

35

WORKING PAPERS IN

Early Childhood Development

Young children and HIV/AIDS sub-series

HIV/AIDS:

What about very young children?

by Alison Dunn



About the paper

This paper is the third one of a dedicated 'Early Childhood and HIV/AIDS' sub-series of our long-standing 'Working Papers in ECD' series. The purpose of the sub-series is to generate work that responds to emerging needs, or that present information, experiences, ideas, and so on, to inform all those concerned with young children impacted by HIV/AIDS – including ourselves.

Papers will often be 'think pieces' deliberately produced quickly to reflect the fact that ideas, understandings and approaches are developing rapidly, and to share emerging lessons fast and efficiently.

Each is tightly focused and has a specific purpose. *HIV/AIDS: What about very young children?* responds to the fact that young children impacted by HIV/AIDS often seem to be almost invisible in the wider HIV/AIDS field. With a few notable exceptions, if they are mentioned at all, it is as minor footnotes in the general discourse on children and HIV/AIDS.

This is bewildering: no group impacted by HIV/AIDS is more vulnerable, no group is more deserving, and no group has greater potential to benefit from proper programming. In addition, young children have needs and rights that are particular, distinct and special, and that cannot be met through programmes for children generally – especially when such programmes collectively can cover an age range from pre-conception to as high as 25 years.

HIV/AIDS: What about very young children? is based on research carried out for the Bernard van Leer Foundation between February 2004 and May 2004.

The aim of the research was to review the literature and identify current responses taking place to meet the needs of very young children (age 0–8) in HIV and AIDS-affected communities. The overall results show that at local, national and international levels, there are gaps in programming and policy to engage ideas and mobilise resources to address the needs and experiences of very young children infected/affected by HIV and AIDS. The question is then raised: What can we actually do to include very young children in programming and policy responses in HIV and AIDS affected communities?

We present papers in this sub-series because we believe that they have something useful to offer and are therefore worth publishing. We do not claim they are necessarily exhaustive or balanced in their coverage, nor will we always agree with what they say. In the case of this paper, we believe that it offers a highly useful desk-based review of the field, and we also believe that it will help funders, policy makers and practitioners to understand who is doing what, why they are doing it, the kinds of issue that they are working with, and the kinds of outcomes that they are achieving.

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By Alison Dunn

March 2005

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Preface

Thank you to the following people for valuable suggestions and comments on an earlier draft of the paper: Professor Priscilla Alderson at the Institute of Education, University of London; Andrew Chetley at Exchange, London; Chanel Croker at Amani Child, Tanzania; Bernard Coombes at UNESCO, Paris; Dr. Geoff Foster, Consultant in Paediatrics and Child Health, Zimbabwe; Staff at HelpAge International, London, UK; Sarah Hammond at Healthlink Worldwide, London; Kate Harrison at the International HIV/AIDS Alliance, Brighton, UK; Penny Lancaster at the Coram Family Trust, London; Professor Andrew Tomkins at the Institute of Child Health, University of London; John Williamson; Dr. Rob Vincent at Exchange, London. Thank you to Alison Clarke at the Institute of Education, University of London, for introducing an interesting perspective on the participation of very young children; to Christiana Brown of Healthlink Worldwide for examples of good child-to-child programming practice; and to Tina Hyder of Save the Children Fund UK for providing direction to key resources and information.

This paper is a result of three months of research in the UK. It identifies some key themes and issues in the area of HIV and AIDS and early childhood in developing countries with the aim of stimulating thought and action. I have tried to cover as many examples of work in progress as possible, from grass roots to international levels. Any omissions or errors are my own.

The sources (papers, reports, websites, organisations) used to produce this paper are listed in the reference section at the end of this document. They also form part of an Information Hub managed by the Bernard van Leer Foundation <www.bernardvanleer.org> and currently hosted by SOURCE International Information Support Centre. Many of the documents used in this paper can be found on-line at the SOURCE databases at <www.asksource.info> and all can be accessed physically at SOURCE's resource centre in London - 2nd Floor, Institute of Child Health, 30 Guilford Street, London WC1N 1EH.

The Bernard van Leer Information Hub is dynamic and any further information or resources on early childhood development and HIV/AIDS will be added continuously. Any contributions or suggestions can be given on-line through SOURCE.

Alison Dunn

Executive Summary

The research reviewed and the current responses identified in this paper show that at local, national and international levels there are gaps in programming and policy to engage ideas and mobilise resources to address the needs and experiences of very young children infected/affected by HIV and AIDS. This is especially true if it is accepted, as it is by the early childhood development community, that all children need and deserve support for their holistic development. The question is then raised: What can we actually do to include very young children in programming and policy responses in HIV and AIDS-affected communities?

Communities and families are drawing on their own resources to care for young children made vulnerable by the HIV and AIDS crisis. Under conditions of poverty and stress, they are finding it difficult to provide the stimulation, nutrition and healthcare needed to ensure the young child's development at this critical stage in life. It is clear that while families and communities are making efforts to meet the needs of very young children, they themselves need support so that their youngest members receive proper care and attention to ensure their optimal development.

Chapter one identifies some key areas where the lives of very young children are affected by the pandemic. A review of literature shows the far-reaching impact of HIV and AIDS on very young children at a critical formative stage in

their lives. Responses to mitigating this impact are initially at family and community levels. Supporting existing family and community networks and current efforts that are being made by people confronting HIV and AIDS on a daily basis are therefore important strategies. Community care and support for very young children is not easily defined and its vagueness can translate into inertia.

Chapter two reveals that HIV and AIDS and ECD programming has shown a limited response so far. It then looks at some meanings of holistic and community care and support and ways of supporting very young children and their families and communities through development intervention. During this process, as part of increasing the well-being of young children and to uphold their rights as defined in the UN Convention on the Rights of the Child, it is vital that very young children participate in planning, implementing and evaluative processes. Examples of grass-roots activity show that certain non-governmental organisations (NGOs) are providing services to very young children and their caregivers. The realities on the ground in sub-Saharan Africa have meant that responses have sprung up where it is obvious that very young children need such support. There are other regions where the context of poverty and HIV and AIDS presents a daily crisis to very young children, yet they remain invisible.

Finally, in Chapter three, conclusions are drawn that indicate that services are required urgently to support very young children both directly and through the families and communities in which they live. Partnerships need to be developed between parents, families, NGOs, community-based organisations (CBOs) and governments to ensure the holistic development of the child. At policy levels, very young children need to be included in programmes that address children, HIV and AIDS and community development. All government ministries can participate in meeting the needs of very young children in HIV and AIDS-affected communities.

This paper is not exhaustive but it does start to identify themes, issues and current action. It is intended to stimulate thought and action and raise questions around the lack of attention being given to very young children in HIV and AIDS-affected communities. It is also hoped that it will play some role in promoting respect for capable young children and reduce age-based discrimination against them.

Acronyms and Use of Language

AIDS	<i>acquired immunodeficiency syndrome</i>
ARV	<i>anti-retroviral (medication)</i>
CABA	<i>children affected by AIDS</i>
CBO	<i>community-based organisation</i>
CCATH	<i>child-centred approaches to HIV/AIDS</i>
CG	<i>Consultative Group on Early Childhood Care and Development.</i>
CRC	<i>UN Convention on the Rights of the Child (1989)</i>
ECD	<i>early childhood development.</i>
ECDG	<i>Early Childhood Development Group</i>
ECDNA	<i>Early Childhood Development Network in Africa</i>
FBO	<i>faith-based organisation</i>
HBC	<i>home-based care</i>
HIV	<i>human immunodeficiency virus</i>
MTCT	<i>mother-to-child transmission</i>
NACWOLA	<i>National Community of Women Living with HIV/AIDS</i>
NGO	<i>non-governmental organisation</i>
OVC	<i>orphans and vulnerable children</i>
PMTCT	<i>prevention of mother-to-child transmission</i>
UDHR	<i>Universal Declaration of Human Rights, United Nations (1948)</i>
UNESCO	<i>United Nations Educational, Scientific and Cultural Organisation</i>
UNICEF	<i>United Nations Children's Fund</i>
USAID	<i>United States Agency for International Development</i>
VCT	<i>voluntary counselling and testing</i>
WGECDD	<i>Working Group on Early Childhood Development.</i>
WHO	<i>World Health Organisation</i>

A note on the use of language

'HIV/AIDS' or 'HIV' and 'AIDS'

For the sake of consistency, this paper will use the term HIV/AIDS in relation to existing programmes and documents. However, there has been recent discussion by a number of NGOs and people living with HIV and AIDS, on the need to distinguish between the terms HIV and AIDS. Using the term

HIV/AIDS can imply that HIV is the same as AIDS or that HIV is a death sentence. In the light of ARV treatment and different forms of stigmatism, it is clear that a distinction can be made and recommendations are being made to use HIV and AIDS.

‘Prevention of mother-to-child transmission’ or ‘Prevention of parent-to-child transmission’

There have been suggestions to replace the term ‘prevention of mother-to-child transmission’ with ‘prevention of parent-to-child transmission’ to reduce the sense of blame which is inadvertently put upon mothers. While acknowledging the need for careful use of language, this document will use ‘prevention of mother-to-child transmission’ with reference to the established body of knowledge that has grown in this field.

‘Orphans’ and ‘vulnerable children’

Orphans and vulnerable children are a recent focus of attention. The latter term avoids stigmatising children who were previously called ‘AIDS orphans’ and allow for the inclusion of children who have lost their parents through other illnesses or accidents. In the context of HIV and AIDS, the term vulnerability can mean any children affected by HIV and AIDS. This could include those who are either HIV positive or negative, those whose caregivers are HIV positive or living with AIDS, children who have lost one or both parents to AIDS, children whose families foster orphaned children and even those whose school teachers are HIV positive or living with AIDS. It includes very young children aged 0-8.

‘ECD’ or ‘very young children’

It has been suggested that some people wanting to work with very young children can be put off by the term ECD. This may be because ECD is perceived to be a specialized and technical area. The term ECD can be discouraging to those who may be considering working with under-8-year olds, and so in some instances it is friendlier to use ‘very young children’.

Chapter one

Early Childhood and HIV/AIDS

The nature of the HIV and AIDS crisis and the impact upon very young children calls for an urgent response, yet there has been a limited reaction at NGO, government and international levels. What can be done to support very young children made vulnerable by HIV and AIDS and the families and communities where they live?

The need to link early childhood with HIV and AIDS is clear: the literature shows that the effects of the pandemic on very young children are profound and will have immediate and long-term consequences on their quality of life and personal and social development. Young children living under conditions of poverty and stress are already vulnerable. Those that are dependent on ill and tired caregivers are even more so. The impact of the HIV and AIDS crisis on young children, their families and communities further increases their vulnerability.

There are different experiences of dependency and vulnerability of children under 8 depending on variables such as age, sex or disability. When referring to very young children, this report does not assume that 0–3-year-old infants have similar experiences and needs to 7–8-year-old children. It rather tries to draw attention to children under 8 who are often overlooked.

The situation of children under 8 will also vary according to family and household conditions. Most children born to HIV-positive

parents are at least 5 before their parents die. They rarely receive the proper attention and caregiving required during a critical stage of their development and later witness their parents' traumatic illness and death. In Africa, 15% of under 5-year olds are orphans and are living with extended family members, often grandmothers. Children living with the virus are unlikely to receive any kind of anti-retroviral treatment and many will die before the age of 5.

Due to conditions of poverty and stress, children affected by HIV and AIDS are unlikely to benefit from a holistic package of care and support, and the impact will affect their physical, cognitive and emotional development. This may affect their health, their chances of receiving an education, their social relationships, their future economic production and even the likelihood of becoming HIV positive themselves in later life.

In the context of HIV and AIDS, good-quality early childhood care to ensure optimal development is necessary and important. All children have a right to quality care and this should include access to health, nutrition, education, safe water and environmental sanitation, as well as enjoying growth and psychosocial development. Holistic care and support of the very young child means catering for all of these aspects.

Households and communities are the first line of response to the HIV and AIDS crisis. Household and community members are also the immediate caregivers and supporters of children under 8. It follows that they need support to care for very young children in a holistic way. Strengthening community care and support is a key strategy. This report contains examples of grass-roots activity, mainly in Africa, of NGOs supporting very young children and their caregivers. There are also examples of media, state and multi-lateral intervention to address certain issues relating to HIV and AIDS and children under 8.

Policy and programming recommendations have been drawn from the research. National policies need to be developmentally sensitive and address the particular needs of each age group. Addressing children aged 0-3 who are entirely dependent on primary caregivers will require a different response to working with, for example, 4-8-year olds, some of whom attend school or form part of the labour market. A good early childhood development (ECD) HIV/AIDS programme should have a broad framework, be developed with and for families and with and for communities, respecting cultural values and building local capacity. There should be equal access for all children and it should be flexible and reflect diversity.¹ It should reflect the necessity of holistic care and support of the young child.

Care should be taken to avoid causing stigma and further discrimination of children and

families that are affected by HIV and AIDS. There is a need for research and efforts to advocate change in the wider environment to support very young children in HIV and AIDS-affected communities.

Methodology

Information was gathered from the internet and on-line databases, including Source, Eldis and the Communication Initiative. The search included on-line academic journals, websites relating to HIV/AIDS (and children), websites relating to ECD and abstracts from international HIV/AIDS conferences. Personal contact with professionals working in areas of HIV/AIDS and children, ECD, child health, children and child participation, health communication programming and child health also helped me identify key themes and work operating at grass-roots levels.

The remit of the research was to cover the geographical area of Africa, South-East Asia and the Caribbean. Most of the literature and grass-roots activity I came across was focused in Africa. I found no websites relating to very young children and HIV/AIDS in South-East Asia and only one in the Caribbean. Through personal contacts I identified one project in the Philippines that aimed to include, although not specifically address, very young children in work around disclosure and counselling. The findings are therefore focused in Africa. It may be because the impact of HIV and AIDS has hit sub-Saharan Africa the hardest, and responses are therefore more widespread and visible.

The question is raised, however, why responses are more evident in Africa but not elsewhere in regions where HIV and AIDS is already a catastrophic event.

Internet searches and limited contact with professionals can reveal only a general picture of the current situation of very young children living in HIV and AIDS-affected communities and the responses that are being made to meet their needs. The image is that where HIV and AIDS has had most impact (such as Africa), responses to very young children are slowly emerging. There are now several tools and guidelines accessible on-line to assess the situation of very young children in HIV and AIDS-affected communities; while UNICEF, the World Bank and USAID have produced a set of operational guidelines to incorporate very young children into multi-sectoral HIV/AIDS programmes in Africa.

At grass-roots level only a small number of projects have the finances and technical ability to produce a website promoting their work, and there are undoubtedly more undiscovered responses at local levels. There are also many more responses people are making in their communities outside of the formal remit of NGOs and CBOs. In addition, I did not include the many 'orphanages' or residential and care institutions that can be found. There are too many to list, and it is widely understood that they are not the most appropriate or replicable means of support.

Why link HIV and AIDS with early childhood?

Children living with HIV and AIDS and those living in affected communities bear the brunt of the pandemic at a very early age. HIV and AIDS will affect 15 million children under 5 by 2010. Although vulnerability is difficult to measure, it is safe to say that very young children are more likely to be adversely affected by the impact and consequences of living in HIV and AIDS-affected communities due to their vulnerability to disease and malnutrition; and the consequences of not meeting their psychosocial needs are greater.²

In HIV and AIDS-affected communities, the negative impact of the pandemic on all very young children is profound. This is particularly significant in developing regions, which will have 88% of the world's children age 0–4 years by 2020. Sub-Saharan Africa alone will have 24% of the world's children age 0–4 years.³

New prevention-of-mother-to-child-transmission (PMTCT) initiatives are showing some success.⁴ There has been a rapid decline in the number of AIDS cases in children under 5 in Thailand, since programmes to prevent mother to child transmission (MTCT) have been introduced. Without intervention, MTCT rates can vary from 15% to 30% without breastfeeding and can reach 30–45% with prolonged breastfeeding. In many parts of Southern and East Africa, over 20% of under-5 mortality is attributable to HIV and AIDS.⁵

The number of babies and infants living with HIV is a minority group. The majority of children born to HIV-positive parents are not infected but rather directly affected. A study in Uganda showed that 70% of children born to HIV-positive mothers are over 5 years old before their mother dies.⁶ Living with parents who are ill and tired, young children often take on the role of caregivers, holding responsibilities for which their parents are no longer capable. They spend their days looking after themselves, their parents and other siblings. The intimate relationship between mother and child and the consistency of caregiving is of critical importance to the development of the child. In general studies, research has shown that maternal depression and the lack of social support has a negative impact on mother-and-infant bonding and parenting functions.⁷ This can be linked to depression in HIV-positive mothers, which has the potential to disrupt parenting functions and subsequently the holistic development of the infant.

Worldwide, over 13 million children have lost one or both parents to AIDS.⁸ UNICEF's *Africa's Orphaned Generations* shows that 15% of the orphans are 0–4 years old and 35% are aged 5–9.⁹ By 2010 there will be an estimated 15 million children under 5 orphaned by AIDS, and yet more will be living with ill and tired caregivers.¹⁰ This figure may even be modest as HIV-positive infants and children are not included in estimates of orphans.¹¹ In sub-Saharan Africa almost 5 million children under 5 have lost one or both parents to AIDS. The effects of HIV and AIDS on infants and

young children are profound and threaten to undermine the achievements that have been made so far in reducing infant mortality rates and progress in health and education.

The experiences of very young children affected by HIV and AIDS are to a great extent dependent on their family situation. A child's experience will differ if they have lost one parent (single orphan) or both of their parents (double orphan). Whether a child has lost a mother or a father will also have an impact, especially in the case of babies and infants who are dependent on a primary caregiver, usually the mother.¹² As well as the many children who have lost one or both parents to AIDS, many children have one or both parents who are HIV positive and siblings who are HIV positive.

The lack of availability of anti-retroviral (ARV) treatment means that most children born to HIV-positive parents eventually witness their traumatic illness and death. These children are then absorbed into extended families, and new caregivers are often grandmothers or other siblings. *Africa's Orphaned Generations* shows that in countries such as South Africa, Zimbabwe and Namibia, over 60% of double orphans are living with their grandparents.¹³ In Cameroon, 57% of orphans are raised by uncles and aunts. Where 'breadwinners' have died and any family wealth has been spent on care and treatment, the affected family is sometimes ostracized from its income-earning activities and becomes further impoverished. Older people are expected to fill in the gaps where institutional, agency or donor support is lacking.¹⁴

The significance of age 0–8

The 0–8 age range is a critical period in any child's life; all aspects of their development (emotional, social, cognitive, physical and spiritual) are at their most rapid. The speed of development throughout this age range means that addressing needs will depend on the specific age of the infant or child. The needs of a baby are different to that of a 5-year old to that of an 8-year old, and interventions are often targeted at specific ages within this range. Whatever the focus, it is clear that the nutritional, psychosocial, educational and protection needs of under-8-year olds are different to those of older children.¹⁵

In *A World Fit for All Children*,¹⁶ 180 countries agreed that every child should have a safe, caring and nurturing environment where they can be healthy, both physically and mentally, emotionally secure, socially competent and able to learn. "Children under 5 need diverse food given in frequent feedings, attention to immunization and childhood illnesses, and interactions that nurture mental and emotional development."¹⁷ As the child's brain is developing, it is sensitive to nutrition and stimulation more than at any other time.¹⁸ It is an essential period because it is here that children learn patterns of behaviour that are established for the rest of their lives. The social environment plays a key role as the child grows up and develops.

The 0–3 age is considered to be the most critical period of development. UNICEF's *The State*

of the World's Children 2001 argues, "What happens during the very earliest years of a child's life, from birth to age three, influences how the rest of childhood and adolescence unfolds."¹⁹ The foundations for values and social behaviour are laid in the first 3 years of life, and the external environment has most influence. "All the key ingredients of emotional intelligence – confidence, curiosity, intentionality, self-control, relatedness, capacity to communicate and cooperativeness – that determine how a child learns and relates in school and in life in general, depend on the kind of early care he or she receives from parents, preschool teachers and caregivers."²⁰

When Carole Bellamy launched *The State of the World's Children 2001* she said, "The greatest tragedy is that many decision makers don't know how crucial those first three years of life are."²¹ Ignoring the needs of young children will have an impact on the societies and communities in which they live. "Unless under-fives are cared for in the present, no amount of later intervention is likely to be effective or efficient."²²

What is the impact of HIV and AIDS on very young children?

HIV-positive children

Infant mortality rates are hugely affected by AIDS, and the gains made in child survival will disappear in the 34 worst-affected countries.²³ USAID (1999) reported that 50% of HIV-positive infants die before their first birthday and most of the rest before their fifth birthday.²⁴ One study in Zambia showed that nearly half of

all infected children had died by the age of 2.²⁵ A recent survey presented at the Social Aspects of HIV and AIDS Research Alliance (SAHARA) Conference 2004 in Cape Town, South Africa, showed that nearly 7% of South-African children between the ages of 2 and 9 are infected with HIV. Nearly 10% of the 2–9 age group had already lost at least one parent.²⁶

For those very young children living with the virus, chances of survival are slim. This could affect girls more than boys: one report notes that girls are twice as likely to become infected in the womb than boys.²⁷ Access to ARV is limited. The WHO 3 by 5 Initiative, which aims to treat 3 million people with ARV by the year 2005, does include PMTCT but does not seem to be targeting young children. The Millennium Development Goals (2001)²⁸ refer to reducing child mortality under 5 between 1990 and 2015 by two-thirds. To meet this end, preventing MTCT and providing ARV to young children within strong healthcare systems is a crucial strategy.

PMTCT of HIV

PMTCT specifically tries to stop the HIV virus passing from mother to child. A key element of work with under-8-year olds would include the prevention of MTCT during pregnancy, childbirth and infant feeding practices. In some areas PMTCT has seen transmission levels drop to 10% through ARV medication, caesarean section and locally appropriate feeding practices.²⁹ One way of reducing the risk of infection during pregnancy and childbirth means mothers having access to ARVs (Nivirapine and Zidovudine). In Zambia

a strategic framework and workplan for the expansion of integrated PMTCT services is being run from 2003 till 2005. However, women can only benefit from this if they know their HIV status, and this means having access to voluntary counselling and testing (VCT).³⁰ Access to VCT plays a key role in preventing MTCT, but there is also a need to consider the psychosocial and emotional needs of women and families who test positive. Effective interpersonal communication and support to understand new and important social and health issues related to HIV and AIDS is vital.³¹

The WHO has published a literature review on HIV-positive women and their families, including the role of VCT in preventing MTCT and psychosocial support for women who are infected.³² It deals with stigma and discrimination and the benefits and risks of disclosure. The WHO also publishes a monthly on-line survey of publications and abstracts related to PMTCT.³³

Reducing the risk of HIV infection by not breastfeeding has been promoted in some resource-poor countries. The implication of this practice is that babies may not receive the required protection against malnutrition, infection and premature death.³⁴ In Africa, for example, “alternatives to breastfeeding are frequently unavailable, unaffordable or culturally unacceptable.”³⁵ Exclusive breastfeeding has been promoted during the first 6 months, since babies who are exclusively breastfed are at a much reduced risk of contracting HIV than those who are partially

breastfed and who received other foods and liquids during early childhood. However, practically this is not possible for many rural women who may leave babies with caregivers.

Early cessation of exclusive breastfeeding is also thought to be another means of reducing chances of infection. UNAIDS, WHO and UNICEF suggest this feeding option. However, encouraging mothers to follow this suggestion is extremely difficult, as the average duration of breastfeeding (18–25 months) in Africa shows. Traditionally, experience with breast milk substitutes is low, and if a woman stops breastfeeding early, there may be increased pregnancies. Normal patterns of bonding are also disrupted. The infant may experience emotional and physical trauma, resulting in dehydration, refusal to eat and malnutrition if breastfeeding is suddenly ceased. It is also likely that any woman not breastfeeding will be suspected of being HIV positive and is likely to become stigmatised. Encouraging HIV-positive women who do not want to be stigmatised to change their baby feeding practices is very difficult.³⁶

Mother-to-child interaction

In general studies, research has shown that maternal depression and the lack of social support has a negative impact on mother-and-infant bonding and parenting functions.³⁷ This ultimately affects the infant's development. Post-natal depression has been shown to have an impact on a child's growth in developing countries³⁸ and the disruption of mother-infant interaction also has an impact on the

psychological and cognitive development of the child.³⁹

Depression in HIV-positive women has been linked to negative influences on the psychological, cognitive, social and emotional development of their babies and infants.⁴⁰ Children born to HIV-positive mothers are likely to be exposed to factors that affect their development at all levels. In South-West Uganda, an analysis of a cohort study showed that the loss of a mother was related to an increase in child mortality in the first year after her death. This included orphans who were not HIV positive.⁴¹

Psychosocial impact

Recognising 'psychosocial' needs in children and adults is relatively new. It refers to the psychological and emotional well-being of both the child and the caregiver, including issues of self-esteem, insights into adaptation to the new circumstances brought by the impact of HIV and AIDS, social functioning and social relationships.

Very young children who witness the trauma of their parents' illness and death experience long periods of anxiety and stress and will be affected psychosocially. They are likely to experience tremendous grief and depression when they see their parents suffering from illnesses and dying, and may feel guilty and helpless. They may experience trauma over separation from siblings and they may experience stigmatisation and discrimination from the rest of the community resulting in shame and fear.⁴² In extended family fostering

situations, children under 5 need ‘love and trust from consistent caregivers’ – a primary psychosocial issue that needs addressing.⁴³

Extended family care

Extended families are absorbing orphaned children, and the primary caregivers are for the most part grandmothers. While communities and families are making huge efforts to care for these children, the financial, practical and emotional strains are obvious. It has been suggested that children under 5 are the least popular age group with fostering families, as they are entirely dependent and can contribute little or nothing to household and farming labour. There have been cases reported of discrimination. One orphan reported that he was sent to collect firewood and while he was out the other non-fostered children were fed.⁴⁴ Treatment of fostered children may be related to cultural and spiritual beliefs. The Speak for the Child Case Study⁴⁵ shows that there was little discrimination in South Kabras, Kenya. A cultural belief that the spirits of orphaned children’s parents will punish a family that mistreats an orphan means they are generally well treated although there can be a fear of contact with orphans.

The high numbers of orphans and vulnerable children (OVC) are affecting traditional kinship systems of extended family networks, putting pressure on family structures and creating tensions around issues of inheritance and land.⁴⁶ Households with orphans are more likely to be poorer. With an increased number of dependents and fewer earning adults, households with

orphans reduce the amount of land they cultivate and grow crops that are less labour intensive but also less nutritious. Strategies employed to survive, such as selling land and assets and borrowing from families and friends, are unsustainable over long periods of time.⁴⁷

Caregiving

A UNESCO policy brief on early childhood details the analysis of a survey carried out by the Project on Global Working Families in three different locations in Botswana.⁴⁸ It shows that HIV and AIDS is having a critical impact on the care of children infected and living in families with infected members. Findings show that HIV and AIDS caregivers are worried about the quality of the childcare their children receive. For those parents who look after sick children, 29% leave work at least once a month to attend to sick children (compared to 19% who were not HIV and AIDS caregivers). Absence from work resulted in loss of income and sometimes job loss. This could have a serious impact on a family’s ability to care for young children. HIV and AIDS caregiving also means that parents working to care for HIV-positive family members spent 74 hours per month giving care to their children, which is 22 hours less than non-caregivers. Forty-eight percent of HIV caregivers spent two hours or less per day with their own children.

Child-headed households

Very young children find themselves in caregiving roles, not only to their ill parents, but also when they form part of child-headed households. In South Africa, the President’s

State of the Nation report (2001) showed that in certain areas the ages of children heading households were between 6 and 11 years. Young caregivers in child-headed households as young as this cannot provide adequate emotional, nutritional or financial support to their peers nor themselves.

Health

The belief that the HIV-positive mother automatically transmits HIV to the child is widespread. A child born to an HIV-positive mother may not receive healthcare treatment where resources are scarce and families do not want to invest in what they see as a terminally ill child.⁴⁹ Children under 5 in HIV and AIDS-affected communities are therefore more vulnerable than ever to malnutrition, diarrhoea and malaria. They are also less likely to receive vaccinations.⁵⁰ Older siblings in child-headed households will be likely to ignore immunisation needs and be unable to determine when healthcare is urgently required. Babies who are not breastfed because their mothers are too sick or choose not to because of the risks of infection, are at a greater risk of contracting diarrhoea and acute respiratory infections.⁵¹ Without community support, HIV and AIDS-affected households, food consumption can fall by more than 40% meaning that children are at a higher risk of malnutrition and stunted growth.

Girls

Girls are more likely to be adversely affected in early childhood than are boys, due to discrimination. Yet they need to receive equal

opportunities in terms of nutrition, intellectual stimulation and opportunity to play.⁵² They are also more likely to experience sexual and violent abuse, something that has been documented for older girls in schools in Africa.⁵³ In Southern Africa, the prevalence of gender violence has led some to talk of a 'twin epidemic' of HIV and AIDS and violence against women.⁵⁴ In this context, ideas that sleeping with a virgin cures AIDS places girls as young as 6 at risk⁵⁵, and a report from South Africa reveals the tragic incident of the rape and death of a 2-year-old girl.⁵⁶ In one clinic in Zimbabwe, 25% of all cases of sexual abuse are reported in children under 5.⁵⁷

Girls are more likely to be adversely affected than boys, as traditional roles of caregiving and subordination are played out in families and communities affected by HIV and AIDS. Girls are not only at risk of HIV and AIDS through being placed in exploitative situations, but also have the burden of the responsibility of care in affected families, which can inevitably affect their chances of access to formal education. It is vital to eliminate discrimination in early childhood. Fostering positive gender socialisation and gender-sensitive early childhood education are vital strategies to reduce inequalities between girls and boys.⁵⁸ This includes addressing patterns of learned behaviour among boys as well as girls.

Financial

From an economic and practical point of view, very young children impacted by HIV/AIDS may lose their inheritance rights and lose family

land and property. As a result, when they are older they will be forced to migrate to cities and towns, where they are likely to become street children.⁵⁹ There is therefore a strong link between child labour and HIV and AIDS, and the numbers of child prostitutes and children working in the street or other hazardous conditions increase.⁶⁰ People in HIV and AIDS-affected communities have acknowledged this consequence and recognise the need to care for orphans and vulnerable children to reduce the number of street children and youth gangs.⁶¹

Long-term risk of HIV infection

It has been suggested that children affected by HIV and AIDS who do not receive essential care when they are young may have fewer skills to be productive when they are older and be less able to respond to later HIV and AIDS prevention strategies.⁶² The Bernard van Leer Foundation also suggests that the reason that awareness of HIV alone does not frequently lead to behaviour change, is “because many of the attitudes and behaviours that promote the spread of HIV and AIDS are learned early on and are difficult to change at an adult or perhaps even an adolescent stage.”⁶³ An individualistic perspective needs to be supplemented with a broader approach that considers the impact of social, economic and political environments. These are also likely to dictate the level of risk a person may find himself or herself facing later on in life.⁶⁴ Current thinking on HIV and AIDS prevention strategies goes beyond individual behaviour change to look at the social context, including poverty, gender inequalities and

power relations, which can set the parameters around options of safe behaviour.⁶⁵

The Bernard van Leer Foundation hypothesis is that well-conceived early childhood development programmes can encourage positive characteristics in terms of self-esteem, respect for others, self-perception in gender terms and critical thinking, which will allow children to grow into adults who have a stronger chance of protecting themselves against HIV. Work on developing negotiation and interpersonal skills in young children⁶⁶ may bring to bear some light on the issue of how young children can be encouraged to develop such skills in the context of living in HIV and AIDS-affected societies. While it is undeniable that both positive and negative early childhood experiences have long-term consequences in terms of developing skills and abilities, in the context of HIV and AIDS it is also important to consider broader socio-economic influences that create the conditions in which HIV is easily spread.

Seeing socio-economic factors as determinants of susceptibility to HIV and AIDS means seeing HIV and AIDS as a developmental issue. The AIDS Foundation for South Africa argues that in the context of HIV and AIDS, main contributors to the spread of the epidemic are the deprivation trap as a result of poverty, physical weakness, isolation, vulnerability and powerlessness; negative impacts of socio-economic development in relation to labour migration, urbanization and cultural modernisation; and the low status of women in

many societies, which results in powerlessness to negotiate monogamy, safer sex practices and decisions around childbearing.⁶⁷ It therefore follows that global structures of inequality, international economic relationships and state welfare policies and programmes play key roles in improving socio-economic environments and reducing gender and power disparities.

Seeing positive early childhood experiences in relation to risk reduction of HIV infection in adulthood needs to take account of the broader social context. As the AIDS Foundation for South Africa says, “prevention needs to engage, and be relevant to the context in which behaviour takes place. This is the single biggest challenge for HIV prevention and one that will require a great deal of effort in the future.”⁶⁸

Chapter two

Levels of Intervention

The early years in wider social, economic and political contexts

Social, economic and political conditions are the context in which HIV and AIDS is spreading, and these conditions will have an effect on the likelihood of individuals being both infected and affected by HIV and AIDS. At the same time, HIV and AIDS is fundamentally challenging development processes, so that all development intervention needs to be seen in the context of HIV and AIDS. The development of very young children is being negatively affected in the context of HIV and AIDS, and this in turn will negatively affect the development of countries.

Reasons for intervening to improve the conditions of very young children reach into social, economic and political realms. Ensuring that early childhood experiences are positive and equal can play a role in reducing power disparities between men and women. For example, learned social behavioural patterns of subordination and domination and expectations of roles are set very early on in childhood. This can have a huge future social impact. It is now understood that there is a strong relationship between the disparate power relations between men and women and the spread of HIV and AIDS.

From an economic perspective, the World Bank recognises the need to tackle ECD because very young children who do not develop to their full

potential will not have the skills and abilities to lead economically productive lives. There is a USD7 return for every USD1 invested in the physical and cognitive development of babies and toddlers, mostly from costs savings in the future.⁶⁹ These savings could be in “remedial education and health care and rehabilitation services and higher earnings for parents and caregivers who are freer to enter the labour force.”⁷⁰

When competencies are set early on in life, investment in early childhood can extend into the political realm in which a country’s position in the global economy can depend on the competency of the population.⁷¹ The developmental impact is also great. UNICEF says, “Healthy children – healthy in the total sense of the word – are basic to a country’s development.... Poor, malnourished and unhealthy children make for poor and powerless states that are then at the mercy of stronger states. As the lives of young children are short-changed, so the fortunes of countries are lost.”⁷²

When examining this broad long-term perspective, it is important to remember children are seen as investments in the future mainly within the framework of the modern industrial state. Consideration for the future is also undoubtedly important in developing countries. This emphasis must not undermine the importance of current experiences of young children. Recent analyses of childhood and society and of boundaries of authority between

adults and children notes the importance of seeing children as 'beings, not becomings'.⁷³ Here it is important to reinforce the importance of meeting the immediate developmental needs of very young children living in HIV/AIDS-affected communities today: children need to be seen as existing in the present, not just as investments in the future of countries.

What are the current responses?

Early childhood development often focuses on the 0–8 age range, while appreciating that experiences within this range are of course very different. The fact that children under 8 as a target group have distinct experiences of the HIV and AIDS pandemic has so far largely been ignored. Main activities tend to be around prevention and treatment, the prevention of MTCT, or the wider impact on the education system.⁷⁴ There tends to be an overt focus on OVC. This category includes children orphaned by AIDS, HIV-positive children and HIV-negative children who are living with HIV-positive parents or siblings. However, the latter two categories are addressed to a lesser extent.

Programming responses have often attempted to institutionalise orphaned children to varying degrees, rather than support community-based efforts and attempt to meet the emotional and psychosocial needs of very young children and infants. This would include both orphaned children and those who are living with HIV-

positive/ill parents. The resulting gap in programming raises many questions around the best type of approach to support such young infected and affected children and how to work with young children under 5.

Major HIV and AIDS programmes do not seem to be engaging overtly with children aged 0–8. All HIV and AIDS programming has the potential to trickle down and benefit young children, but a specific focus on 0–8-year olds is missing. HIV and AIDS work also tends to overlooks the 60+ age group. These two age groups are crucially linked in the HIV and AIDS crisis as the pandemic is effectively wiping out the middle generation and older people are becoming primary caregivers under difficult conditions.⁷⁵

There are, however, some new initiatives that are starting to address the issue of very young children.

In 2003, UNAIDS, the World Bank and UNICEF published *Operational Guidelines for Supporting Early Childhood Development (ECD) in Multi-Sectoral HIV/AIDS Programmes in Africa*,⁷⁶ which give direction on how to integrate effective broad-scale interventions to ensure the healthy physical, emotional and cognitive development of young children. The ECD HIV/AIDS Initiative in sub-Saharan Africa featured a prominent workshop in Dar es Salam in 2004 on ECD and HIV/AIDS and focused on these operational guidelines. It aimed to accelerate

the early child development response in the context of HIV/AIDS, to learn how to access World Bank Multisector HIV/AIDS Program funding for ECD and AIDS activities, and to prepare a two-year ECD HIV/AIDS Action Plan.⁷⁷

The International HIV/AIDS Alliance will be adding a booklet on working with very young children to its Building Blocks package of resources for working with OVC.⁷⁸ ECD organisations such as the Working Group on Early Childhood Development (WGECD)⁷⁹, the Consultative Group on Early Childhood Care and Development (CGECCD)⁸⁰ and the World Bank⁸¹ are also closely associated with programming in this area.

UNESCO has initiated activities in the area of young children and HIV and AIDS which concentrate on building partnerships for documenting young children and HIV and AIDS issues and initiatives, information sharing and contributions to discussions through on-line e-mail dialogue and the development of a website. They aim to develop multimedia materials and modules to use for working with young children in the context of HIV and AIDS. They also aim to provide support through networking and partnerships for workshops around issues of young children and HIV and AIDS.

The WGECD was created in 1997 with UNICEF as the lead agency. In 1998, the leadership of the group was moved to the Netherlands Ministry of Foreign Affairs. It is guided by a consultation group of representatives of African Countries

who have demonstrated an interest in ECD, and by international agencies and subregional organisations with strong commitment to ECD. Its goal is to support national governments in Africa that commit to and invest in ECD, and they are encouraging countries to develop strategies to help young children affected by HIV and AIDS. The CGECCD is an international inter-agency group dedicated to improving the condition of young children at risk. It includes a broad network of agencies and regional organisations that each represent (or are involved in developing) broader regional networks of early childhood planners, practitioners, researchers and policy makers. The World Bank ECD programme and website is a collaborative effort of the World Bank, CGECCD and the Organisation of American States. The website contains useful resources, including documents, reports and addresses of other websites, with a regional focus on Africa, the Caribbean and Latin America. It also contains a useful HIV and AIDS section.

The Early Childhood Development Network for Africa (ECDNA), created in 1994, is a group of professionals in the sector of development programmes for young children in Africa. It contributes to the development of holistic approaches to child development, survival, protection and education. It does this through information and communication strategies, documentation, case studies, training, action research programs, and contribution to policy dialogue and policy development of integrated early childhood development programs. It

recently set up an initiative called Young Child and HIV/AIDS to try to meet the needs of OVC in Africa.

The Bernard van Leer Foundation has for a long time had an ECD focus, aiming to improve the chances of young children living in disadvantaged situations, and it has been funding ECD programmes with an HIV/AIDS focus for almost 10 years. In 2002 it completed the development of its multi-year Young Children and HIV/AIDS Initiative, which aims to be an appropriate short- and long-term response to the particular needs of young children affected by HIV/AIDS. It complements the efforts of others who are working at micro or macro levels. Its objectives are:

- to improve young children's developmental opportunities in areas impacted by HIV/AIDS;
- to develop, document and share models of best practices and effective programmatic choices for partners working with children and HIV/AIDS;
- to develop effective advocacy and communication strategies about children and HIV/AIDS;
- to develop the Foundation's expertise in the field of children and HIV/AIDS.

The Initiative aims to act as a bridge between the ECD and HIV/AIDS communities by identifying how ECD programmes are responding to HIV/AIDS and by bringing ECD concerns to the attention of HIV/AIDS organisations and programmes.⁸²

Holistic approaches: Survival, development and participation

It is established that ECD is critical and that the external environment has as much of an impact on the development of the child as does good nutrition, hygiene and healthcare. Balancing needs, rights, survival and development is therefore a key element of working with very young children. ECD refers to all efforts made to support children or their caregivers that encourage the holistic development of the child. Support should include attention to health, nutrition, education, water, and environmental sanitation in homes and communities, as well as to promoting the growth and psychosocial development of children.⁸³

Leoning-Voysey and Wilson's (2001) study of approaches to caring for children orphaned by AIDS and other vulnerable children⁸⁴ suggests that essential elements to providing quality care and realizing rights include:

- **survival** – food, clothing, a good home environment including shelter and protection against environmental hazards, cleanliness and bedding, access to water and sanitation, treatment and healthcare;
- **security** – protection from abuse, neglect and exploitation, and against discrimination and stigmatisation, and the presence of a caring and consistent adult who offers affection and security;
- **socialisation** – identity through birth registration, respect for kinship and identity, cultural identity, education and schooling, participation, understanding, information

and communication, counselling and support for children who are experiencing social and emotional difficulties;

- **self-actualisation** – through recreation and play with peers to allow freedom of expression;
- **palliative care** – caring presence and pain relief, acknowledgement of death, after death services.

Viewing the situations of very young children affected by HIV and AIDS through a human-rights lens can be helpful establish a holistic framework for addressing their needs. The HIV/AIDS pandemic is reversing many rights that children in developing countries have recently been starting to enjoy. The UN Convention on the Rights of the Child (1989) is applicable to all children under 18 (depending on national law) and all of the articles apply to all children, including babies, infants and children up to 8 years old.⁸⁵ States are legally and morally obliged to do all they can to fulfill the rights set forth in the Convention on the Rights of the Child. (All States except the USA and Somalia have signed.) The four key areas of rights that States have to respect and ensure are:

- **survival rights** – the right to life, and to the things children need to stay alive;
- **development rights** – things children need to achieve their full potential;
- **protection rights** – safeguards that children are entitled to against all forms of neglect and abuse;
- **participation rights** – rights that allow children to take part in affairs that affect their lives.⁸⁶

States are also obliged to respect and ensure the rights set forth in the declaration based on the principle of non-discrimination and take all appropriate measures to ensure that the child is protected against all forms of discrimination. The best interest of the child should always be the primary consideration. In terms of the right to participation there are complex arguments around if and how it is appropriate to include the participation of very young children and infants.⁸⁷

A rights-based approach can be useful in that its universal application can ensure that all categories of children under 8 are included in policy and programming. Gender issues are obvious, yet are often still overlooked. Groups that tend to be excluded from policy and programming – such as disabled children, nomadic children and children from religious and indigenous minorities – also need to be included. Attention to all categories of children is critical.

A good ECD programme will incorporate the principles of the CRC, including the right to survival and development, non-discrimination and the best interests of the child. Save the Children have taken a rights-based approach to their programming based on these principles and have started to monitor and evaluate their programmes against the CRC.⁸⁸ A good ECD programme would also build on the Convention on the Elimination of All Forms of Discrimination against Women, recognizing that ensuring women's rights is basic to ensuring children's rights.⁸⁹ A woman's physical

and emotional condition influences her pregnancies and her baby's development.

Other international documents can also be referred to in the promotion of ECD. Article 26 of the Universal Declaration of Human Rights (1948) says that "Everyone has the right to education... Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship". In respect of early childhood this means ensuring that the very young child has access to explore all areas of its personality, to learn through play and interaction with others and to build confidence and understanding of its environment.

UNESCO has also taken a rights-based approach and in 2002 held an international workshop entitled 'Protecting the Rights of Young Children Affected and Infected by HIV/AIDS in Africa: Updating strategies and reinforcing existing networks.' The workshop was set within the framework and principles of the Dakar Framework for Action and the CRC and examined services and programmes that touch on the links between children under 8 and HIV and AIDS. The report argues that culture, HIV and AIDS and children's rights are closely interacting issues that end up as a triangular interaction. The denial of children's rights makes children more vulnerable to HIV and AIDS and cultural destabilization. HIV and AIDS is exposing children to economic and social destabilisation and a loss of identity.⁹⁰

The United Nations Committee on the Rights of the Child held a 'Day of General Discussion on Implementing Child Rights in Early Childhood' in September 2004.⁹¹ The UN General Assembly 2002 Special Session on Children adopted a plan of action that commit member states to the "development and implementation of national early childhood programmes to ensure the enhancement of children's physical, social, emotional, spiritual and cognitive development." The Committee on the CRC decided at the 33rd session to devote the 2004 Day of Discussion to this area. Key issues covered include:

- rights to survival and development; health, nutrition and education; and leisure, play, rest and recreation;
- states parties must give appropriate assistance to parents and legal guardians; young children need to be seen as full actors of their own development: what are the best practices and those to be avoided to involve young babies and young children in their own development?
- child participation in family, school settings and community – in all matters affecting him or her. It is strongly process-oriented, based on social interaction skills: a learning process for adults and children;
- states parties must ensure there are child sensitive and centred programmes and services offering a sound environment for the development of participatory rights – in day cares, EC programmes, preschool, pre-primary and first years of primary education. In all, the child should be promoted as a rights holder.

The invisibility of very young children – assessment tools

One of the givens in the field of ECD is that most young children are not in formal institutions such as schools – or even preschools – and it is therefore difficult to identify vulnerable children and subsequently find ways to support them. Reaching under-8-year olds through formal programmes is difficult, since, for example, more than 95% of 5–6-year olds in Africa do not have access to ECD programmes.⁹² Children of school-going age that are either in preschool or primary school will be easier to identify and work with. Very young children may also have different needs depending on their age and circumstances. Some children may need nutritional support or health support. All young babies need vaccinations. Children of school-going age will need assistance related to educational access, for example.

Tools with which to assess the situation of very young children are starting to appear. *Assessment and Improvement of Care for AIDS-Affected Children under Age 5* by LINKAGES, for example, is a highly useful book addressing the main issues confronted by children under 5 affected by HIV and AIDS.⁹³ It looks at the specific problems facing vulnerable children, such as risk of infection, nutrition and health concerns and psychosocial requirements. It then addresses beliefs and traditions that impact the children around feeding, VCT, orphans, household assets and so on. It later looks at who is caring for very young children, programmes and concerns about orphanages

and finally considers some of the assessment tools for caring for vulnerable young children.

The World Bank ECD team subsequently launched a *Child Needs Assessment Tool Kit: A Tool Kit for Collecting Information for your Organisation Needs for Designing Programmes to Help Young Children in Areas Heavily Impacted by the HIV/AIDS Epidemic*.⁹⁴ This tool kit is aimed at assisting World Bank task managers, NGO service coordinators and others, enabling them to base their work on sound data and to design appropriate activities. It suggests ways to design, collect and analyze data in order to focus programmes on areas of greatest need in the community. The assessment provides information about the household, the family, the main caregivers, each child under 8 years old, and whether their basic needs – housing, food, clothes, bedding, daily activities, health, education and childcare – are being met or not.

The *Speak for the Child Case Study*⁹⁵ shows how identifying and targeting the most vulnerable children in a community is critical, since the limited funding and resources of most local programmes make it impossible to reach all young children. Targeting of the most vulnerable children was achieved by a community-based targeting survey, refining survey forms to key areas understood by all and by giving the community choice and control over the geographic distribution of identified children. Inevitably, children over 5 were identified as under 5 by families who wanted to benefit from opportunities. Where it is impossible to define a child's age it is suggested that local

cultural practices are used to identify very young children not old enough to go to school.

Assessment tools from the *Speak for The Child Project* were designed with three components: questions for caregivers, caregiver observations and child observations. The tools addressed different aspects of care (a) orphan-caregiver relationship (love), (b) nutrition and health, (c) psychosocial issues, (d) cognitive development and (e) language development. The home visitors carried out the surveys in the community amongst 18 households where it was known that both parents had died and four others where there was a serious illness or disability.

USAID has produced *Conducting a Situation Analysis of Orphans and Vulnerable Children Affected by HIV/AIDS*, a useful overall guide although it does not provide any focus on early childhood.⁹⁶ Geoff Foster suggests that conducting a situational analysis can sometimes be misleading and can end up undermining community coping strategies and the empowerment of beneficiaries.⁹⁷ He notes that Salole's (1991) work points to the need for 'contextual analysis', which tries to understand the environment in which the problem has unfolded. There is a need to observe everyday life with an open mind and to spend time to even begin to understand the "enormous depth and resilience of local cultures." There may be a lot to learn from the application of a contextual analysis to the situation of very young children in HIV and AIDS-affected communities.

Programming to strengthen communities

Families in HIV and AIDS-affected communities are responding by absorbing orphaned children and taking on roles as caregivers of adults and children, some of whom are ill and dying and others who are coping with depression and loss. It is popular to think of communities in developing countries as strong enough to endure any obstacle, but "the reality, particularly in developing countries seriously affected by HIV and AIDS, is of coping mechanisms strained to the breaking point and traditional safety nets unravelling."⁹⁸ Williamson, however, notes the danger of being negative about the actual capacities of communities to cope. While they are struggling under conditions of poverty and stress, the effort being made by communities to integrate orphaned children into families and to care for their youngest members is remarkable. When this effort is played down, he notes that US donors may be less inclined to inject funding into supporting community initiatives.⁹⁹

Many child development programmes fail because they do not recognize the achievements and resourcefulness of family and community in realizing children's rights, and so do not address their potential in programming. Save the Children's 'Bringing up Children in a Changing World' is a study that looks at the importance of recognizing primary caregivers, families and communities as the primary agents in the achievement of young children's rights.¹⁰⁰ Foster (2002) discusses community responses to

children in HIV and AIDS-affected communities and notes that although fostering families are under enormous strain, local initiatives at community level have been little studied or documented. Few organisations have sought to encourage their development. His paper analyses some of these initiatives and encourages external agencies to support them through building the capacity of existing local responses rather than imposing external solutions.¹⁰¹

A continuum of care and support

There are wide-ranging opportunities to provide care and support to very young children from formal full-time residential orphanages and day care centres to more informal preschool educators and family-based support. This can be seen as a continuum of care and support.

It is now well understood that residential institutional care may not always be the best option for children, especially very young children. Institutions can range from orphanages, children's homes and hospitals, to safe houses and centres for street children.¹⁰² These are generally expensive to run, needing continued external funding, and most vulnerable children do not have access to them. In some countries it is common to place very young children in institutional care, then for the father or extended family member to collect them when they are 18 months or 2 years of age. This is particularly ill-considered in development terms.¹⁰³ Orphanages tend not to encourage children to be part of their community and local environment. Institutional care cannot replace

the everyday experiences of cultural customs and practices where roles and expectations are learned.¹⁰⁴ Children can also find it difficult to re-enter society upon reaching adulthood.¹⁰⁵ Sometimes communities can be hostile to external intervention when traditional care systems such as extended families are undermined or ignored.¹⁰⁶

There are, however, some instances where institutional care is necessary. Some HIV-positive mothers abandon their babies in hospitals in the knowledge they will be unable to care for them properly.¹⁰⁷ Under these circumstances institutional care may be necessary before foster families can be found. Young street children may also need to be initially looked after in institutions as a first point of contact. ECD programmes often focus on preschools as a means of supporting very young children. Preschool costs mostly include small fees, uniform costs, snacks and school supplies, which are beyond the means of most caregivers. ECD planners have become overly occupied with preschool programmes as a unit of analysis to the extent that home-based, parent-support and community-development programmes are overlooked.¹⁰⁸

Government-sponsored foster care is rare in developing countries, and community-based foster care is better as it is more cost effective and keeps children in a familiar social, cultural and ethnic environment.¹⁰⁹ Sometimes group foster care takes place in a 'community home' where a few children live together under a guardian (i.e., a housemother). Children share

the household responsibilities and most group homes have agricultural land to farm for household food production. Generally the community donates the home and land, and caregivers are selected on the basis of their experience and interest.¹¹⁰

Gow and Desmond in 2001 undertook an analysis of the most cost-effective way of providing care for orphaned children in South Africa. It examines six models of care: statutory residential care; statutory adoption and foster care; unregistered residential care; home-based care and support; community-based support structures; and informal fostering/non-statutory foster care. It takes a detailed look at the various categories of care and follows with an outline of the method used to evaluate cost. It examines six case studies and draws conclusions and makes recommendations as a result of evaluations. The most cost-effective models were those based in the community, but they did struggle to provide adequate material care. Case studies showed that avenues of support were through income generation and government grants.¹¹¹ The paper is part of a combined study, the other part of which looks at the quality of different types of orphan care and their associated costs.

The complementary research study is Leoning-Voysey and Wilson's (2001) *Approaches to Caring for Children Orphaned by AIDS and Other Vulnerable Children: Essential Elements for a Quality Service*. This examines responses to the care of orphaned children with a view to developing policy recommendations for the

care of OVC in South Africa. Here quality care is that which meets the needs of children in a culturally acceptable way and enables them to realize their rights. It examines a variety of approaches to care, from formal through to non-formal ways, and it looks at examples and case studies to evaluate quality. Conclusions and recommendations are made around the continuum of approaches for the care of OVC, the capacity of households to care for OVC, mobilizing communities to care for OVC and providing a safety net for OVC.¹¹²

Community-based care and support

Community-based responses are difficult to define. Jan Williamson's study *A Family is for Lifetime (2004)* notes the lack of 'how-to' information on the provision of community family care. Her study contains a review of 80 documents concerning the provision of care for children lacking family care in countries affected by HIV and AIDS. There is a discussion on the need for family care for children living in HIV and AIDS-affected communities followed by an annotated bibliography. It pulls together the best research and experience from practice to provide important guidance to responses at family levels. This work identifies the need to find a consensus on the meaning of community-based and family care in order to provide a way forward for action.¹¹³

Development intervention in the family sphere raises ethical issues of the appropriateness of working in this area. However, leaving families and communities to cope alone with pressures

caused by national and international economic and political forces also raises serious questions. In reality, projects and programmes are already intervening in households. Interventions in households with regard to children can be justified in order to uphold the UN Convention on the Rights of the Child. Where intervention does take place, again a strong emphasis on understanding the cultural context of the community and society is critical. Community-based care should reflect the culture and values of the families and communities and support existing coping mechanisms that families are using. It should identify who is carrying out the basic tasks of caregiving and protection while considering the availability of local resources.¹¹⁴

There is no one definition of family and there is no one model of family support.¹¹⁵ There is a need to recognise the diverse character of households and ‘family’ set-ups where parents have died.¹¹⁶ When parents die, the roles in households change and new responsibilities arise. Where beliefs prevail that all children born to HIV-positive parents are themselves HIV positive, it is difficult for caregivers to invest time, money, energy and emotion in caring for children they think will soon die.¹¹⁷

Caregivers can be empowered when programmes try to understand their motivation and situation. Interventions vary according to the context of the child, and several approaches can be taken simultaneously and can reinforce each other.¹¹⁸ Practical responses could include providing information, training and encouragement towards practical outcomes, such as shared

childcare. The support they receive needs to be encouraging and informative. Support to caregivers can include ensuring access to treatment to prolong and improve their quality of life if they are living with HIV or AIDS. It can also include psychosocial support and counselling, material support and health education. A problem faced by the child when he/she becomes orphaned is the uncertainty often experienced about who will care for them and where. Many parents fail to make adequate arrangements before their death. Such a lack of preparation can be caused by sheer illness or by cultural beliefs.

The two current areas of programming that have the potential to reach out to under-5-year olds in families and communities are home-based care (HBC) and home-visiting programmes. Through these programmes, trainers and caregivers can monitor the condition of young children in households; be trained to identify and respond to children’s needs; link with local community resources; and encourage parents to make wills, memory boxes and books; and talk to their children about their future.¹¹⁹ In addition, the HIV-Insite website is a valuable resource for looking at a third area of programming: community-based care in developing countries;¹²⁰ while reaching young children can also be achieved through current HIV and AIDS programmes by including information campaigns about MTCT and awareness campaigns to caregivers, health providers, teachers and community leaders about the special needs of children under 5.

Existing services for children can be adjusted to focus on children under 8. For example, health services can include transport to local health posts and nurses, and can increase awareness of diarrhoea and acute respiratory illness and immunizations for children through child-to-child health programmes in schools. Alternative childcare services, such as community cooperative crèches and rotating neighbour or volunteer babysitting, can be organised within the community and through NGOs and religious groups.¹²¹ Caregivers could receive support such as counselling and training in parenting skills through HIV and AIDS clubs or sports clubs, and local committees and religious groups could provide practical and spiritual assistance. Community-based responses could include burial and credit lending associations, agricultural projects, childcare projects, vocational training and micro-enterprise.¹²²

The kinds of approaches to ECD, HIV and AIDS should also depend on whether the environment is rural or urban. Urban environments can create more formal opportunities to set up ECD programmes, such as factory care facilities, child-minding services and preschools. A rural environment may create opportunities in the commercial farming industry and more community-based and localized responses.¹²³ Urban strategies may also need to focus on street children: those who have emigrated to cities when foster families see that the children are no longer dependent on them and allow them no rights to land, work, food and so on. People also have different levels of access to information and health services depending on

their rural or urban environment; and areas with high HIV and AIDS prevalence will also have different experiences and needs.¹²⁴

Child participation

Children, including those age 0–8 need to be recognised as key agents and contributors. Many projects and programmes focus on caregivers without due consideration of the inclusion of the very young child; they too have a right to participate and add value to community life. There needs to be more focus on including them in planning, setting of questions and targets, and in assessing of services.

The *Speak for The Child Case Study*¹²⁵ carried out by the Ready to Learn Centre (Academy for Educational Development¹²⁶) describes a unique pilot project specifically aimed at addressing the particular needs of children under 5 affected by HIV and AIDS. It shows that it is not always obvious or easy to include the participation of very young children. The case study noted the experience of participatory learning and action (PLA) with community members (unmarried men, women, and youths, aged 15–49) to identify the problems for young children and caregivers in vulnerable households. Even in this study, which was specifically aimed at young children, it revealed that attention focused automatically on the caregivers and not on the young children: “Perhaps focusing on children under 5 – their problems, their activities – just made no sense to participants or to the facilitators responsible for guiding such discussions.”

Communication with very young children

Working directly with children (as opposed to caregivers alone) is challenging and difficult, particularly in contexts where children are subservient and of less ‘importance’ than adults. It is easy to assume that children under 8 – especially those who are very young – are unable to communicate. There are of course differences in communicating with 2-year olds, 4-year olds and 8-year olds. Communication with very young children needs to take place, not only to inform processes of interventions that care and support them and their caregivers, but also to encourage openness around difficult subjects like HIV and AIDS status and death. Parents may find it hard to disclose their HIV and AIDS status to very young children, and indeed it is important to reflect on this and about how and when to give them messages about HIV and AIDS.¹²⁷

Lessons may be drawn from projects like the memory box or book, which have shown success with older children. From work based on addressing issues like racism in very young children, a new project is due to start in South Africa using persona dolls. Very young children are encouraged to talk and think about HIV and AIDS and other issues of discrimination through playing with dolls.¹²⁸ Although ECD programmes and resources are acknowledging the ability of very young children to communicate and participate, methodologies to address issues of HIV and AIDS are few.

There is a need for research on how to include the views of young children in programme planning, development and evaluation, and to find ways in which young children can be listened to and consulted. While UK-based methods should not simply be imported to developing countries, it may be worth considering innovative work already being done there with young children to encourage their participation.

Alison Clark at the Institute of Education, University of London, has been using multi-sensory approaches that aim to identify a view of the world according to very young children. For example, disposable cameras were given to 3-year-old children to take pictures of important places or people and they were also encouraged to make audio recordings. Other methods that have their roots in participatory appraisal in an international development context include allowing children to take an adult on a tour, and making maps.¹²⁹ Similar methods could possibly be used – sensitively – in different cultural contexts. Hart (1998) has written about community development and cultural sensitivity in older children and this could give some pointers towards ways of working with younger children in community settings.¹³⁰ Marchant (1999) carried out work with disabled children listening in ‘on all channels’ – speech, sign, symbols, body language, facial expression, gesture, behaviour, art, photography, objects of reference, games, drawing and play. This work could be useful in encouraging adults to think differently about the ways in which young children communicate.¹³¹

A new pack from the Coram Family Trust, *Listening to Young Children*, has been designed to encourage professionals to listen to children.¹³² Aimed at people working with children under 8, it shows how to develop good listening skills and how to encourage children to express their ideas and feelings, especially through the arts. A related project is working to overcome entrenched attitudes in which children are seen as the property of their parents, unable to speak for themselves.

Clark suggests that before deciding on methods, a change in attitudes among adults is required for them to understand that listening to children is important.¹³³ Listening to children does not mean responding to their particular choices. When the voices of children are heard there are additional and different views, and what adults decide to do with this information is part of a process. It is important that the process and structures exist to allow children's voices to be heard.¹³⁴ Penny Lancaster's work suggests that listening is a reflective practice. There need to be changes in attitudes and behaviour so that children are enabled to express their concerns, feelings, perceptions and aspirations. Children need to be listened to in order to enhance their wellbeing, and adults need to take their views seriously. Listening is not just a technique, it is a 'social transaction'.¹³⁵

It is also important to tap into children's everyday experiences, not just those that are specialised. As Langstead (1994) argues, "young children are experts in their own lives."¹³⁶ *Never Too Young* (Miller 1997) is a handbook on how

young children can take responsibility and make decisions. It really focuses on under-8-year olds.¹³⁷ In development fields, publications such as *Listening to Smaller Voices* by Action Aid (1995)¹³⁸ and *Stepping Forward: Children and Young People's Participation in the Development Process* (1998)¹³⁹ would seem to suggest that thinking and practice is going in this direction, although very young children are still not addressed as overtly as they could be.

Psychosocial support

Ensuring that very young children participate, are valued as community members and have their voices listened to, not only upholds their rights as defined by the CRC, but can also fall within the remit of psychosocial support. The Regional Psychosocial Support Initiative for Children Affected by HIV/AIDS (REPSSI) defines psychosocial support (or PSS) as the provision of the possibility of individual disclosure of feelings and emotions and expressions of personality ('psycho') combined with influencing the social environment to reintegrate affected children into normality and encourage broader understanding of their specific situation ('social').¹⁴⁰ Emphasis on psychosocial support should not override the health and nutritional needs, but rather form part of the holistic care for the child. Although there has been much research into the health, shelter and nutritional needs of young children in developing countries, there has until recently been less focus on psychosocial support. "Early childhood years are when experiences and interactions with parents, family members and other adults influence

the way a child's brain develops, with as much impact as such factors as adequate nutrition, good health and clean water."¹⁴¹

Developing a supportive environment for very young children is crucial. Any interventions in the area of ECD, HIV and AIDS must be holistic and all about 'creating safe spaces for children'. Children in HIV and AIDS-affected communities need to rebuild and restore what they have lost, they need time and space to re-establish relationships and they need time to play.¹⁴² There may be similarities between young children in conflict and refugee situations and in communities affected by HIV and AIDS. Cassie Landers (1998) has written extensively on the role of ECD in conflict situations for UNICEF as a point of reference.¹⁴³

The mid-term evaluation of the Child Centred Approaches to HIV/AIDS (CCATH) project (although focusing on older children) notes the danger of focusing on the individual child's capacity to cope: the environment around the child also needs to be addressed because the emotional, social and practical support they get from neighbours, peers and families plays a vital role.¹⁴⁴ Support can also come from CBOs, faith-based organisations (FBOs), schools and health services – all of which should be accessible. In terms of very young children this means making sure they also cater for the particular needs of that age group.

Examples of local intervention

The following examples of local intervention have been found on the internet, and they are mainly from Africa. This may be because the levels of HIV and AIDS are extremely high in certain regions of Africa and responses are therefore more advanced. The types of organisations that can promote their work on websites are also generally larger and better funded. There are undoubtedly many more examples from all developing country regions that other NGOs, CBOs and FBOs are implementing. This range of examples neither includes the responses that groups of people in communities are making outside of the remit of formal and funded work.

Reaching young children

ECD and HIV and AIDS interventions can address very young children through community and family support and support to caregivers, while trying to ensure the maximum participation of the child at the same time. An excellent example of this is REPSSI, which has provided technical support to one of its partners called the Salvation Army Masiye Camp. The project runs 'lifeskills' camps for orphans and vulnerable children under the age of 5 affected by HIV/AIDS.

This new initiative started in mid-2003. So far about 50 children and 50 caregivers have directly received psychosocial support through the "lifeskills" camps program. During the

camp process, children are engaged through counselling processes largely using play skills. There is deliberate effort to get the caregivers to better understand the children they are supporting and particularly to provide care and support to children infected with HIV/AIDS. On the camp site, a series of discussions or informal training sessions are held with caregivers around issues of children's rights, effects of child abuse, living with HIV/AIDS, caring for sick children, parenting skills, how to prepare a memory book for your children, nutrition and health.¹⁴⁵

The Masiye Camp has produced a training manual that is especially designed for people working with children under 6 years old affected and infected by HIV and AIDS. The manual, currently in draft form, is an excellent example of how to engage with very young children affected by HIV and AIDS. It is aimed at youths and workers with the intention of helping them to provide PSS to very young children, and covers what PSS means, its principles and what happens if children don't get it. It is sensitive to culture: for example, it encourages people to think of locally used words and expressions that represent PSS. Child development also receives attention: it examines children's characteristics at certain ages, how they express themselves and how they show they are social beings. Myths and beliefs around very young children are exposed. People are encouraged to identify the internal and external resources children have and also look at the things that families and communities can do to meet PSS needs.

Methods using stories, puppets, art, clay, pictures, feeling charts and role plays are explored and games are suggested as a way to develop psychosocial skills. A section on HIV and AIDS includes definitions, ways of transmission, signs and symptoms, ways in which children's rights are compromised by HIV and AIDS and counselling for infected children. There are also methods for working with bereaved children in groups.

Toy libraries can also play a key role in areas of poverty where buying toys to stimulate children is not a possibility. An active toy library is a service that lends toys, games, puzzles and educational aids to individual families and to groups such as home-based daycare centres, nursery schools and primary schools. They create opportunities for children to learn through imitation, exploration, invention, creation, cooperation, negotiation and problem solving. In South Africa, for example, there are over 80 toy libraries catering for ECD centres and schools, but few focus on families and communities. Such libraries can be a valuable resource for young children who are at risk. "Early intervention in the form of outcomes-based stimulation can minimize later problems."¹⁴⁶ These libraries are also valuable for children with physical and learning disabilities. This approach, however, is culturally specific: in some countries and cultures (in Ghana, for example) young children respond better to storytelling and verbal communication than to toys that they are unused to.¹⁴⁷ It may also be quite a limited

approach in that it is not easily reproduced on a large scale.

Issues around the disclosure of HIV and AIDS status may be difficult for children under 8 to understand, particularly in terms of the stigma and discrimination that can arise. A small project in the Philippines between Pinnoy, Remedios AIDS and Healthlink Worldwide is supporting parents in disclosing their HIV status to their children and is likely to include under-8-year olds. The project emerged from a personal experience of a mother disclosing her status to her 12-year-old son in a positive way, which he then shared informally with his peers. Twenty young people affected by HIV and AIDS and their HIV-positive parents will attend a residential camp using various participatory methodologies, based around play and fun, and will develop some good practice guidelines based on experience to help come to terms with grief and bereavement.

The Memory Book Project could also be useful to under-8-year olds to help them cope with grief and death by ensuring their family histories, photographs and so on are available for them. The National Community of Women Living with HIV/AIDS (NACWOLA) in Uganda is a partner in the CCATH initiative.¹⁴⁸ NACWOLA introduced the Memory Book idea and through the CCATH initiative has developed its use and demonstrated how the processes used to create Memory Books can be understood. In the Memory Book, parents living with HIV record their own and their children's pasts and celebrate good and loving memories. It helps prepare the

child for bereavement and make concrete plans for the future. It also enables parents to disclose their status to their children. The initiative focuses on older children but it could be adapted to cater for children under 8 as well.

In 2003, the Southern Africa AIDS Training Programme produced guidelines on how to counsel children and communicate with them on HIV and AIDS issues.¹⁴⁹ These stress that children need to be met 'on their level' and should involve creative and non-threatening methods to explore issues and help children express their feelings. They suggest drawing, storytelling, drama and play; include working with under-5-year olds; address strategies for one to one work with children, and for working with families; and look at natural reactions children that may have and the social effects experienced by infected and affected children.

Another key resource in psychosocial support is the *Manual of Psychosocial Support of Orphans* produced by HUMULIZA/Terre des Hommes Switzerland (1999). It is intended for use by NGOs, CBOs and government agencies to train teachers in schools and daycare centres in Nshamba/Kagera in Tanzania.¹⁵⁰ It focuses on children who are already in institutions and, as so often the case, attends to the needs of older children rather than younger, but it is nevertheless a good example.

One of Christian Aid's partners, Kondwa Day Care Centre in Lusaka, Zambia provides day care for 0-7-year-old OVCs, getting them ready for primary school and helping them with

counselling and emotional support to cope with loss and/or illness of parents and family members.¹⁵¹

Supporting caregivers

Catholic AIDS Action, Namibia, has published *Building Resiliency Among Children Affected by HIV/AIDS*, by Sr Silke-Andrea Mallmann (2002). This handbook is aimed at helping parents, caregivers and teachers to understand children who have lost a parent or parents or are nursing ill parents.¹⁵² It provides practical advice on supporting children experiencing loss or death and offers ideas for discussions with children at home or in a classroom. It looks at developing resiliency in children and how they can be supported to cope, including coping with the death of a parent, involving them in decision making, and dealing with HIV and AIDS in social situations. It focuses on children from birth to 2 years and how they understand death and how they can be helped, on children aged 2–4 and on supporting preschool children age 4–7 years.

The Early Learning Resource Unit (ELRU) in South Africa addresses HIV and AIDS by providing training to parents and teachers in both urban and rural settings about the vulnerability of young children and the effects of HIV and AIDS on them and their families. It says that ECD work provides a logical framework to strengthen and sustain families and projects. It plays a key role in developing in-service training for people working in preschool centres, crèches and playgroups. ELRU's influence on preschool education and care in South Africa is immense, with nearly

all paraprofessional training relying on ELRU materials and methods.¹⁵³

Preschool educators

The Training and Resources in Early Education (TREE) in South Africa has recently received funding to implement a plan to address the impact of HIV and AIDS on young children. It is needed because in one of the provinces where they are working, over 60% of pregnant women are testing HIV positive. All staff receive training in understanding HIV and AIDS so that they can dispel myths such as that having sex with a virgin cures AIDS.

TREE trains up to 3000 women annually to run quality ECD programmes for disadvantaged communities. During workshops, toys and educational kits are provided so that parents and caregivers learn to play with their children. They are also given space to discuss parenting issues and practices. Teachers, parents, communities and ECD site committees are also to benefit from training in HIV and AIDS and counselling skills. TREE will also further develop their parenting programme to assist parents and caregivers. This could be through financial support or psychosocial support such as looking at ways to assist children in retaining their links to the past through memory boxes or books.¹⁵⁴

Support to grandmothers

Older caregivers, often grandmothers, also need to be supported. Action for Children (AFC) is a Ugandan NGO that has set up a programme called Grandmothers Action Support (GAS)¹⁵⁵, funded by the Bernard van Leer Foundation.

The idea is to support grandmothers who are looking after grandchildren under the age of 8 who are infected or affected by HIV and AIDS. It aims to enhance the capacity of grandmothers to care for children and includes activities such as lessons in nutrition and health, counselling, child rights, health and hygiene, and micro-credit programmes.

Child to child

Older children are often direct caregivers or at least take a lot of responsibility for looking after younger children. Supporting them is therefore a more indirect but nevertheless essential way of promoting the needs of very young children. *Young People – We Care!* is a resource manual produced by John Snow International (UK) Zimbabwe and funded by DFID Zimbabwe.¹⁵⁶ Although it does not have an ECD focus, it does encourage and help groups of young people to support younger children or their peers. It suggests community activities that young people can carry out, and it contains a training guide for facilitators to use in preparing young people to invest in their communities.

The CCATH work referred to above aims to develop and strengthen community coping strategies for children in Kenya and Uganda, and one of its strategies is to support older children and parents/guardians in providing appropriate care for younger children. The aim is to provide emotional support and help them enjoy themselves through creative and rewarding activity. NACWOLA (see above) also provides training to older children on their own growth and development and that of younger children.

The Mother's Welfare Group¹⁵⁷ (St. Rita's Rural Centre Kadi, Kadun, Nigeria) is developing work to build an early childhood curriculum around the Child-to-Child method. Child-to-Child methods and materials enable teachers to encourage participation and understanding by children. This complements work to set up more than 50 nursery and primary Child-to-Child schools. The family resource centre that they operate is for people living with HIV and AIDS and includes pre- and post-test counselling and continuous support counselling with information for a healthier lifestyle. There is a drop-in playground providing a friendly atmosphere for children affected by HIV and AIDS and the organisation also gives support to the local children's home, which has a high rate of HIV-positive children.

Case studies

The Young Child and HIV/AIDS Initiative set up by the Early Childhood Development Network for Africa (ECDNA) has, among other activities, promoted the development of several case studies.¹⁵⁸ These will develop over the next two years. In Namibia¹⁵⁹ a team is collecting basic information and carrying out an evaluation of existing services for OVCs and children living in difficult circumstances in HIV and AIDS-affected areas. The research team is paying attention to the psychosocial development of children age 0–8 years, with particular reference to their health, nutrition, education, housing and access to traditional healing.

In South Africa¹⁶⁰ the case study focuses on documenting community action and capacity

building for effective ‘safety-nets’ for young orphans and vulnerable children in different contexts, differentiating between children age 0–3 years and age 4–8 because of their distinct developmental needs. The ‘safety-net’ is about critical partnerships between key role players in the life of a child: parents, families, NGOs, CBOs and government.

The Nelson Mandela Trust Fund 2002 is investing in a case study to understand how to develop and transfer skills between and across initiatives. Lessons learned need to be shared and distributed widely. In Uganda, another case study will take a systematic evaluation of some community care systems, looking at the psychosocial components of the programmes offered to young children in the Mulago district. The Kenya case study originally addressed some of the issues related to MTCT, as part of an initiative of the UNICEF Nairobi office. It is now starting to document child care practices offered by grandparents who have been called upon in Kenyan society to extend traditional roles to include parenting too. The case study will focus on grandparents’ perception of their new roles and evaluate their care practices. It will also look at the child’s perception of their caregivers and their new situation in life.

Media advocacy

“Public knowledge about HIV/AIDS and attitudes toward people living with HIV/AIDS can determine whether the community response to orphans is one of compassion and support or one of fear, stigmatisation and

discrimination.”¹⁶¹ A literature review called *Children, HIV/AIDS and Communication in South Africa* by the Centre for AIDS Development, Research and Evaluation¹⁶² has some excellent examples of media communication and HIV and AIDS communication with children, some of which focus on under-8-year olds, but rarely under-6-year olds.

The media can be used effectively through advocacy, and the sensitivity and knowledge of journalists of HIV and AIDS can play a key role. Recognising this, REPSSI held a media advocacy course on psychosocial support for children in Johannesburg, South Africa, in November 2003 (funded by Family Health International, USA). Over 30 broadcast and print journalists from African countries attended to learn more about the rights of children and improve their understanding of psychosocial issues. The aim was also to equip the journalists with practical skills so they that can write in a ‘sensitive, ethical and sustained’ manner.

Ethical issues included understanding that informed consent means that children properly understand the processes in which they are involved; it is not just a signature on a form. They also understood that they could re-traumatise a child if they were insensitive to the children’s and caretakers’ needs and situations. Issues concerning payments for interviews when families are living in poverty were discussed, and conclusions were that each case should be taken up on its own merits. Journalists were encouraged to think of themselves as human beings first and journalists second.

Mass-media communications can play critical roles in raising awareness and reducing stigma in the general public and within specific age groups. Takalani Sesame (Sesame Street) was introduced in 2000 to support the national ECD policy of the Department of Education of South Africa.¹⁶³ The project consists of multi-lingual television and radio programmes supported by print resources and training initiatives. It was launched to achieve the mass reach of young children to encourage learning in the areas of literacy, numeracy and life skills. ECD educators are now using the programme in homes and community centres or where young children spend their days in the four most disadvantaged and poor provinces of South Africa. Aimed at children age 3–7, the show also helps educate viewers about HIV and AIDS, and a recent new addition to the cast is a young vibrant female muppet who is HIV positive. The character, age 5, is expected to help de-stigmatise HIV and AIDS and encourage positive behaviour towards infected people.

UNICEF have realised the opportunities there are to develop the muppet's reach in mass appeal, and in November 2003 formally appointed Kami, as a global 'Champion for Children.' Kami's first appearance with UNICEF was when she helped launch UNICEF's latest report, *Africa's Orphaned Generations*, which details the impact of HIV and AIDS on children in Africa.¹⁶⁴

State obligations – national policies

Under the UN Convention on the Rights of the Child, the state is obliged to take measures to

ensure the optimal survival and development of the child and have the best interests of the child in mind in all its actions. The fact that logical programme choices revolve around increasing family and community capacities to care for very young children should not exempt the state from providing services to young children made vulnerable by HIV and AIDS.¹⁶⁵ Family and community care projects need resources and they need state welfare and education subsidies and support.

Malawi is a good example of how the state can play a key role in supporting young children. In Malawi, 85% of the population lives in rural areas, and 90% of the children in these areas have no access to any form of organised early childhood care. Demand for services grew, however, when the Government of Malawi and UNICEF stepped up their efforts to support 0–3-year olds through extension workers and local plans of action at district level. This was a community-based effort focusing on care for women, breastfeeding and complementary feeding, food preparation, psychosocial care, hygiene practices and home health practices.¹⁶⁶

Very young children need a supportive environment at national level; and policies, legislation and structural support are needed to protect and support this age group. In June 2001, the UN General Assembly Special Session set targets for nations, stating they must develop and implement strategies by 2005 to:

build and strengthen governmental, family and community capacities to provide a supportive

environment for orphans and girls and boys infected and affected by HIV/AIDS including by providing appropriate counselling and psychosocial support, ensuring their enrolment in school and access to shelter, good nutrition, health and social services on a equal basis with other children; and protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance.

There should also be an active policy of de-stigmatisation.¹⁶⁷ These statements do not explicitly include children under 8 but presumably the General Assembly Special Session would acknowledge that young children have special vulnerabilities and needs because of their age and stages of development; and would expect these to be addressed.

ECD as a national priority

In September 2000, 147 heads of state and government of 191 nations in total adopted the Millennium Declaration. The Declaration outlines peace, security and development concerns, including in the areas of environment, human rights, and governance. It represents a global agenda for development that builds on the international development goals set over the 1990s at the various UN-sponsored world summits and global conferences. Within this framework, ECD should be an essential part of a nation's development priorities, and in countries where there are communities significantly affected by HIV and AIDS it follows

that ECD and HIV and AIDS programming should take place. At the moment,

[a]nyone attempting to respond to the needs of children is doing so in a policy vacuum, an open field with no guidelines and often-insufficient safeguards against establishing inappropriate services.¹⁶⁸

The UN General Assembly 2002 Special Session on Children adopted a plan of action that committed member states to the

development and implementation of national early childhood development policies and programmes to ensure the enhancement of children's physical, social, emotional, spiritual and cognitive development.¹⁶⁹

It is clear that governments need to define and adopt comprehensive strategies involving all appropriate ministries and districts to meet the broad needs of young children.¹⁷⁰ Few states have national policies regarding OVCs (except Botswana, Malawi, Rwanda and Zimbabwe)¹⁷¹ and where they do, early childhood is largely overlooked. For example, the Zimbabwean National Plan of Action for Orphans and Other Vulnerable Children 2003 emphasises the special importance of OVCs having access to health, education, food, birth registration and so on, and be free from abuse and exploitation. However, it does not address the specific and different needs of the under-8 age group.¹⁷²

At the 2nd International Conference on Early Childhood Development in Asmara in 2002 (collaboration between the Government of Eritrea, the World Bank, UNICEF and ADEA), a framework for action was developed.¹⁷³ It aims to ensure that investment in ECD is “intrinsically related to the promotion of child rights, poverty alleviation, sustainable human resource development, basic education for all and health for all.” Emphasis is on the holistic development of the child and it makes specific reference to the need to avert the consequences of HIV and AIDS for young children, and the importance of programmes for reintegrating orphans into family settings and developing approaches for young children infected and affected by HIV and AIDS.

It suggests that policy should be developed to support a country framework on ECD as an integral part of the macro-level national development strategy of every country. Research and information should be promoted, policy makers should integrate the Asmara Declaration, and there should be monitoring and follow up to assess the impact. The conference also recommends that indigenous knowledge be respected in the ECD package. There is reference to a complex ‘ecology’ of the child, where factors ranging from nurturing micro-systems, larger family and community influences to macro policy environments, all have an impact on the child’s survival and development.

A practical example of changes starting to happen on the ground is the Early Childhood Development Virtual University (ECDVU)

at the University of Victoria, Canada.¹⁷⁴ It is an innovative and multi-faceted approach to addressing ECD leadership needs in Africa through training and capacity building, using face-to-face and distance-learning methods. It aims to “further develop African ECD leadership capacity as a key strategy in support of child, family and community well-being and broader social and economic development.” Candidates for the programme emerge from an in-country process that brings together an ECD committee which then identifies the most suitable leaders.

Supporting HIV and AIDS in ECD programming

Supporting HIV and AIDS in ECD programmes is now also a necessity. The outcome of a ‘knowledge, action and practice’ study in South Africa revealed that most ECD practitioners are ill equipped to deal with children living with HIV/AIDS. ECD practitioners should therefore be trained in HIV/AIDS and non-discrimination in the ECD environment.¹⁷⁵

In 2001, UNICEF African regional offices, in association with WGECD, met to brainstorm about ideas, problems and issues and about some of the initiatives that had already begun. Also in 2001, UNICEF raised the question of how to respond to their programming priorities in ECD, HIV/AIDS, child protection and immunisation while using girls’ education as an entry point.¹⁷⁶ Eming Young also points out the importance of ECD programmes as they address the intersecting needs of women and children. Girls are more likely to become caregivers in

HIV/AIDS-affected communities and are more likely to attend and continue school if they begin with an ECD programme.¹⁷⁷

UNESCO plans to establish a North-South collaborative programme on HIV as a sustainable development issue, and one of the programme's aims is to examine the results of evidence-based research and country experiences in integrating HIV related issues into reproductive health, life skills and other health education. The point is to gain knowledge of concepts on the links between HIV/AIDS and sustainable development, and to disseminate best practice and programme evaluations among policy makers, educators and the media.¹⁷⁸ There will be guidelines for the establishment of trans-disciplinary educational methods and approaches to address the epidemic.

UNESCO also adopted recommendations in light of the Millennium Goals and of the key goals of *A World Fit for Children*. These were to prioritise the integration of early childhood approaches in UNESCO-sponsored programmes; to use a meaningful portion of extra budgetary funds to support under-8-year olds in areas most affected by HIV/AIDS; and to make technical support available to initiatives for OVCs under 8, such support to include advocacy workshops, training and capacity building, materials development, information sharing, education and communication.¹⁷⁹

The *Coordinator's Notebook*¹⁸⁰ identifies five key things that need to be better understood to ensure that OVCs under 5 are properly

addressed in national, international and local AIDS agendas. These are:

- the scale of the problem;
- the likelihood of survival for young children in HIV/AIDS-affected households;
- the consequences of inadequate care for young children;
- the special vulnerabilities of the under-5 age group in HIV/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.

National AIDS action plans should include ECD issues and all stakeholders should be part of the planning. A comprehensive OVC policy needs to be developed within which the holistic needs and rights of children under 8 should be included. National policies and laws should be renewed or created to protect adults and children who are stigmatised because they are living with HIV and/or AIDS, or are suspected of being HIV positive. Within this framework, children's rights should be protected and promoted.

In 2003, UNAIDS, the World Bank and UNICEF published *Operational Guidelines for Supporting Early Childhood Development (ECD) in Multi-Sectoral HIV/AIDS Programmes in Africa* (Seifman and Surrency 2003), which is a useful tool for decision makers and policy planners. The guidelines give direction on how to integrate effective broad-scale interventions to ensure the healthy physical, emotional and cognitive development of young children. This

“should be an essential component of any well designed, integrated national programme to prevent and reduce the impact of HIV/AIDS.”

The guidelines note that the specific situation of each country should be taken into consideration, and interventions should reflect the urban or rural environment, differences in cultural attitudes and behaviour and the prevalence of HIV/AIDS. They also note that it is important to acknowledge the availability of support and treatment that can help ill parents live longer, and recognise that is a great barrier to implementing effective ECD and HIV and AIDS programmes. Stressing that an inclusive approach emphasising the needs of all vulnerable children is needed, the guidelines outline practical ways in which ministries can address young children affected by HIV and AIDS. These include situational assessment, geographical targeting of beneficiaries, developing indicators, monitoring and evaluation, and key policies. Examples of where each ministry can include early childhood and HIV and AIDS issues are given, and the main areas for programming intervention are stated as delivery of services to young children, education and support for families and caregivers, training and support of care providers (paid or volunteer workers), awareness raising through mass media and community mobilisation.

A recent HIV/AIDS and ECD video-conference in Tanzania, convened by the World Bank and supported by UNICEF in Tanzania, brought together a number of ECD stakeholders in Africa to discuss the guidelines. There will be a discussion group set up on HIV and AIDS and

ECD.¹⁸¹ Tanzania is taking the forward step of developing a national ECD HIV/AIDS action plan and will be working to develop an HIV/AIDS and ECD country team with representatives from all ECD-related sectors, UN agencies and NGOs. The coordinator for the team will be based in the national AIDS commission.

Including the private sector

Both Eming Young (2003)¹⁸² and the Bernard van Leer Foundation (2002)¹⁸³ note the importance of government collaborating with the private sector to maximize use of limited resources in HIV and AIDS-affected areas. Care initiatives need state and welfare subsidies and the support of a strong public-private partnership, and they need to liaise with other family and community services and link directly to private sponsorship, industry and commerce. The UN Declaration of Commitment on HIV/AIDS also suggests that the international community, civil society and the private sector act to complement national programmes to support OVCs.¹⁸⁴

For pharmaceutical companies this means collaborating to prolong the lives of parents of very young children by making drugs more affordable and accessible. There will need to be continuing advocacy and pressure from the international community to ensure that this happens. If ARVs are to be used effectively to prolong and improve the quality of life, health service delivery must be improved: the effective use of drugs cannot be achieved within poorly coordinated and resourced health-care systems.¹⁸⁵

UNAIDS notes that businesses and companies have been slower in recognizing the impact of HIV and AIDS on the private sector, and many leaders still need convincing that prevention programmes for employees can be marketed as the protection of valuable human capital and prevention of profit loss. Working with private business can be advantageous as they usually have plenty of resources, while workplaces present opportunities to reach large numbers of people.¹⁸⁶ Companies attentive to the needs of their employees in the context of HIV and AIDS could be well placed to create ECD initiatives for their workforce. Programming could focus on providing early childhood care facilities for factory workers and in commercial farming industries.

Advocacy

The implementation of efficient and low-cost early childhood programmes adapted to the needs of children, life conditions of families and the culture and resources of a country depends mostly on political and social will.¹⁸⁷ Considering the current lack of attention, it will take considerable efforts to address ECD in the context of HIV and AIDS.

Lusk and O’Gara suggest some key areas for advocacy.¹⁸⁸ These include to advocate for legal and economic support for child headed households so that children can stay with siblings and have land rights. Also, attempts to combat stigma should come from administrators and community members, and local leaders should be encouraged to

support children and widows over access to local resources. They recommend advocating affordable and accessible ARV drugs for mothers to reduce MTCT, prioritization of ARVs and treatment of opportunistic infections for caregivers of young children, and counselling and support group centres for caregivers of young children.¹⁸⁹ Other examples of advocacy come from the AMANI Early Childhood Care and Development Trust Foundation in Tanzania, which is currently involved in mobilising advocacy regarding HIV/AIDS and ECD.¹⁹⁰

Chapter three

Conclusions and Recommendations

Obstacles to providing services

Primarily it is poverty and the lack of access to resources that weakens the capacity of households to care for very young children in HIV and AIDS-affected communities. The stigma and discrimination that is generated by HIV/AIDS also presents difficulties in working with those that are affected and the invisibility of very young children in communities means they are easily overlooked. Identifying young vulnerable children most affected by HIV and AIDS requires great effort and sensitivity, but limited time and resources means that government workers, NGOs and CBOs are restricted in the activities they can engage in. Children that are easily identified as vulnerable are often to varying degrees cared for in institutions as a knee-jerk response to the problem. Overcoming attitudes and practices that perceive orphanages as the best option is also an obstacle.

Providing the appropriate services can also be difficult: knowing who is HIV positive or ill with HIV or AIDS is difficult due to the unavailability of voluntary counselling and testing. This is linked to poor access and the lack of availability of healthcare services and treatment, itself another obstacle to providing services.¹⁹¹ HIV and AIDS is exacerbating conditions of poverty and stress, and young children in affected communities are even less likely to have access to good nutrition, sanitation and education. The impact of HIV and AIDS in communities is relatively new

and is certainly unique. Parents, caregivers and community members may also not have the skills or experience to deal with the psychosocial requirements of very young children. An additional element to difficulties with providing services for very young children is that agencies too often see ECD as a specialised topic and therefore too difficult or technical to broach.

Evident gaps

With the exception of the prevention of MTCT, children under 8 tend to be ignored in HIV and AIDS strategies: it is older children and youth who are targeted. Likewise, programmes and policies aimed at improving the life conditions of orphans and vulnerable children overlook the under-8 age group. There has been much worthwhile attention to PMTCT and very little to the impact of children growing up in their most formative stages with ill and tired parents. This gap needs to be addressed in both policy and programming. The CRC pays attention to the holistic development of children, including their survival, development and participation. But the focus is often on children in older age ranges, and addressing very young children in this context is missing to a large extent. In terms of holistic care and support, a relatively new understanding of the psychosocial support of very young children remains overlooked in many programming responses. Community-based responses have received very little attention compared to institutions and orphanages.

Recommendations

*Children on the Brink 2002*¹⁹² makes five recommendations, which are widely referred to:

- strengthen and support the capacity of families to protect and care for their children;
- mobilise and strengthen community-based responses;
- strengthen the capacity of children and young people to meet their own needs;
- ensure that governments develop appropriate policies, including legal and programmatic frameworks as well as essential services for the most vulnerable children;
- raise awareness within societies to create an environment that enables support for children affected by HIV/AIDS.

These recommendations cover all children. Within them, a focus on very young children age 0–8 years will need the following emphases:

- strengthen and support young children, families and communities;
- integrate ECD and HIV and AIDS into national policies and plans of action;
- change research and advocacy priorities to address very young children affected by HIV and AIDS.

Strengthening and supporting children, families and communities

Working with children under 8 raises complex issues, the first of which is the varying stages

of development that exists within this age range. There cannot be a ‘one-size-fits-all’ approach on trying to meet the developmental needs of under-8-year olds in HIV and AIDS-affected communities. Notwithstanding the cultural context, the experience and needs of a 2-year-old girl living with an ill and dying mother in one community will be entirely different to those of a 7-year-old boy in another community who has been orphaned and is fending for himself through income-generating activities. Children throughout this age range will have very different needs, and meeting them cannot be achieved simply.

There needs to be a direct delivery of services to young children, plus the education and support of parents, training and support to caregivers, awareness raising in the general public on ECD and HIV and AIDS, and the mobilisation and strengthening of community-based activities to protect and improve the care of children. Key points for a minimum intervention package of ECD and HIV and AIDS activities have been listed as the following:

- local tracking and monitoring of the conditions of vulnerable children 0-8;
- family-based care for young orphans and for children who are neglected or abused;
- food assistance to households, community-based groups and institutions that are supporting young children in communities affected by HIV and AIDS;

- community care centres/crèches to free up caregivers for income-generating activities, education and healthcare;
- training of volunteers on topics related to the care of HIV-infected young children, including feeding, health and development.¹⁹³

Any effort to address children age 0–8 years in communities confronting the HIV and AIDS crisis needs to take into account the cultural context and build upon existing coping strategies that communities and families are employing on a day-to-day basis. Sustainable community-based initiatives should be prioritised over institutions, and cultural resources should be used. Existing interventions such as home-based care and home-visiting programmes have the potential to reach very young children and should be tapped. The process of planning and evaluating services would benefit from including children. In doing so, methods of hearing young children's voices need to be researched and implemented in a developing-country context, something that could include advocacy by older children for the youngest. This requires effort and resources on the part of agencies willing to engage with young children and provide structures to hear their voices. In programming terms, it is important to strengthen capacities so that agencies and workers know and understand the issues and do take their stories into account.

Integrating ECD and HIV/AIDS into national policies and action plans

Within national policies, national AIDS action plans need to include strategies to meet

the needs of children under 8. Similarly, all governments should include ECD as part of their national development plan. Also, ECD programmes need to focus on HIV and AIDS-affected communities. Governments need to increase the supply of early childhood care and education, and to change the nature of early childhood care to address specific HIV and AIDS issues. There should be multi-sectoral collaboration between key statutory bodies, health, education and social welfare agencies, voluntary organisations and community initiatives. Williamson suggests that, rather than separate policies for the 0–8 age group, national policies need to be developmentally sensitive and address the particular needs of each age group. The needs of infants are quite different to children age 6–7 years to youths age 16 or 17. All age groups should be addressed in differentiated national policies and programmes.¹⁹⁴

The state's role in protecting very young children against stigmatisation, discrimination and neglect is key. When countries report to the UN Committee on the CRC they do refer to HIV and AIDS but do not provide separate information on very young children. This could be because reporting guidelines do not clearly reflect this component. An additional measure therefore would be to ensure that ECD and HIV and AIDS is addressed in reporting mechanisms to the CRC Committee. In this framework, the importance of addressing all categories of very young children (such as children with disabilities, nomadic children, and children of religious and indigenous minorities) comes to the fore.

Strategies designed to provide support and guidance to young children and their communities affected by HIV and AIDS need a conducive policy environment within which to operate. Eming Young's (2003) suggested policy package includes principles of non-discrimination, prosecution for violence against children, VCT, a civil service and educators/social workers training policy to ensure awareness of HIV and AIDS issues relevant to young children, a young child surveillance policy, a food assistance policy and an HIV and AIDS treatment access policy.¹⁹⁵ It also mentions the importance of making sure that the needs of older carers are met.

Lusk and O'Gara (2002) also make some key policy recommendations. These include the broader socio-political issues of making HIV and AIDS a priority in debt relief to reduce poverty; investing in poor communities; and linking social assistance in international programmes. Political will must be built to acknowledge OVCs and HIV and AIDS at highest government levels. Data collection on OVCs is also required; while NGOs, INGOs, CBOs and religious groups must all participate in strategic planning, and the popular media needs to be used effectively.¹⁹⁶

The state can make provisions and provide welfare and education subsidies to support local communities and caregivers in caring for and supporting very young children. Understanding and taking account of the differences between rural and urban approaches would also be beneficial. In terms of paid employment, the

state could also introduce labour codes and public policies that allow employees to take paid leave to look after sick family members.

Where institutional care does exist and there are no better alternatives, governments should ensure that a basic minimum care package exists. There should be a wide survey of government and child welfare policies and a collection of practical lessons learned. There should be fundamental standards of care for orphans and vulnerable children and training modules designed to prevent or decrease the number of institutions and increase community care.¹⁹⁷

Research and advocating change in the wider environment

There is a need to promote dialogue and partnerships among researchers, ECD professionals, policy and decision makers and planners. If a rapid assessment is made of current policies that have the capacity to support very young children in HIV and AIDS-affected communities, this may be a foundation on which to work. Evaluating current 'safety nets' and assessing information and communication strategies is also useful. Finding out what other countries are doing and applying best practices would be a way forward. UNESCO is developing a "Young Children and HIV/AIDS in Africa Action Plan", and this will follow a number of directions. It intends to undertake advocacy, raise awareness and create dialogue through case studies, reports, documentation, websites and presentations at meetings and conferences. UNESCO also

recommends identifying and using supporting networks, partnerships and affinity groups.¹⁹⁸

There needs to be advocacy to get very young children on local, national and global agendas to ensure that governments and NGOs focus on the needs and rights of very young children affected by HIV and AIDS. Raising awareness in the political community and among other leaders of the need to address very young children in HIV and AIDS-affected communities is necessary. Identifying and supporting champions of early childhood and HIV and AIDS at every level is an important strategy.¹⁹⁹ The media can be used to publicise cases of discrimination against children infected and affected by HIV and AIDS. It is also vital to advocate affordable and accessible ARV to adults and children within a solid and reliable healthcare system. Prolonging the lives of parents and improving their quality of life will enable children to have a more stable early childhood.

Forthcoming publications and future events

- International HIV/AIDS Alliance Building Blocks: Africa-Wide Briefing Notes Resources for Communities working with OVCs are due to produce a booklet on very young children.
- UNESCO are developing a Young Child and HIV/AIDS website to enhance information sharing and experience exchange that will be accessible to all people working with young children at a global level. The pilot phase will focus on sub-Saharan Africa and will be launched in association with the ‘Young Child and HIV/AIDS in Africa Initiative’, run by the Early Childhood Development Network for Africa (ECDNA).
- Horizons, USAID, UNICEF and FHI are compiling practical ethical guidelines for the conduct of gathering information from children for programmes and research, especially children affected by HIV/AIDS. This could include under-8-year olds – due to be published in August 2004.
- Associate Professor Jaqueline Hayden from the USW Research Centre for Social Justice and Social Change will be working with the University of Namibia to document the experiences of young Namibian children who have been affected or infected with the HIV virus. They presented the progress of the project at the OMEP conference in Melbourne 2004 and will also do so the World Forum for Early Childhood Development in 2005. (University of Western Sydney 2003)
- World Forum for Early Childhood Development in 2005.
- AIDS Impact Conference, Capetown, April 2005.

Resources

On-line ECD and HIV/AIDS documents

Bartlett K and Zimanyi L (Eds) (2002) *The Coordinator's Notebook: An International Resource for Early Childhood Development. HIV/AIDS and Early Childhood 26.*

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<www.bernardvanleer.org/downloads/AR2002-web-fullversion.pdf>

Discussion forum

Children Affected by HIV/AIDS Electronic Discussion Forum
<www.synergyaids.com/caba/cabaindex.asp>

Websites

The Consultative Group on Early Childhood Care and Development
<www.ecdgroup.com>

Early Childhood Development: World Bank
<www.worldbank.org/children/hiv.html>

Academy of Educational Development
<www.aed.org>

AED Ready to Learn Centre
<www.readytolearn.aed.org/ECDlinks1.htm>

Association for the Development of Education in Africa (ADEA)
<www.adeanet.org>

AIDS Orphans Assistance Database (AOAD)
<www.orphans.fxb.org/db/index.html>

Women, Children and HIV
<womenchildrenhiv.org>

HIVInSite
<hivinsite.ucsf.edu>

Panos AIDS Programme
<www.panos.org.uk>

UNAIDS
<www.unaids.org>

UNESCO
<www.unesco.org/culture/aids>

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About the Bernard van Leer Foundation

The Bernard van Leer Foundation, established in 1949, is based in the Netherlands. We actively engage in supporting early childhood development activities in around 40 countries. Our income is derived from the bequest of Bernard van Leer, a Dutch industrialist and philanthropist, who lived from 1883 to 1958.

Our mission is to improve opportunities for vulnerable children younger than eight years old, growing up in socially and economically difficult circumstances. The objective is to enable young children to develop their innate potential to the full. Early childhood development is crucial to creating opportunities for children and to shaping the prospects of society as a whole.

We fulfil our mission through two interdependent strategies:

- Making grants and supporting programmes for culturally and contextually appropriate approaches to early childhood development;
- Sharing knowledge and expertise in early childhood development, with the aim of informing and influencing policy and practice.

The Foundation currently supports about 150 major projects for young children in both developing and industrialised countries. Projects are implemented by local actors which may be public, private or community-based organisations. Documenting, learning and communicating are integral to all that we do. We are committed to systematically sharing the rich variety of knowledge, know-how and lessons learned that emerge from the projects and networks we support. We facilitate and create a variety of products for different audiences about work in the field of early childhood development.

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Working Papers in Early Childhood Development is a 'work in progress' series that presents relevant findings and reflection on issues relating to early childhood care and development. The series acts primarily as a forum for the exchange of ideas, often arising out of field work, evaluations and training experiences.

The purpose of the *Young children and HIV/AIDS sub-series* is to share information, ideas and emerging lessons with readers who are concerned with young children affected by HIV/AIDS. As 'think pieces' we hope these papers will evoke responses and lead to further information sharing from among the readership.

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