caring for Young Orphans

> For decades now, 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. . . . While most HIV/AIDS programs have at least the potential for benefiting children under five, programs specifically designed to meet the needs of this age group are rare. (Nyesigomwe, 2004, pp. 12-17)

Lydia Nyesigomwe is the Director of Action for Children (AFC), an NGO founded in 1998 to rescue children from immediate danger and to advocate for the rights of children. The organization undertakes various community programs for women and children in poverty eradication, children's health and survival, early learning programs, advocating for the rights of children, and supporting orphans. Strategies employed by AFC are intended to have long-term impact on the well-being of children through economic and social empowering of families of young OVC.

Traditional Ugandan societal norms are changing and are gradually undermining the respect, care, and social support of older people in the society. A contributory factor to this change is the onset of the AIDS epidemic, which has also compounded women's challenges. Gender roles and relationships are determinants of the extent of risk which women face in contracting the HIV infection. Experience has shown that male orphans are prone to life on the street, truancy, and delinquency. The girl orphans are more likely to drop out of education, while widows are likely to be disinherited and often lose their property (Anyuru & Anyuru, 1994; Cobb, 2002; Kihinte, 2000; UAC, 2001, all cited in Nyesigomwe, 2004).

Nyesigomwe's final ECDVU report details a one-year pilot project, the Grandparents Action Support (GAS) Project, designed and implemented by AFC to strengthen the capacity of grandparents in providing care to children under the age of 8 and improve the overall welfare of the families taking care of the children. Nyesigomwe notes that the project was formed because, by eroding the fulfillment of the family's cardinal functions of reproduction and socialization, AIDS is resulting in increased infant mortality and morbidity and the disintegration of family structure by leaving the elderly and the very young ones. Before death, HIV/AIDS-infected parents have a tendency to shift the responsibility of caring for their children to the grandparents. Grandparents, who traditionally depended on their children for financial support during old age, are currently faced not only with the lack of this support, but with having to take care of their dead children's children. A needs assessment carried out in 1993 indicated that households headed by grandparents faced more

hardships in looking after orphans than any other household type (Nyesigomwe, 2004). Minker et al. (1997, in Nyesigomwe, 2004) reported high rates of depression, poor self-related health and/or the frequent presence of multiple chronic health problems in several studies of grandparents raising grandchildren.

Supported by the Bernard Van Leer Foundation, the three-year project is to target 200 homes but has started with 30 households in Kyanja community, Nakawa Division, Kampala District, Uganda:

> Twenty-two households cared for between two and four children under the age of 8, four households had five or more children, while four had only one child below the age of 8 . . . two grandparents were overwhelmed by the responsibility of taking care of seven and eight children below 8 years respectively, in addition to having more children above the age of 8. (Nyesigomwe, 2004, p. 33)

Nyesigomwe describes the GAS Project as unique in that "the vulnerable care for the vulnerable," meaning that grandparents who are old and frail are supported to provide quality care for orphaned children under the age of 8. The goal of GAS is to work with individual families to ensure that grandparent caregivers reach a level where they can support themselves and the children in their care.

Grandparents are strategically organized in economic and social mutual support groups in which they identify and accept the challenges facing them in caring for very young orphans and work together towards solving them. The groups are also provided training by AFC in optimum ECD practices, including nutrition, sanitation, stimulation, and health care, and understanding the particular psychosocial supports required by young orphans.

At the heart of the project is a strategic approach called Family Preservation and Empowerment (FAP), whereby a development plan is worked out with the head of the household using seven key indicators: food security, housing, health and nutrition, education, household income, family mentorship, and training in meeting emotional needs of both children and grandparents. The household is then monitored over a period of time until it can sustain itself with little or no external support. During the implementation of the FAP project, AFC noted the particular vulnerability of young children under the care of aged grandparents who were no longer strong enough to effectively take part in existing community interventions introduced by AFC, nor to give adequate care to the children. The GAS Project was subsequently initiated to provide additional support to these grandparents to enable them to become effective caregivers.

A needs assessment exercise was held with the full participation of the grandparent caregivers, and the findings were shared. One idea generated by the grandparents themselves was to form Action Support Groups (ASGs):

> Each zone formed a group of six people called 'Bubondo.' They formed committees and elected chairpersons and secretaries who could read and write. The main purpose of these ASGs was to bring grandparents together to share their experience, discuss opportunities, challenges, and possible solutions to their problems. They held meetings weekly to share information about their children's well-being and family projects. Their projects were based on the seven indicators, some of which included: how to prepare food for malnourished children, grow vegetables in their back yard gardens, keep the children free from sickness, make play materials and play with children, to ensure that every home has enough food and that every grandparent has an Income Generating Activity (IGA). Five (5) ASGs were formed and ten (10) committee members trained on leadership skills. The role of zone leaders in the ASGs was to monitor the group activities, attend their weekly meetings, and hold a review meeting at the end of the month to discuss issues that came out of ASGs. Issues not handled or solved in the review meeting would be forwarded to AFC. (Nyesigomwe, 2004, p. 48)

Participants together with AFC trainers grouped the challenges facing grandparent caregivers into three categories: those to be discussed and solved by grandparents (such as preparing nutritious meals for children, keeping homes and children clean, teaching children good morals, digging food gardens, building utensil racks, cleaning toilets and buildings where there were no toilets); those to be handled cooperatively by zone Action Groups (such as holding and attending GAS meetings, making home visits for mutual support, assisting each other to own and tend gardens for food production, assisting each other to take sick children to health centers, ensuring that households have projects that generate income); and those to be shared with the wider community (such as starting community ECD centers, sharing food and garden tools, mentoring each other, sharing ideas and information, planting trees in common areas). To avoid perpetuating a cycle of dependency on external support, AFC sponsored simple competitions to encourage grandparents and Action Groups to work on identified challenges. After one month an assessment was conducted, and AFC awarded "prizes" to all participants according to a list which the grandparents had generated during the needs assessment of equipment that they needed but could not afford to buy (such as plates, cups, bed sheets, blankets, and mosquito nets, with overall winners receiving extra prizes such as hoes and mattresses).

Nyesigomwe's final report includes descriptions of innovative and pragmatic community-based strategies initiated by the ASGs to help themselves. Cooperative income-generating strategies, for example, included rearing goats, chickens, and pigs, selling eggs, making crafts, and making and selling pan cakes. The following passage briefly describes how the grandmothers addressed the pressing issue of food security:

> ASGs agreed to grow food as a group and as individuals. There were those grandparents who did not have land and those who were too old and frail to cultivate. Groups agreed that those with no land get together and find a group member who has land to give them. It could be one of the very old and frail grandparents, then they would grow food and share with her or him. Twenty two (22) personal and 5 group gardens of cassava, potatoes and vegetables were established. (Nyesigomwe, 2004, p. 49)

Nyesigomwe notes that a mid-term evaluation of the GAS Project was conducted to assess progress and performance. While no attempt was made at that time to evaluate the overall impact of the project, as the implementation period of seven months was too short, a review was conducted to assess the project's performance during that period and the achievements and challenges encountered and to recommend improvements. Issues looked at in the mid-term evaluation included care, development, and support for orphans, knowledge and behaviour change related to HIV/AIDS, knowledge and behaviour change related to psychosocial support for children, and income-generating activities. A simple questionnaire was used among grandparents in the ASGs, and a home-visit exercise was carried out in the households. Findings are summarized below:

> The project had registered significant achievements both tangible and qualitative. Overall the project had achieved beyond the targets. While the plan was to support 50 children, 99 children had been reached in less than the planned period of implementation and the effects of the project had gone beyond the targeted 30 homes to involve non-project homes. The project had a multiplier effect in that non-project families are already copying and learning from the GAS homes. Non-project families had started cleaning their homes, making utensil racks and digging rubbish pits. The zone leaders had gained popularity in the community and were now attracting more development projects for their community. (Nyesigomwe, 2004, pp. 53-54)

The report also lists a number of qualitative and indirect achievements, including: better community mobilization and organization; increased ease of entry of development projects into the community; improved income for caregivers (grandparents had some income on reserve for emergencies); availability of a health post, better access to

health care, and improved health of the children; and increased food security.

In the conclusions of her report, Nyesigomwe notes that young OVC in the care of grandparents are not targeted by most HIV/AIDS mitigation or care and support projects because the grandparents cannot enroll in projects that emphasize financial sustainability. The GAS Project demonstrates that significant positive change can take place in a short period of time by involving the larger community in addressing the issue of quality care for OVC in their early childhood years.

Nyesigomwe has received funds to extend the approach to other communities in Uganda

Assessing Caring Practices and Developing/Delivering a Nutrition Training Program to Staff of Motherless Babies' Homes in Nigeria

Olive Erinma Uzoamaka Akomas is a Deputy Director in the Department of Public Health/Primary Health Care, Ministry of Health, Umuahia, Nigeria. In addition to her studies with ECDVU, Akomas holds a B.Sc. (Nutrition and Dietetics) from the University of Nigeria, a M.Sc. (Foods and Nutrition) from the University of Manitoba, Canada, and a Post-Graduate Diploma in Rural Extension and Women from the University of Reading, Berkshire, UK. Akomas' main objective is the reduction of infant and under-five morbidity and mortality through proper nutrition and adequate care.

The Nigerian federal government in collaboration with UNICEF is actively endorsing an integrated health, nutrition, and psychosocial stimulation program addressing children's holistic development. While mothers and caregivers at home and in early childhood centers are targeted to receive training, caregivers in orphanages have been missed. Akomas therefore chose, as her final report for ECDVU, to assess the caring practices in two motherless babies' homes (orphanages for infants and toddlers) in Abia State, Nigeria by comparing her evaluation with selected key practices identified by the World Health Organization (WHO) and UNICEF to be of the utmost importance in providing good care for children to ensure survival, reduce illness, and promote healthy growth and development.

> The survival, growth and development of children are greatly affected by the care that they receive in their immediate environment. Children in orphanages (motherless babies' homes) in Nigeria constitute a vulnerable group that needs better care. The aspects of care, which tend to receive attention at the moment, are feeding and disease treatment/prevention. The psychosocial aspect of care is, however, inadequate. (Akomas, 2004, p. 1)

Practices assessed included quality of complementary foods; micronutrient supplementation and dietary diversification to ensure adequate micronutrient intake; feces disposal and general hygiene; immunization schedule; protection against malaria, child stimulation vis-à-vis interaction with caregivers; nutrition care of sick children; care for HIV/AIDS-infected orphan infants and actions against further HIV infection; protection against injury; prevention of child abuse and neglect; fathers' involvement in childcare (if fathers of some institutionalized children are alive); treatments given to the child for infection; ability of caregivers to recognize when sick children need treatment outside the home, and ability of caregivers to follow health workers' advice on treatment and to follow up on advice and referrals. This study is certainly one of the pioneer works, and perhaps the first research, on caring practices in orphanages in Nigeria.

Akomas began from a strengths-based perspective by approaching the assessment with the specific objectives of listing all the caring practices in the participating motherless babies' homes that enhance child development and building capacity of the caregivers so that they would be able to offer adequate care to the orphaned infants. Akomas reports that, since her approach to the institutions began with a letter of introduction by the Executive Secretary of the State Planning Commission (who is also the Chairman of the State Committee on Food and Nutrition), the staff believed that government involvement in the project would lead to some positive outcomes for the institutions.

Two data collection methods were used: (1) questionnaires based on the key practices identified by UNICEF/WHO and (2) observations of behaviours and activities of caregivers and children, including: child stimulation interaction and activities; child to child interactions; food preparation techniques to determine the level of hygiene in food preparation and whether the methods ensure maximum retention of nutrients; sanitary conditions of kitchen and toilet areas; and sleeping areas, especially with regard to malaria prevention. The authorities of the home permitted visits at her convenience. A detailed summary of findings is included in Akomas' final report *Assessment of the Caring Practices in Two Motherless Babies' Homes in Abia State, Nigeria and Developing and Delivery of a Nutrition Training Program to the Staff of these Homes to Improve Nutrition of Children in Their Care*.

Positive practices were noted (commencing complementary feeding after 6 months, proper feces disposal, immunization during National Immunization Days, giving home treatment for infections, and recognizing when sick children need treatment outside the home and taking them for care from appropriate providers) as well as those areas needing

improvement for optimal development (e.g., about half of the caregivers did not know the causes of malaria; children were not monitored for growth; bright colours, toys and other simple forms of mental stimulation were in short supply; and, while caregivers usually wash their hands with soap and water after using the toilet, this is not practiced after diaper change for infants and toddlers). The assessment determined that in the two homes, attention was more focused on the health aspects of care than on the nutritional or psychosocial aspects – in fact, the psychosocial and mental stimulation aspects of care necessary for optimal development were almost absent.

The second component of the ECDVU project was the development of a training manual and delivery of training to the caregivers. The findings of the assessment helped inform the base of the manual. Other points that were considered in its development include: nutritional aspects of preparation of adequate complementary foods and meeting the micronutrient needs of infants; methods of food preparation to ensure that nutrients are retained; other food-related aspects such as hand washing during food preparation; the promotion of mental and social development of infants and toddlers by responding to their needs for care and through talking, playing, and providing a stimulating environment via the responsiveness of the caregiver feeding the child; and regular growth monitoring.

The report concludes with Akomas' recommendations to enhance the caring capacity of caregivers and thus improve the care of young children:

1. More support should come from government, especially with regard to the payment of caregivers and provision of water and materials for indoor and outdoor games for the children.

2. Government should employ more nutritionists whose job it is to give dietary advice.

3. Soya bean flour should be used to enrich children's complementary foods.

4. Routine immunization and growth monitoring should be encouraged until the child is six years old. Administration of vitamin A routinely would further help to strengthen the immune system of the children and protect them from constant coughs and fevers.

5. Children should be provided with more toys that would stimulate them mentally.

6. Hand washing (by caregivers) after the change of diapers should be encouraged.

7. Fathers should be educated on the importance of their interactions with their children when they visit, especially to encourage bonding.

8. The caregivers should be trained not only on nutrition but also on health and psychosocial aspects of the development of the children.

9. Since government has shown interest in this study, the work could be carried out in all the Motherless Babies Homes (orphanages) in the state and should be sponsored by government.

10. Finally, government should take over the running of the private orphanages, instead of leaving them to be run by donations from the public. (Akomas, 2004, pp. 71-72)

Adapting and Piloting an Established Measure to Assess the Quality of Orphanage Child Services

As noted in the policy section of this special edition, Margaret Akinware is well-recognized in African ECD, having worked for many years with UNICEF in her home country of Nigeria. Akinware chose as the focus for her ECDVU thesis research the assessment of quality of care for OVC. Her topic directly relates to the type of decisions she makes on a regular basis in her current role as a Project Officer in the Education Section in collaboration with the Child Protection Section, UNICEF Zambia, where she is frequently asked to assess the quality of care provided by orphanages seeking UNICEF assistance. To be able to do this professionally, she determined that UNICEF Zambia needed to know what constitutes quality basic care, have a usable and acceptable assessment tool, and know the most appropriate way to measure elements of quality care in a home setting in ways appropriate to the cultural context of Zambia. The research was undertaken within the context of an IECD initiative which aims to provide a good start to life within a nurturing family and community environment in the context of the Convention on the Rights of the Child (CRC), to which the Government of the Republic of Zambia and UNICEF are both signatories.

While the vast majority of orphans in Zambia are still being absorbed by the extended family network, the ever-increasing number of AIDS-affected children in Zambia has resulted in a growing demand for alternative care options. Akinware describes the current struggle in Zambia, as in other Sub-Saharan countries, to come to terms with the seemingly inevitable transition to ever larger numbers of young children requiring institutionalized care as the extended family system becomes taxed beyond its coping capacity.

The assumption among social scientists and development workers was that orphans who were taken care of by members of the extended family network received better care and affection than their counterparts in orphanages or in such residential facilities. This assumption, according to

Orphans and Vulnerable Children—A Situation Analysis (USAID, UNICEF, & SIDA, 1999), was based on the cohesiveness of the extended family and the fact that families and communities were in the front line coping with the problems of orphans in Zambia. McKerrow (1996, in USAID et al., 1999, p. 94) revealed that rural households were better able to feed their members, including orphans, while a higher proportion of urban orphans were able to attend school. On the other hand, scholars like Kelly (2002) posited that orphans in Zambia who were living with grandparents, especially elderly grandmothers, were particularly vulnerable because of the inability of elderly grandparents to provide for the material, social, and psychological needs of another generation of children (p. 2). Furthermore, because of the HIV/AIDS situation, there were more orphans than grandparents; therefore, even if orphanages were 'second best,' they were an inevitable reality in the current context (Akinware, 2004, p. 3).

To better understand the nature and quality of care provided by orphanages and the attendant child development implications, Akinware adapted and conducted a pilot study of an established qualitative assessment instrument, the Inclusive Quality Assessment (IQA) tool, in a selected orphanage in Zambia. The purpose of her study was twofold: (1) to contribute to the scientific knowledge about the quality of care provided to children in a Zambian orphanage and (2) to pilot an adaptation of the IQA tool to determine its suitability for Zambia. Originating as the Inside Quality Assurance tool of the University of North London Centre for Environmental and Social Studies in Aging and subsequently adapted for use in British Columbia, Canada (1998), IQA involves the participation of orphans and caregivers in identifying their needs and workable strategies to fulfill those needs, as well as the involvement of frontline managers in planning and improving the quality and assurance of care to orphans in the institution:

> As stated by Anglin and Dolan (1988), 'Inclusive Quality Assurance is a client-centred quality assurance review process that helps people in service settings focus on what they hold to be important and what kind of environment they want to create' (p. 1). It is a specific technique for undertaking a client-centred review of the quality of life experienced by clients receiving services within a residential program. . . . IQA is concerned with everyday events by looking through the eyes of participants and those who work within the setting. It emphasizes the residents of the program and includes their perspectives, experiences and interest as a key component of the process (Akinware, 2004, pp. 3-5). . . . With the IQA, the assessment of quality relates directly to children's needs as voiced by the children—which is in contrast to other approaches for quality assessment that do not respect children's rights as strongly by putting their needs in the center. (Akinware, 2004, p. 12)

The researcher selected an orphanage located in the center of Lusaka City, Zambia, whose Founder was known to be amenable to suggestions that add value to the quality of life of residents. Three levels of orphanage care were examined: senior management, comprising the Founder and one selected care provider; all the children in the selected orphanage; and a group created during the process, called the Quality Assessment Group, consisting of 3 representatives of the children in the orphanage (two- 21 year old orphans and one caregiver), outside interest represented by a member of the ECCD NGO, the Founder of the orphanage who was deeply involved with the care of the children in this particular orphanage, a post-graduate student in Psychology (Child Assessment) from the University of Zambia, and the researcher.

The research study combined qualitative and quantitative designs, including:

1. IQA Observational Guidelines. How do children in this care model interact with caregivers and services? In other words, what is going on in this caregiving arrangement? The Quality Assessment Group developed a set of observational procedures to obtain objective information on daily interactions in the orphanage based on issues relating to children's best interests (Anglin, 2002). A general observation sheet was developed and utilized during researcher interaction in the orphanage.

2. Interview. What type of care and services are provided in the orphanage? The Quality Assessment Group developed an interview guide that was used for structured interviewing of the children in the orphanage and to conduct the focus group discussion. The interview guide included questions based on safety, respect, hygiene, freedom of choice, interpersonal relationships among the children, equality of opportunity, and food. Akinware notes that interviews were conducted at the orphanage with no adult caregivers present; the children were not rushed, and the interviewers built a rapport with them to encourage free expression.

3. Questionnaires. What type of care and services are provided in the orphanages? What is the impact of this arrangement on children's experience of care? An open-ended questionnaire was administered to a sample group of caregivers on issues relating to physical care, safety and health care, decision making in the orphanage, freedom of expression and participation, linkages with life outside the orphanage, promotion of family life, relationship between the staff and the children and among the children themselves. The caregivers were assisted to complete the questionnaires due to low literacy level. A second questionnaire was administered to the founder of the orphanage by the Quality Assessment Group.

The combination of observations, interview guides, and questionnaires helped the researcher to ascertain the consistency of the tool.

The orphanage founder was well-informed about IQA; the researcher notes that she was careful not to raise unfulfilled and unrealistic expectations in seeking permission and explaining the goals and objectives of the review. Response from participants indicates that the IQA tool allowed for both flexibility and modification. Participants understood the concept of IQA and had no difficulty developing questions based on the values outlined in the IQA process (Anglin & Dolan, 1988, p. 4).

IQA provided the opportunity for self-assessment by the frontline managers, and the Founder was delighted with the appraisal of her efforts as seen through the eyes of outsiders. Participants had the opportunity to take part in the refinement of the interview schedules and observational indicators and in piloting the instruments. The IQA drew heavily on the experience of the frontline officers, the children themselves, and ECD practitioners as well as the researcher: residents participated in an action research in the true sense of the word, as they were involved in analyzing and evaluating their experiences and operations. Participants concluded that the IQA is an innovative, experiential, and rewarding—albeit time-consuming—assessment tool, relevant for investigating the quality of care within the context of the study.

The qualitative research approach yielded much useful information about the orphanage. It was both inclusive and innovative in that hearing the voices of children as beneficiaries and users of services was a critical concern. Children had the opportunity to identify issues of importance to their situation. The Quality Assessment Group found the children to be friendly and talkative; the children enjoyed being asked questions, and reported feeling "very important" as a lot of attention was focused on them. The Founder and the caregivers felt satisfied that the IQA tool brought to the fore their contribution to childcare, which could be replicated by other orphanages.

IQA provided the opportunity for the orphanage Founder, caregivers, and children in care to develop a Plan of Action that was doable and result-based to improve and increase services rendered in the best interest of the children and from their perspectives. The plan looked at what should be done for the preschool-aged children as part of a comprehensive development and learning preparedness for school, including training of caregivers who would manage the ECCD facility with a multisectoral approach, with emphasis on cognitive, psychosocial, and physical development as well as on health and nutrition. The voices of children were captured and taken into consideration in deciding the way forward; for example, the plan includes provision of recreational facilities to satisfy a variety of the physical, emotional, and psychosocial developmental needs of the children, who had generated a long list of desired play materials and

games in the course of the study. Akinware notes that the "big surprise" for the orphanage Founder that emerged from her work was the demand on the part of the children for a more readily accessible surrogate father.

Akinware concludes that:

> This was a pioneering study as the IQA was being introduced for the first time in a non-Western culture, typically African . . . the IQA tool is quite interesting and relevant to the culture in Zambia; it is not regarded as meddling . . . this research has highlighted the dire need for the government to evaluate on a regular basis the quality of care being provided to its young children. It is envisaged that this will become the norm rather than the exception in the future. The IQA has proved to be a culturally appropriate, innovative and inclusive tool that may be used to ensure quality care for orphans in Zambia. (Akinware, 2004 p. 111-117)

Development of an Alternative Orphan and Vulnerable Care Model in Ghana

Susan Sabaa has been directly involved with child development issues in Ghana since 1996. In her current position as National Coordinator of the Ghanaian NGO Coalition on the Rights of the Child, Sabaa promotes a rights-based approach to child development, trains and educates stakeholders in basic child rights, advocates for effective implementation of child rights via national policies and increased public awareness of pertinent issues affecting children at national and local levels, provides technical assistance for community-level ECD programming and especially for OVC care, and documents early childhood development programs in Ghana.

Sabaa's project first profiles the care of young OVC in three Ghanaian orphanages according to the yardstick of holistic and integrated ECD as defined by Evans, Myers, and Ilfeld (2000), whereby child development involves both a gradual unfolding of biologically determined characteristics and traits that arise as the child learns from experiences; health, intellectual, emotional, spiritual and physical development, socialization, and attainment of culture all interact and are interrelated in a young child's life.

Key recommendations arising from this comparative study include a strong call to empower caregivers through training in appropriate concepts and practices to meet the cognitive and psychosocial needs of young OVC and to strengthen the protection and care of young OVC within their extended families, thereby making institutional care a last resort. The need to ensure that young OVC have the opportunity to bond with consistent caregivers is particularly highlighted.

Sabaa strongly advocates for ECD/OVC-focused provisions that address the special needs of young OVC in legal and policy frameworks,

including ongoing monitoring and evaluation of OVC care programs, and for a close linkage of program content and process principles. She encourages program planners to pay attention to relevant contextual, social, and technical aspects so that programs and services meet the contextual developmental needs of young OVC. Noting that current ECD program planning and packaging in Ghana are mostly being carried out by churches and community-based organizations, central and decentralized government departments and agencies, benevolent individuals and development partners, usually in collaboration with beneficiaries who may not necessarily know much about ECD, Sabaa emphasizes the need to provide a framework of principles based on early childhood developmental needs to guide the content of such packages, as well as programming principles to direct any programming process for OVC care at any level, whether family, community or national.

Second, Sabaa presents feedback from a focus group discussion she facilitated with key national stakeholders responsible for meeting the needs of young OVC. Key points that arose in this timely discussion include stakeholders' concerns regarding low awareness of ECD/OVC issues in-country, the need for serious networking and integration of efforts, the need to promote intersectoral reviews on policy on OVC care to reflect the special needs of ECD/OVC, and strong concerns about lack of monitoring, coordination, and evaluation of programs. Discussants expressed a particular desire for increased public awareness and education regarding the intricacies of infant brain development.

Third, Sabaa proposes an alternative care model for young OVC, emphasizing that programs responding to ECD/OVC should empower families and communities and minimize institutionalization as much as possible. This alternative care model is based on the principles of honoring the fundamental rights of children, promoting training and education in quality integrated early childhood development practices, encouraging community involvement in holistic ECD programming, strengthening economic coping capacities of extended families and communities, and promoting smooth integration of OVC into society. Within these parameters, communities are encouraged to establish and maintain flexible care approaches that can be regularly adapted to meet current needs: program interventions should support children's psychosocial well-being, respect cultural context, take political and social realities and children's rights into consideration, and mobilize a community care network around children.

Sabaa's concluding recommendations focus on establishing appropriate policies and laws regarding the provision of quality OVC care nationwide, including maintaining effective implementation and service

monitoring mechanisms, building effective data for OVC identification, and promoting effective networking and partnering. She emphasizes that the most cost-effective, child-friendly response to ECD/OVC care in Ghana is the home- or community-based one, with a community, family, or church-based development and support partner. Households must be supported to deliver care services for young OVC in their care.

A key challenge identified by Sabaa is the effective monitoring of home- and/or family-based care centers. It is difficult to know what takes place on a daily basis in individual homes and families. This situation calls for effective interactive supervision by the programmer or service provider in ways that bring them into close contact with the child without unduly interfering or escalating tensions in the daily life of the family. The direct duty bearer within the family must also be given adequate economic and psychological support.

Sabaa highlights the need for an effective legal framework in Ghana to strengthen the environment for OVC care and extend monitoring responsibility to include the larger community of stakeholders. She notes that vigorous advocacy and awareness programs, as well as strong provisions for legal protection of the right of young OVC to inheritance, are urgently needed.

Conclusion: Ensuring a Healthy, Capable Cohort of Adults 15 years into the Future

Support systems that aim at helping the young child to thrive must of necessity address the many facets of the child's development as well as the contexts in which they live (Evans et al., 2000). Is it possible, then, to provide adequate quality care for the numbers of young children being orphaned by the HIV/AIDS pandemic in Sub-Saharan Africa at an almost incomprehensible rate? This unprecedented challenge must be met with as many immediate and diverse strategies as can be mobilized now; these children cannot wait for a "grand plan" to be put into motion at some future time.

Stephen Lewis (2004), UN Special Envoy for HIV/AIDS in Africa, reports that the number of medical treatment sites for the prevention of mother to child transmission (PMTCT) is abysmally low; as a result, only a miniscule fraction of HIV-positive pregnant women receive the drug nevirapine. Lewis (2004) supports a concerted focus on women as the priority entry point for treatment; this will require an urgent roll-out of PMTCT facilities to reduce the number of HIV-positive infants and then

an equally urgent roll-out to ensure that women actually get full course antiretroviral treatment (para. 7). With appropriate treatment, the lives of millions of HIV-infected parents could be prolonged, allowing many of them to care for their children at least during the early childhood years. International funders must honour their financial commitments and provide the treatment funds they have pledged. The governments of Sub-Saharan countries must commit to directing treatment funds first to the provision of full course, low-cost anti-retroviral treatment with fixed-dose combination, generic anti-retroviral drugs, pre-approved for first-line use by the World Health Organization, coordinated by the national public health systems of Sub-Saharan countries (Lewis, 2004, para. 5). Profiteering from the human misery generated by the HIV/AIDS pandemic – for example, through forcing the sale in Africa of brand-name anti-retroviral drugs that cost three to four times as much as the WHO-approved generic drugs[3]—must be curbed.

The work of Nyesigomwe, Akomas, Akinware, and Sabaa emphasizes the critical urgency of providing quality holistic care for young OVC in Sub-Saharan Africa. Each of the four ECDVU researchers has undertaken a project that highlights specific aspects of the multifaceted challenges inherent in providing quality care for young OVC impacted by the HIV/AIDS pandemic. Nyesigomwe's work with grandmothers caring for young OVC provides a hopeful glimpse into how much can be accomplished with meager material resources when community interest, involvement, and training is mobilized to assist aged extended family caregivers to support themselves and each other as well as the young children in their charge. Akomas' assessment of the care provided in motherless babies' homes in Nigeria and the resultant staff training program to promote positive nutritional and psychosocial care of orphaned infants speaks to the need for quality training and monitoring of all caregivers, whether in extended family or institutionalized care settings. Akinware, while piloting a quality assessment tool that emphasizes both child participation and institutional self-reflection in the creation of a proactive action plan to improve overall quality of care, concludes that the IQA could indeed be applied as an appropriate tool to monitor the quality of OVC care throughout Zambia. Finally, Sabaa proposes a flexible alternative care model emphasizing child rights and the need for national policies to implement training and ongoing monitoring of ECD/OVC care and advocates for pragmatic support for the overburdened extended family system of care for young OVC, so that institutionalization becomes the "last resort" choice.

These modest projects underscore both the unique growth potentials of the early childhood years and the pressing need for community-based,

national and international stakeholders to reach beyond the undeniably difficult challenges of providing survival-level support for these children. Good early childhood care is associated with higher levels of physical, cognitive, and emotional well-being and increased lifetime learning and earning; timely provision of integrated quality ECD training and care is urgently needed if today's young OVC are to mature into productive and contributing members of Sub-Saharan African society in their adult years. Ignoring their needs will result in a tragedy of truly global proportions—and the opportunity to respond in time is fast slipping away. Every effort must be made now to increase awareness of the particular vulnerabilities of young OVC, and to mobilize national and global responses commensurate with their needs.

Governments of Sub-Saharan nations must move swiftly to adopt and implement national policies that provide culturally appropriate ECD training and resources for both over-burdened extended family and institution-based caregivers of young OVC. Mechanisms to monitor the delivery of quality ECD care must be put into place and maintained. Issues of food security, housing, health and nutrition, education, household income, family mentorship, and training in meeting emotional needs of both children and caregivers must be adequately addressed. International monetary aid must be increased, efforts of donor organizations must be coordinated, and a global resolution that ends the crippling national debt payments by Sub-Saharan nations must be put into effect. The adult world must not fail these millions of vulnerable children in their time of greatest need.

Notes

[1] It is still the case that approximately half of the orphans in Africa were orphaned by causes other than AIDS, although AIDS will soon surpass all other causes combined.

[2] Marasmus is one of three forms of serious protein-energy malnutrition (PEM); the other two are kwashiorkor (KW) and marasmic KW. These forms of serious PEM represent a group of pathologic conditions associated with a nutritional and energy deficit occurring mainly in young children at the time of weaning (Gehri, 2004). PEM is frequently associated with infections, mainly of the gastrointestinal tract. WHO estimates that 49% of the 10.4 million deaths occurring in children younger than 5 years in developing countries are associated with PEM (Gehri, 2004).

[3] See *The Price of Life: Hazel Tau and Others vs. GlaxoSmithKline and Boehringer Ingelheim: A Report on the Excessive Pricing Complaint to South Africa's Competition Commission* (2003). Complainants, including people livingly openly with HIV/AIDS, health care workers treating people with HIV/AIDS, and others,

allege that GlaxoSmithKline and Boehringer Ingelheim are acting in violation of competition law by charging excessive prices for their anti-retrovirals to the detriment of consumers.

References

Akinware, M. A. (2004*). Pilot study of the adaptation of an established measure to assess the quality of child services in a selected orphanage in Zambia: the Inclusive Quality Assessment (IQA) tool.* Unpublished master's major project report, University of Victoria, Victoria, British Columbia, Canada.

Akomas, O. E. U. (2004*). Assessment of the caring practices in two motherless babies' homes in Abia State, Nigeria and the development and delivery of a nutrition training program to the staff of these homes to improve nutrition of children in their care.* Unpublished master's major project report, University of Victoria, Victoria, British Columbia, Canada.

Anglin, J. P. (2002). *Discovering what makes a "well-enough" functioning residential group care setting for children and youth: Constructing a theoretical framework and responding to critiques of grounded theory method.* School of Child and Youth Care, University of Victoria, Victoria, British Columbia, Canada.

Anglin, J., & Dolan, N. (1988). *Integrated quality assurance process adapted for use in British Columbia.* (Unpublished report.) Victoria, BC: Government of British Columbia, Ministry for Children and Families.

Bartlett, K., & Zimanyi, L. (2002). HIV/AIDS and early childhood. *Coordinators' Notebook, No. 26*. Consultative Group on ECCD. Washington, DC: World Bank.

Evans, J. L., Myers, R. G., & Ilfeld, E. M. (2000). *Early childhood counts—A programming guide on early childhood care and development*. Washington, DC: World Bank.

Gehri, M. (2004). Hôpital de L'enfance, Centre Hospitalier Universitaire Vaudois, Lausanne, Switzerland. Geneva: World Health Organization.

Kelly, M. J. (2002). The orphan crisis in Zambia. *Jesuit Centre for Theological Reflection (JCTR) Bulletin 42.*

Lewis, S. (2004). *Briefing by Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa, on his May 19-23 trip to Ethiopia*. Retrieved October 4, 2004, from http://www.waltainfo.com/Conflict/BasicFacts/2004/June/state_01.htm

Lusk, D., & O'Gara, C. (2002). The two who survive: The impact of HIV/AIDS on young children, their families and communities. *Coordinators' Notebook, No. 26.* Consultative Group on ECCD. Retrieved September 15, 2004, from http://www.ecdgroup.com/pdfs/CN26withphotos.pdf

Nyesigomwe, L. (2004*). Strengthening the capacity of grandparents in providing care to children less that 8 years old affected by HIV/AIDS.* Unpublished bachelor's major project report, University of Victoria, Victoria, British Columbia, Canada.

Petito, M. L. (1996). *Nyumbari Orphanage, Nairobi: Internet report*. Retrieved January 7, 2005, from http://www.ecdgroup.com/pdfs/CN26withphotos.pdf

Sabaa, S. (2004). *Development of a model framework for orphans and vulnerable children in their early years in Ghana.* Unpublished master's major project report, University of Victoria, Victoria, British Columbia, Canada.

The price of life: Hazel Tau and others vs. GlaxoSmithKline and Boehringer Ingelheim: A report on the excessive pricing complaint to South Africa's Competition Commission. (2004, January/Febuary). *Children First*, 53. Retrieved January 7, 2005, from http://www.childrenfirst.org.za/shownews?mode=content&id=19003&refto=3542

UNICEF. (2003, December 31). *UNICEF names top five concerns for children in 2004: Overcoming the challenges facing children is key to human progress*. Press release. Retrieved September 14, 2004, from http://www.unaids.org/en/in+focus/topic+areas/impact+on+children+and+families.asp

USAID, UNICEF, & SIDA. (1999). *Orphans and vulnerable children – A situation analysis.* Lusaka, Zambia: Government of Zambia.

USAID & U.S. Department of Commerce. (1999). Focus on HIV/AIDS in the developing world. *World population profile 1998*. Washington, DC: Author.