

# Where the heart is

Meeting the psychosocial needs of young children  
in the context of HIV/AIDS



Linda Richter, Geoff Foster and Lorraine Sherr

**CALL TO  
ACTION**  
TORONTO 2006

## **CALL TO ACTION TORONTO 2006**

The Coalition on Children Affected by AIDS commends to participants at the XVI International AIDS Conference in Toronto, August 2006, the following call to action:

1. Prioritise everyday systems of care – families, schools and communities
2. Invest long-term in integrated services to promote psychosocial wellbeing
3. Realise the right of all children to access these integrated services
4. Demand that more governments take the lead in guaranteeing this right
5. Earmark resources for applied research to expand the evidence base

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in the context of HIV/AIDS**

**Linda Richter, Geoff Foster and Lorraine Sherr**

**July 2006**

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This publication was made possible thanks to a contribution from the Dutch Ministry of Foreign Affairs.

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The opinions expressed herein do not necessarily reflect the view and policies of the organisations that supported and took part in the development of this paper.

#### **About the authors**

**Linda Richter** is the Executive Director of the Child, Youth, Family and Social Development programme at the Human Sciences Research Council in South Africa. She holds honorary positions at the Universities of KwaZulu-Natal, Witwatersrand and Melbourne (Australia). Her research interests centre on children and youth in difficult circumstances, including the impact of HIV/AIDS on development.

**Geoff Foster** works as a government paediatrician in Zimbabwe. He was the founder of Family AIDS Caring Trust, one of Africa's first AIDS service organizations, and has written extensively and conducted research on the subject of children living in communities affected by HIV/AIDS.

**Lorraine Sherr** is Professor of Clinical and Health Psychology at UCL, London. She is editor of *AIDSCare* and *Psychology Health and Medicine* and is on the editorial team of *Vulnerable Children and Youth Studies*. She has written several books, chapters and numerous journal articles on HIV/AIDS, as well as conducted a variety of research projects nationally and internationally. She sits on the World Health Organization Strategic Advisory Committee for HIV/AIDS.

#### **Citation**

Richter, L., Foster, G. and Sherr, L. (2006) *Where the heart is: Meeting the psychosocial needs of young children in the context of HIV/AIDS*. The Hague, The Netherlands: Bernard van Leer Foundation

**ISBN 90-6195-091-0**

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# Acknowledgements

*Where the heart is: Meeting the psychosocial needs of young children in the context of HIV/AIDS* is an opinion piece developed through a series of four workshops organised by the Bernard van Leer Foundation entitled "On the Road to Toronto." This paper benefited from input, feedback and discussion within these workshops, as well as comments received following the wide distribution of the draft document in April 2006. We especially thank the following people for their thoughtful comments: Kurt Madoerin, from the Humuliza Programme in Tanzania; Jonathan Morgan and other members of the 10MMP; and Patrice Engle and Doug Webb.

*Where the heart is* draws on previous work by the authors, including a review conducted by Linda Richter and Geoff Foster on commission to the Department of Child and Adolescent Health and Development at the World Health Organisation in Geneva (2005) entitled *Strengthening systems to support children's healthy development in communities affected by HIV/AIDS*; Lorraine Sherr's 2005 reviews entitled *Young children and HIV/AIDS: Mapping the field*, and *HIV and young children: An annotated bibliography on psychosocial perspectives*, both published by the Bernard van Leer Foundation; and primary work done by Geoff Foster on related topics, including *Study of the response of faith-based organisations to orphans and vulnerable children* (2004, published by UNICEF and the World Conference on Religions for Peace), *Bottlenecks and dripfeeds: Channelling resources to communities responding to orphans and vulnerable children in Southern Africa* (2005, published by Save the Children, London) and *Under the radar: Community safety nets for children affected by HIV/AIDS in extremely poor households in sub-Saharan Africa* (2005, published by the United Nations Research Institute for Social Development, Geneva).

Ideas and information from many other documents have been included without specific acknowledgement. The chapter "References and background reading" (p. 52) lists the main documents consulted.

# Participating organisations

The following played a key role in the workshops that contributed to the development of this publication.

**Bernard van Leer**  *Foundation*

 **children's  
institute**  
child rights in focus  
Research • Advocacy • Education

 **HSRC**  
Human Sciences  
Research Council

**ICDP**  
International Child Development Programmes

International  
HIV/AIDS  
**Alliance**


 **Buitenlandse Zaken  
Ontwikkelings  
samenwerking**

  
**REPSSI**

 **Save the Children**  
UK

 **Save the Children®**  
USA

  
**The Teresa Group**

 **Tulane  
University**  
School of Public Health  
and Tropical Medicine

 **World Health  
Organization**

The following organisations also participated in the meetings:

- Clacherty and Associates, South Africa
- Early Learning Resource Unit, South Africa
- Farm Community Trust of Zimbabwe
- Hesperian Foundation
- Hospital for Sick Children, Toronto
- International Catholic Child Bureau
- Long Island University, Brooklyn Campus
- Population Council, Washington
- Royal Free and University College Medical School
- Soul City Institute for Health & Development Communication
- World Vision International, Africa Technical Services
- World Vision International, Nairobi

A special thanks to UNICEF.

The participants at the workshops endorse the content of this publication, but the opinions expressed herein do not necessarily reflect the view and policies of their organisations.

# Foreword

A number of child-focused organisations attending the XV International AIDS Conference in Bangkok in 2004 were struck by the lack of attention to children's issues, particularly non-medical issues. Where children's concerns were mentioned, discussion was often superficial. One striking example of that was the use of the term "psychosocial support" – much cited, yet poorly understood. We at the Bernard van Leer Foundation felt that there was major unrealised potential in this term and the opportunities for action that it implies.

Since "Bangkok", the Bernard van Leer Foundation and other child-focused organisations have launched several parallel efforts aimed at ensuring that children are higher on the agenda at the XVI International AIDS Conference in Toronto in 2006. Among these was the foundation's decision to convene a series of workshops on psychosocial support, under the banner "The Road to Toronto", to explore the concept and articulate it more clearly to a wider audience.

The first of these workshops, which took place in Johannesburg in November 2004, was tasked with defining psychosocial support. In April 2005 the second meeting, in Cape Town, looked at questions of evidence and measurement. In Abuja in December 2005, our third workshop focused on the differing needs of practitioners and policymakers.

During the course of these workshops a significant shift occurred from a narrow focus on externally providing psychosocial *support* to a limited number of the most affected children, to a broader emphasis on promoting the psychosocial *wellbeing* of all vulnerable children.

Throughout this process, one of our main aims was the development of this opinion piece, *Where the heart is*. Its draft contents formed the basis for our discussions at the fourth and final workshop in The Hague in March 2006, which was focused on refining the fruits of our discussions into clear and comprehensible messages to take to Toronto. This resulted in our "Call to Action", overleaf.

Since first stepping onto this Road to Toronto it has been the Foundation's pleasure and privilege to work with over 40 representatives, researchers, advocates, field workers, civil servants, and academics from some 20-plus interested and concerned organisations. Every participant has made their own particular and valued contribution to what has been a fascinating and productive journey, resulting in this publication. My sincere thanks and gratitude go to you all, particularly the authors, Linda Richter, Geoff Foster and Lorraine Sherr.

*Peter Laugharn*  
Executive Director  
Bernard van Leer Foundation



# Call to Action

## **1. Prioritise everyday systems of care – families, schools and communities**

The most appropriate and sustainable sources of psychosocial wellbeing for young children come from caring relationships in the home, school and community. Supportive families and communities nurture and sustain children's resilience. All efforts to enhance the psychosocial wellbeing of young children must ensure the support of these natural systems of care in everyday life. Children under stress are calmed and reassured when their familiar surroundings and everyday activities are restored.

## **2. Invest long-term in integrated services to promote psychosocial wellbeing**

The psychosocial wellbeing of children and their primary caregivers is best supported by integrated services that address economic, material, social, emotional and spiritual needs. Long-term investments in community development, health, education and family support services are more sustainable and successful than short-term, crisis-driven interventions.

## **3. Realise the right of all children to access these integrated services**

Rights are fulfilled through state provisions to which all caregivers and their children are entitled. These include education, health and social services. Universal access also addresses many of the most pressing needs of very vulnerable children. Services and programmes must take account of the differing needs of younger and older children, boys and girls, and children living in a variety of settings.

## **4. Demand that more governments take the lead in guaranteeing this right**

Governments must lead and resource a coordinated effort that matches the generally vigorous responses to support vulnerable children that have come so far from civil society. Systems to guarantee universal access to health and education must be strengthened. Social security underpins formal and informal, community-based, safety nets.

## **5. Earmark resources for applied research to expand the evidence base**

We need to learn from experience and apply lessons learnt from other fields, rather than treat HIV/AIDS as a special case in all respects. More evidence, including impact assessments, is crucial to guide and sustain appropriate and effective action.

# Where the heart is (Abridged version)

All young children require protection and nurture that meets their nutritional needs and ensures their health, affectionate relationships with stable caregivers that support their developing psychological and social capacities, and ongoing interactions with encouraging adults that promote their language and cognitive development. As they grow, children need friendships with same-aged peers and to be members of formal cultural institutions, including educational, play, social and/or religious groups. These associations help them learn the behaviour and moral values expected of people in their society. The psychological, social and material needs of young children during their development are best met by a constant group of dedicated people, related to one another, in lifelong family-type groups.

**Poverty conditions**, including lack of access to services, poor environmental conditions, inadequate material supplies, social instability, and overworked and demoralised caregivers **negatively affect children's development** directly and often simultaneously. When this happens, children fail to grow to their expected size, they are more vulnerable to severe illness, they lack energy to engage with their environment and to actively learn about the world, they are insecure and clinging, and their physical and psychological development is delayed and/or distorted. When these conditions persist unchanged for most of a child's early years, they have permanent effects on the child's developmental, cognitive and social capacities.

**HIV/AIDS exacerbates poverty effects on young children.** In addition, it increases disabling deprivations suffered by young children, because family livelihoods and employment income are lost when breadwinners become ill and die, and when available family resources have to be shared amongst affected kin. There are also features of the HIV/AIDS epidemic that pose particular threats to early childhood development. Young children may have to live with withdrawn, preoccupied and ill caregivers, they may lose parents through illness and death, and suffer social instability if they are moved from one home to another during a time in their lives when such loss and instability is maximally injurious to their health and wellbeing.

**The problems facing children and their families living in communities affected by AIDS are many and varied.** No single intervention or type of intervention can achieve significant or sustained support and protection for the wellbeing of the very large numbers of children affected by HIV/AIDS over the extended time scale of the epidemic.

**For a long time since the start of the AIDS epidemic, children have been something of an epiphenomenon** – a tragic by-product, relegated to mitigation efforts that fell somewhere between child survival and child welfare programmes. An overview of community, research, programme and policy responses over the past two decades shows that the earliest responses to children affected by AIDS came from families, starting in the early 1980s. At the time, there were no support programmes for affected children, but grandmothers, aunts and stepmothers took on the care of children who were destitute, neglected because of the illness of their parents, or orphaned by their death. Communities began to organise responses to cope with increasing numbers of affected children, and later international agencies started to make recommendations for dealing with the problems; nonetheless, faith-based and non-governmental organisations remained at the helm of

programming and research on children affected by AIDS. USAID catapulted international agencies into the arena of children affected by HIV and AIDS, with its 1997 publication of *Children on the brink*, starting a process that culminated in 2004 with the publication of the *Framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS*. Throughout this time, though, government action has been minimal, often the result of funding and initiatives supported by international agencies, donors and NGOs. The time has come for a strong, well-founded entry by governments to ensure national responses to protect the wellbeing of vulnerable children and to ensure that HIV positive children have equal access to treatment, monitoring and provision as adults.

**Hindsight provides an opportunity to reflect on the road traveled and the unintended detours taken along the way.** The first detour was an excessive emphasis placed on the category of orphaned children in HIV and AIDS programming and policy. Whilst not negating the suffering of children who lose their parents by any cause, “orphans” are a kind of shorthand for highlighting the cumulative community impact of the epidemic, following the waves of infection and illness. However, the success in promoting orphans as the bellwether of the impact of the epidemic on children and communities has had a number of unintended consequences. The preoccupation with orphan numbers has led to efforts being put into enumeration and registration without action, as well as to the proliferation of the confusing and stigmatising term “AIDS orphan”, by both agencies and the media. Children whose parents are presumed to have died of AIDS are often thought to be HIV+ themselves, stigmatised, excluded from school and denied treatment when they are sick. The preoccupation with orphans has meant that the plight of children living with sick parents has been overlooked. While we have been concerned with the category orphans, vulnerable children – the VC in the acronym OVC – have been largely invisible.

**Many children, including orphans, are vulnerable, as a result of poverty, conflict and family problems, as well as AIDS.** Established measures of child vulnerability indicate that large numbers of children living in Africa either lack access to health care and treatment, are malnourished, out of school or involved in excessive forms of child labour. Such a large number of vulnerable children requires the urgent strengthening of systems to improve the situation of *all* children living in communities affected by HIV and AIDS – to complement programmes that support the most vulnerable children.

**A second detour is the emphasis being placed on psychosocial interventions for children affected by HIV and AIDS.** This emphasis evolved to counter programmes that addressed only material or physical needs, without taking into account the social, psychological and spiritual aspects of children’s lives. But the pendulum may have swung too far. There is now concern that some approaches address only psychosocial needs and overlook the educational, health, material and physical needs of children and families. By placing an excessive emphasis on externally provided, stand-alone psychosocial programmes we are in danger of discounting the importance of everyday love, support and reassurance that children receive from families and communities. Many caregivers, families and communities need support to be able to provide these conditions for young children.

**Young children affected by HIV/AIDS and other major disruptions in their lives, have critical psychosocial needs that are best addressed when embedded in their everyday lives** – through responsive parental care, a return to normalcy (such as routines and opportunities to play), and social participation (such as returning to school and in other community activities). Psychosocial care, support and rehabilitation are all best provided by families and communities, sometimes with assistance. And when families are supported to be able to provide care, few children need specialised psychological or social programmes.

**What is needed to address the impacts of HIV/AIDS and poverty on children is a set of collective community and programme responses that acknowledge, support and strengthen the commitment and care of families and households for children.** These responses must be supported by constructive national policies and the mobilisation of resources. Within the mix of required responses, activities to protect, support and promote the psychosocial wellbeing of children and families are urgently needed. In the face of disaster of the magnitude of the AIDS epidemic, these activities are critical for two reasons. Firstly, children are able to be resilient, that is, to bear and recover from significant suffering, when they are surrounded by people who love and care for them. The sense of belonging and hope that is nurtured in these relationships enables children to cope with hardship, including hunger, illness, discomfort, and other privations of poverty and loss. Secondly, such efforts are key investments in human capital development. Children who receive affection and support in early childhood have a good foundation for coping with challenges, overcoming disadvantages and making positive contributions to society.

**Despite agreement about the importance of children's psychosocial needs in the face of the AIDS epidemic, considerable confusion surrounds the use of the concept *psychosocial*.** The term frequently refers to a range of intervention tools, processes and programmes for children in difficult circumstances to address their non-material, especially their social and emotional needs. Psychosocial interventions are different from the (psychosocial) care and support that children receive from affectionate caregivers in their everyday lives. It is the day-by-day, consistently nurturant care that constitutes the building blocks of children's psychosocial wellbeing, including how children learn, develop and adapt. Supportive family environments are sustained by community membership and initiatives, and governments need to provide the facilitating environment, with services and legislative protection.

**The heart of psychosocial care is to be found in the home** and it is here that the main thrust of external efforts to improve the wellbeing of vulnerable children must be directed. Young children have many needs, most of which are met through everyday activities in their families, supported by communities and assisted by government services. All children need stability, affection and reassurance. Some children – especially those living outside families on the streets or in institutions, with chronically ill caregivers, and orphans – are more vulnerable and especially in need of psychosocial support. However, this social support needs to be provided in family settings, with the same characteristics of commitment, continuity and individualised affectionate care. Specialised assistance by professionals or well-trained para-professionals may be needed for a small number of children who develop psychopathology as a result of their experiences. However, nothing can

replace the need of all children, especially those who are very vulnerable, for affectionate and stable family care.

**The growing numbers of children made vulnerable as a result of the HIV/AIDS epidemic has focused attention on the need to provide support to children who slip through the cracks of increasingly stressed extended families.** This has led to the development of programmes that target children affected by HIV/AIDS (CABA) and orphans and vulnerable children (OVC), and to the establishment of psychosocial interventions. The most important determinant for deciding whether children need additional support beyond their extended family is vulnerability, rather than targeting children who are members of an identifiable risk group, such as orphans. The primary aim of all psychosocial support programmes should be on placing and maintaining children in stable and affectionate family environments and, only secondarily, on direct service provision to affected children.

**Rather than reinventing the wheel, organisations moving into psychosocial areas need to learn from, and apply, lessons learnt from other fields,** including experience gained in addressing poverty, and assisting children affected by war, violence and displacement. Programmes should not try to meet the psychosocial needs of children and their caregivers in isolation. Resources being made available for children living with and affected by HIV/AIDS, as well as all AIDS interventions for adults who are parents, can be used effectively to strengthen the provision of services to benefit a broad cross-section of vulnerable children living in communities severely affected by the epidemic.

**Integrated responses are needed, and these are best provided by local community-based organisations.** To date, family and community safety nets have supported the majority of vulnerable children. However, there is now a need to ensure that government actions give all children, including the most vulnerable, universal access to services, and the security and assistance families need to care for children.

**Governments have a crucial role to play, particularly in providing education, health and social services** that meet the needs of vulnerable children, and in developing policies that promote children's physical and psychosocial wellbeing, and the capacity and stability of their families. Governments need to lead as well as resource coordinated efforts that match the vigorous responses to vulnerable children that have, thus far, been mounted by civil society.

**The best way to support the wellbeing of young children affected by HIV/AIDS is to strengthen and reinforce the circles of care that surround children.** Children are best cared for by constant, committed and affectionate adults. When the caregiving circle is broken for some reason, extended families normally plug the gap. When the circle of care provided by kin is broken, community initiatives need to stand in, and when the circle of care provided by community is broken, external agencies need to play a part. Embracing all efforts should be a strong and continuous circle of support provided by government provision and legislative protection. The optimal use of the resources of external programmes is to assist communities in supporting families. Families are best placed to provide for the psychosocial needs of young children. When it is necessary for external

agencies to provide direct services to children and to families, their touch should be light and, to be sustainable, it should be balanced by appropriate actions to strengthen extended family and community supports.

# 1. Introduction

All young children require affection, protection and nurture. This includes relationships with stable caregivers that support their developing psychological and social capacities, and ongoing interactions with encouraging adults that promote their language and cognitive development. As they grow, children require friendships with same-aged peers and to be members of social and cultural associations, including educational, play, social and/or religious groups. This sociality helps children acquire the behaviour and moral values expected of people in their society and equips children to become full participants in their communities.

During their development, the psychological, social and material needs of young children are best met by caregivers – a constant group of dedicated people, related to one another, in lifelong family-type groups. All children must have at least one person who uniquely loves them and has a deep vested, future-oriented interest in their wellbeing. Where these conditions are missing, every effort must be made to encourage, support or establish them as they are the *sine qua non* of optimal human development.

Poverty conditions – including lack of access to services, poor environmental conditions, inadequate material supplies, social instability, and overworked and demoralised caregivers – negatively affect children's development. When this happens, children fail to grow to their expected level, they are more vulnerable to severe illness, they lack energy to engage with their environment and to actively learn about the world, they are insecure and clinging, and their physical and psychological development may be delayed or reduced. When these conditions persist unchanged for most of a child's early years, they have permanent effects on children's cognitive and social capacities.

During the early years, various aspects of a child's development are vulnerable to environmental deficits. Children in the first few years of life are most susceptible to growth retardation, infectious diseases and injuries. They are especially vulnerable to developmental delay and adjustment difficulties if they are separated from familiar caregivers, by impoverished learning environments that fail to stimulate their cognitive and language development, and by experiences which damage their sense of identity and self-esteem.

HIV/AIDS exacerbates poverty effects on young children. It increases disabling deprivations suffered by young children because family livelihoods and employment incomes are lost when breadwinners become ill and die, and when already stretched family resources go to medical care for sick adults and are shared amongst affected kin. Young children may live with withdrawn, preoccupied and ill caregivers, they may lose their parents, and they may suffer social instability when they are moved from one home to another during a time in their lives when such loss and instability is most injurious for them.

This is why interventions for young children should support affectionate family caregiving, and continuity and stability, through access to essential services and association with social groups in the community, including faith groups, child care associations and the like.

## 1.1 Defining “psychosocial” concepts

Within the range of responses necessary to strengthen the support systems around young children made vulnerable by HIV/AIDS, it is generally agreed that activities to protect, support and promote the psychosocial wellbeing of children and families are critical for two reasons.

Firstly, children are most resilient – that is, able to bear and recover from significant suffering – when they are surrounded by people who love and care for them. The sense of belonging and hope that is nurtured in these relationships enables children to cope better with hardship, including hunger, discomfort, and other privations of poverty and loss.

Secondly, such efforts are key investments in human capital development. Children who receive affection, stimulation and support in early childhood have a good foundation for growth and development, coping with challenges, overcoming disadvantages and making positive contributions to society.

Despite agreement about the importance of children’s psychosocial needs in the face of the AIDS epidemic, considerable confusion surrounds the use of the concept *psychosocial*. The term is frequently used to refer to a range of intervention tools, processes and programmes delivered to children in difficult circumstances to address their non-material needs, especially their social and emotional needs.

The confusion arises because psychosocial interventions and programmes are not the same as the psychosocial care and support that children receive from affectionate caregivers in their everyday lives. It is day-by-day, consistently nurturant care that constitutes the building blocks of children’s psychosocial wellbeing, including how children learn, develop and adapt. Psychosocial interventions and programmes are only needed for a very small number of children for whom family care is not sufficient.

In the context of HIV/AIDS, large scale efforts are required to support families to care for young children. Governments must ensure a facilitating environment, through services and legislative protection, to enable families to provide care for children. Governments and other agencies must support and resource community initiatives that provide assistance for vulnerable families and children. State and civil society programmes must help link families to available services and community initiatives.

When using the term psychosocial, it is important to be clear about the meanings of psychosocial needs, psychosocial wellbeing, psychosocial interventions and psychosocial support programming, and psychosocial care and support.

**Psychosocial needs** are the needs that all people have – especially young children, whose brains, bodies and social lives are developing – to be happy, creative, to belong in social groups, and to have hope for the future. When children face difficulties and deprivations, particularly when these are chronic or repetitive, they are especially in need of stability, affection and reassurance.



**Psychosocial wellbeing** is the positive age- and stage-appropriate outcome of children's physical, social and psychological development. It is determined by a combination of children's capacities and their social and material environment. Psychosocial wellbeing is essential for children's survival and development, especially in chronically difficult circumstances.

**Psychosocial interventions and psychosocial support programming** are specific and formalised activities, programmes and services. Psychosocial interventions include counselling, debriefing and cognitive behaviour therapy. Psychosocial support programmes are efforts by individuals and groups outside of the child's usual social networks, such as memory work, play and camp groups.

**Psychosocial care and support** is provided through interpersonal interactions that occur in caring relationships in everyday life, at home, school and in the community. This includes the love and protection that children experience in family environments, as well as interventions that assist children and families in coping. Care and support enable children to have a sense of self-worth and belonging and are essential for children to learn, to develop life skills, to participate in society and to have faith for the future.

Readers will note that the above does not offer a definition for the familiar phrase "psychosocial support". This is deliberate. While in theory the meaning of "psychosocial support" can and should encompass all means of supporting the psychosocial needs and wellbeing of young children, including family and community care, in practice the phrase has come to be identified more narrowly with external interventions. This has resulted in lack of recognition of caregiving and family care as the most fundamental form of psychosocial care and support for young children.

In an attempt to achieve greater clarity, we have adopted the terms "psychosocial interventions" and "psychosocial support programming" to refer to external interventions, and "psychosocial care and support" to refer to the everyday family systems of care which support children's psychosocial wellbeing. We believe these formulations reduce current confusion about psychosocial terminology and we commend them to practitioners.

## 2. Who are vulnerable children?

The difficulties experienced by children, caregivers and families living in communities affected by AIDS are increasing dramatic as the epidemic matures and deaths increase. The worst affected children experience multiple losses, including:

- **health and vitality**, through infection, inadequate nutrition and poor health care;
- **economic support** through the collapse of livelihoods resulting from the illness and death of breadwinners and other adults in the extended family who were previously engaged in economic support and subsistence activities;
- **parents** and other primary caregivers to illness, death and abandonment;
- **families**, as they are parted from caregivers and siblings following bereavements and poverty-induced migration;
- **connections to social institutions** as a result of stigma in the community and withdrawal from school because of poverty, work and/or care obligations in the home;
- **human right to development** in an environment that supports their basic needs for health, education, care and protection;
- **opportunities to learn from caregivers and play** with other children because parents may be too ill, because of stigma leading to exclusion, or demoralisation in the family environment;
- **hope and opportunities** for the future.

Large numbers of children are affected by the HIV/AIDS epidemic, in different ways. They include the following groups.

### Children indirectly affected by the AIDS pandemic

Many children in sub-Saharan Africa are vulnerable irrespective of the HIV/AIDS epidemic due to such factors as child labour and lack of access to health and education (see figure 1). In addition there are children with disabilities, street children, working children, children in institutions and children in conflict zones who may all be considered to be vulnerable children living in especially difficult circumstances.

**Figure 1: Indicators of widespread child vulnerability in sub-Saharan Africa**

Sector	Measure of vulnerability	%
Health	1-year-old children not immunised against diphtheria/pertussis/tetanus (DPT3)	35
Health	Under-5 mortality rate in 2004	17.1
Health	Under-5s who are moderately or severely underweight	28
Education	Primary school entrants not reaching grade 5	34
Protection	Child labour (5–14 years), boys	37
	girls	34

Source: UNICEF (2005b)

HIV/AIDS indirectly affects large numbers of these already vulnerable children because social institutions and services are weakened when teachers, health service providers, civil servants and others become ill or are distracted by their responsibility for sick and dying relatives. Catholic Relief Services estimate that some 90 percent of children in Zimbabwe have, in some way or other, suffered as a result of the impacts of HIV/AIDS (Catholic Relief Services 2004).

### **Children in households that foster children**

The mainstay of the response to orphaned and vulnerable children is family fostering, a practice common throughout Africa that predates the AIDS epidemic. Children who live in poor households that foster vulnerable children face similar hardships because resources in receiving households are stretched to accommodate additional dependents.

### **Children living with chronically ill adults**

Children living with chronically ill adults endure severe economic and psychosocial effects, but remain generally invisible to service providers. When caregivers are ill, children may not only suffer compromised parenting and childcare, but the diversion of income and assets to pay for the treatment of sick adults deepens poverty. In addition, caring for sick and dying relatives imposes a physical and psychological burden on children. The impact of chronic parental illness on children is one of the most poorly understood and neglected difficulties faced by affected children.

### **Children living with HIV/AIDS**

Deaths from poverty-related diseases account, for the most part, for the extremely low life expectancy of children living with HIV/AIDS (CLHA)<sup>1</sup> in sub-Saharan Africa. For this reason, public health measures to promote the general health and wellbeing of all children in communities affected by HIV/AIDS are as important in extending and improving the quality of the lives of CLHA as the delivery of paediatric antiretroviral treatment in a child-appropriate manner.

There are also major psychosocial challenges facing children living with HIV/AIDS and their caregivers, including stigmatisation and the pain and distress of chronic illness.

### **Children orphaned or abandoned as a result of AIDS and other causes**

Loss of a mother, father or other parenting figure is an extreme and ongoing challenge for a young child. This is especially true when the experience is repeated when more than one parenting figure dies. The order, spacing and nature of death experiences have a bearing on the effects on children, as it does on the support of kin and the closeness of family networks.

Adult mortality due to HIV/AIDS is causing a new and precipitously increasing form of orphaning – but it is not the only cause; others include war, violence and accidental death. “AIDS orphan” is a particularly stigmatising, and even objectifying, term; despite its charitable appeal, efforts should be made to stop its use.

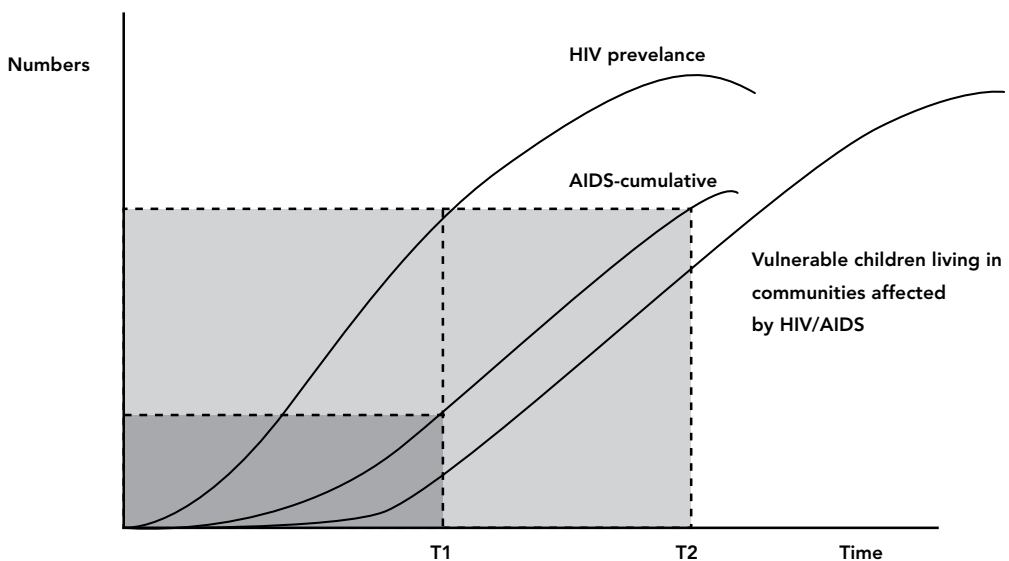
<sup>1</sup> The term “Children living with HIV/AIDS” (CLHA) is preferred to “infected children” or “paediatric AIDS” because it links children to the rights-based PLHA (People Living with HIV/AIDS) movement.

The impact of the AIDS epidemic on children and families is frequently illustrated by the increase in orphaning, often referred to as the third wave of the epidemic – following infections and AIDS deaths. The proportion of children being orphaned by AIDS is cumulative, creating a “long wave”, and many children are losing both parents.

Figure 2 shows three curves. The first curve shows HIV prevalence and, because of the long incubation period, adult AIDS illness lags behind infection by 5–10 years. People with AIDS require treatment and care and will die unless dramatic changes occur in the effectiveness, availability and cost of treatment.

The third curve shows the impact of AIDS on vulnerable children, resulting from the death of young adults with consequent orphaning, loss of work and livelihoods and deepening poverty.

**Figure 2: Curves of the epidemic: Prevalence, AIDS illness and impact**

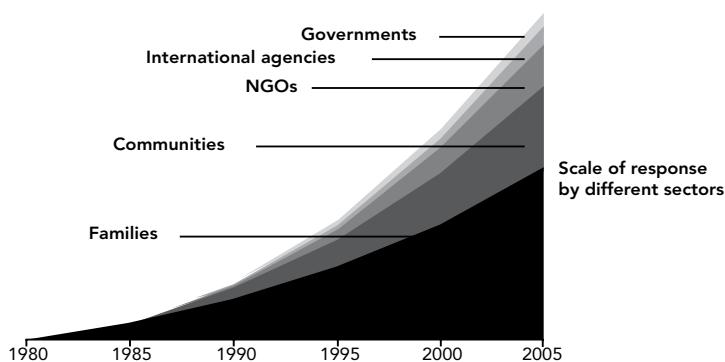


Source: Adapted from Levine, Foster and Williamson 2005

## 2.1 The road travelled and the road ahead

In the first two decades of the AIDS epidemic, children were seen as something of a tragic by-product and relegated to mitigation efforts that fell somewhere between child survival and child welfare programmes. Figure 3 shows that for several years in the early 1980s the only responses to vulnerable children came from families. Thousands of grandmothers, aunts, stepmothers, siblings and sometimes father-figures, took on the care of children who were destitute and neglected because of the illness of their parents or orphaned by their death.

**Figure 3: Speed and scale of responses to children affected by HIV/AIDS**



Source: Foster 2006

By 1987, communities were organising responses to cope with increasing numbers of affected children. In 1990 international agencies began to make recommendations for dealing with the problems, whilst faith-based and non-governmental organisations remained at the helm of programming and research on children affected by AIDS.

Grassroots efforts in AIDS-affected communities continued to increase throughout the 1990s, although they tended to be overlooked by external agencies. Community- and faith-based responses have proliferated, predominantly self-resourced, and in the absence of external technical or financial assistance – a situation that continues to the present.

It was largely the publication in 1997 by USAID of *Children on the brink* that catapulted international agencies into the arena of children affected by HIV and AIDS. This kick-started a process of consultation and consolidation that culminated in 2004 with the publication of the *Framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS*, a document endorsed by many international and national organisations.

In the early 1990s, the governments of Uganda and Zimbabwe became the first to host conferences leading to national policy processes. To date, though, government action overall has been minimal, generally prompted by funding and initiatives supported by international agencies, donors and NGOs.

A view of the historical record provides an opportunity to reflect on the road traveled and two unintended detours taken along the way.

The first detour was an excessive emphasis placed on the category of orphaned children in HIV/AIDS programming and policy. This is not to underplay the suffering of children who lose their parents by any cause, but the fact that the word "orphans" became shorthand for highlighting the cumulative community impact of the epidemic had a number of unintended consequences, not least that it led to a preoccupation with enumeration and registration of orphans rather than action-oriented programmes

It also led to stigmatisation, as children whose parents are presumed to have died of AIDS are often thought to be HIV+ themselves, and as a consequence often excluded from school and denied treatment when they are sick.

The preoccupation with orphans has also meant that the plight of children living with sick parents has been overlooked. We have known for nearly 20 years how many orphans there are likely to be, but we still have little idea how many children are caring for sick parents and under what conditions. While concern is confined to orphans, vulnerable children (the VC in the acronym OVC) remain largely invisible.

Many children, including orphans, may be vulnerable, as a result of poverty, civil conflict and family problems as well as AIDS. Such a large number of vulnerable children is the reason that systems that improve the situation of *all* children living in communities affected by HIV and AIDS must urgently be strengthened, to complement and resource programmes to support the most vulnerable children. "Systems" here includes families, communities, health, education, social welfare and other services.

A second detour is the emphasis, which started in the 1990s, placed on psychosocial interventions for children affected by HIV and AIDS. Psychosocial support programmes evolved to counter programming that addressed only material or physical needs without taking into account the social, psychological and spiritual aspects of children's lives. But there is a danger that the pendulum may swing too far the other way; there is now concern that some approaches address only psychosocial needs and overlook the educational, health, material and physical needs of children and families.

Moreover, by placing an excessive emphasis on externally provided, stand-alone psychosocial programmes, we are in danger of discounting the importance of the everyday love, support and reassurance children receive from families and communities. Efforts to bolster children's psychosocial coping capacities are more effective when they reinforce the circles of care around

young children. The AIDS epidemic and other stressors are reducing the capacity of families to care for children and efforts must be made, across the spectrum, to support, encourage and strengthen families.

Young children affected by HIV/AIDS, and by other major disruptions in their lives, have critical psychosocial needs that are optimally addressed when support is embedded into their everyday lives through responsive parental care, a return to normalcy (such as routines and opportunities to play) and social participation (such as returning to school and other community activities). Psychosocial care, support and rehabilitation are all best provided by families and communities, and when families are supported to be able to provide care, few children require specialised psychological interventions or psychosocial programming.

Integrated responses are important, and these are best provided by local community-based organisations. To date, family and community safety nets have supported the majority of vulnerable children without additional financial and other resources. However, it is now critical that to ensure that government actions give all children – including the most vulnerable – universal access to services, as well as the security and assistance families must have to be able to care for children.

## **2.2 Broadening the emphasis from orphans to vulnerable children**

Focusing on orphaned children restricts attention to only one group of several types of potentially vulnerable children. Whilst the precise definition of “orphan” is less useful at community level, there is wide endorsement in policy and programming of the UNAIDS/UNICEF/USAID definition of an orphan as a child under 18 years of age who has lost one or both parents. By contrast, the definition of vulnerable children is highly variable at the policy and programme level, despite having a fair degree of consistency of meaning in communities.

Generally, at a community level, children are regarded as vulnerable when they are separated from caregivers, are malnourished, abused, neglected, out of school, disabled, ill, required to do excessive work, or lack access to services. By this definition, very large numbers of children are vulnerable.

Many communities in extreme poverty in sub-Saharan Africa have been hard hit by HIV/AIDS. It is difficult to separate the effects of HIV/AIDS on children from prolonged poverty, civil war, migration and displacement. Many studies and programmes concentrate their efforts on orphans, running the risk of overlooking large numbers of children who are vulnerable through other causes. They may also cause orphaned children to be victimised because they are singled out for assistance in a context of pervasive vulnerability.

Issue	Orphans	Vulnerable children
<b>Definition</b>	This is agreed at the international level because an orphan is formally defined. However, a child with a surviving parent is not normally called an orphan at the community level, where there are many different understandings of what it means to be an orphan – only some of which coincide with the death of the child’s biological parent.	There is little agreement at the national and international level on who are vulnerable children, although there is generally consistency in the definition of vulnerability at the community level.
<b>Focus</b>	The focus is on an individual child, usually after a parent has died.	The focus is on all children living in conditions that impair their health, wellbeing and development, including in the difficult years before a parent dies.
<b>Psychosocial needs</b>	The focus of attention is on the psychosocial needs of children once orphaned, and tends to concentrate on bereavement.	The focus of attention includes children affected before and during parental illness and over the longer term, as well as children who are vulnerable or orphaned for reasons other than HIV/AIDS.

## 2.3 Children living with AIDS, or children affected by AIDS?

Increasing attention is being given to children living with HIV/AIDS (CLHA) through healthcare provision and additional resources for their care and treatment. But a narrow approach, focused only on drug provision to those children that have been diagnosed with HIV/AIDS runs the risk of overlooking the health and psychosocial needs of large numbers of other vulnerable children living in communities affected by AIDS.

The recent emphasis on children in the AIDS epidemic, through the provision of anti-retroviral treatment and prevention through the use of co-trimoxazole, is welcome. But it should be expanded to include services for all children living in communities affected by HIV/AIDS. In addition, a stronger health system, with increased reach and access for all children, will also have significant benefits for providing access to prevention, treatment and care for children living with HIV/AIDS.



Issue	Children living with HIV/AIDS (CLHA)	Children living in communities affected by HIV/AIDS
<b>Numbers of affected children</b>	Relatively, smaller numbers of children are living with HIV/AIDS.	Large numbers of children, especially those living in poverty, are affected both directly and indirectly by the AIDS epidemic.
<b>Recognition of psychosocial needs by health services</b>	Psychosocial needs of CLHA may be recognised, especially at diagnosis, the initiation of ART, for adherence, and in dealing with end-of-life issues.	Health services currently do not specifically focus on the needs, including the psychosocial needs, of vulnerable children.
<b>Recognition of child psychosocial needs by community programmes</b>	Little attention is currently being given to CLHA, or their psychosocial needs, in community programmes.	Some community programmes recognise and attempt to address the psychosocial needs of vulnerable children.
<b>Recognition of child psychosocial needs by caregivers</b>	Caregivers may recognise the psychosocial needs of CLHA, especially if health workers and others raise disclosure and adherence issues with them.	Few community programmes actively work with caregivers and families to increase their responsiveness to the psychosocial needs of vulnerable children.
<b>Factors affecting psychosocial wellbeing</b>	CLHA are vulnerable as a result of pain and distress, chronic illness, school absence, and increasing disability, as well as bereavement, poverty and stigmatisation.	Orphans and other vulnerable children experience stress arising from poverty, exclusion, bereavement and stigmatisation.

## 2.4 Diverse children have diverse needs

“Children” is a catch-all term that masks a myriad of differences among young people from birth to 18 years of age. Most notably, girls and boys, older and younger children, and children in rural and urban areas all have different experiences and different needs. Assertions about children affected by HIV/AIDS that do not take these differences into account can be confusing, and they can miss the most important needs of specific groups of children.

Age and developmental stage are particularly important. Younger children have specific needs that include love and affection, stable care, active feeding, a stimulating environment, access to preventive and curative health services, and protection from injury. The loss or chronic illness of a primary caregiver generally has more serious consequences for a young child in the long term.

Girl children more often take up the role of care, for both sick adults and dependent siblings. In addition, the gender of dying and surviving parents affects child outcomes, including who children live with, who takes responsibility for the child's care, their socioeconomic needs, and whether or not a child remains in school. Mothers are more likely than fathers to care for children when their spouse dies. For this reason, fathers should be encouraged and helped to care for their children when their wife or partner dies.

The environments in which children live are also affected by the gender of their carers. Many households are female headed – by a mother, aunt, step-mother, foster-mother, sister or grandmother – and these tend to be poorer than other households.

Girls and boys are different in a number of ways, including their patterns of HIV infection, school attendance, adoption, fostering, family responsibilities, economic inheritance, future prospects, coping and behaviour. Increased attention to gender has drawn attention to the special needs of girls, but issues affecting boys are less often addressed.

Attention to gender in the early years, and combating stereotypes of girl's submission and boy's dominance, is especially important because of its potential long-term role in preventing HIV in the next generation of young adults.

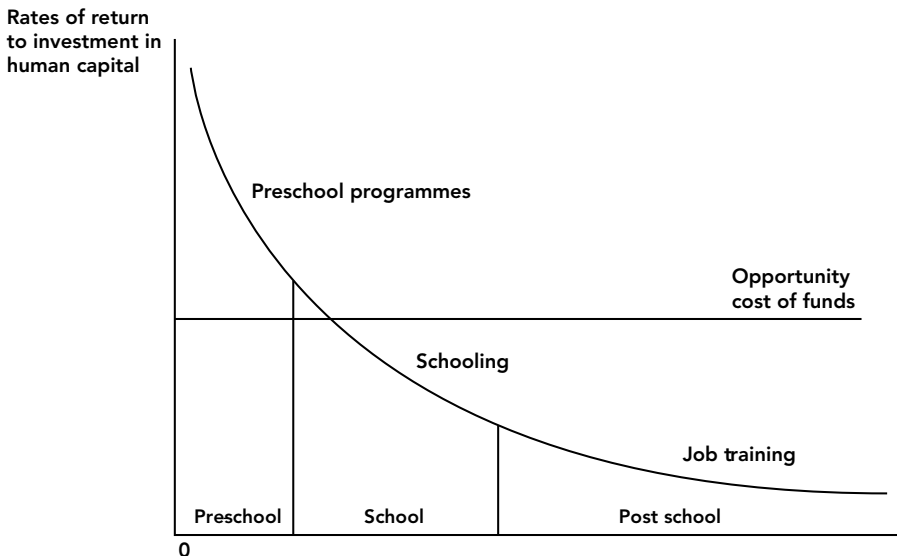
# 3. How are children's psychosocial needs met?

Support for children's psychosocial wellbeing is crucial, firstly because children have a right to develop to their full potential, and secondly because it will help them contribute to the prevention of HIV in the next generation and the long-term advancement of society.

As they grow, young children develop their emotional repertoire, their relationships with other people, their intellectual capacities, and their hope and motivation for the future. These are best developed in nurturing and stable family environments with lifelong social connections, as these provide the necessary conditions for human development.

From society's point of view, the rates of return on human capital investment through support for development, education, health and improvement of environmental conditions are greatest when made early in life. This is illustrated by the work of Nobel laureate James Heckman (see figure 4).

**Figure 4: Rates of return to human capital investment**



Source: Heckman 2004

Specifically, human investment in the early years entails promoting strong caregiver–child relationships for children’s nurture and protection, supporting children’s nutrition and growth, minimising childhood illnesses, decreasing environmental threats to children’s safety, providing opportunities to learn and play, increasing access to preparation for formal schooling, and promoting educational access, retention and achievement.

Early intervention in the context of the AIDS epidemic is an important consideration given that the predominant focus on orphans has drawn attention away from the vulnerability of young children whose parents are still alive. The time lag between adult HIV infection and death results in a mean age of orphaning of about 8 years. Thus it is preschool children who are more likely to suffer inadequate nutrition and health care, who may be neglected if their mother or other primary caregiver becomes sick, anxious and withdrawn through ill-health, and if households become destitute because of adult illness.

Younger children, before they enroll in school, are more likely to be moved from one household to another during the crises of parental illness and death, leading to instability in caregiving, with adverse effects on the development, health and wellbeing of young children.

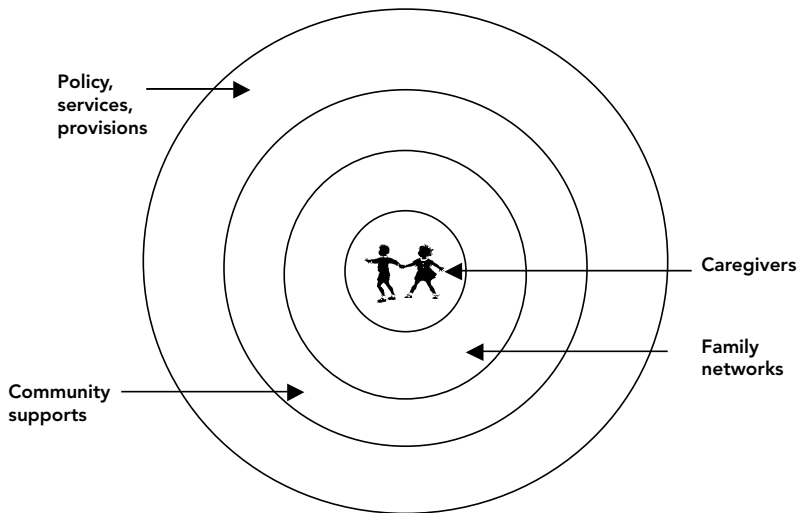
The vast majority of vulnerable children are cared for by extended families. Networks of kith and kin constitute an extensive safety net for vulnerable children – but it is a system of protection that is under strain. The stresses and destitution associated with the AIDS epidemic are negatively affecting family networks and communities. Children’s wellbeing and their emotional, social, health and educational outcomes are dependent on supportive families and communities. For families and communities to be supportive, they need access to essential services, support and assistance, social protection, economic participation and empowerment, and enabling policies and institutions.

Statistics cannot convey the countless examples of domestic heroism by AIDS-affected families. Research in countries such as Kenya, Malawi, Rwanda and Zambia suggests that family structures in sub-Saharan Africa are more resilient than many in the international development field had expected. Instead of disintegrating in the face of AIDS, many families are finding ways to make a living, feed and educate their children, and care for the ill – although frequently at great cost, stress and sacrifice.

*Source:* UNAIDS 2006

The only way to effectively protect, promote and enhance the health and wellbeing of young children is to improve the quality and stability of the care they receive from those closest to them – from their caregivers and families (see figure 5). When this intimate circle of care is functioning well, it can compensate for negative influences on children that arise in the wider environment. For example, children in close and affectionate families are much less likely to suffer the ill effects of poverty and deprivation than children who have families that are unstable and in which adults have little time or attention for young children.

**Figure 5: Circles of care**



Source: Adapted from Bronfenbrenner 1979

### 3.1 Institutions and family care

The vast majority of vulnerable children are being cared for in family environments, and family care is especially important for the most vulnerable children. Children placed in institutions have increased risk of death, illness, language delay, socio-emotional disorders and personality dysfunctions. There is also a greater likelihood that institutionalised children grow up disconnected from their culture, extended families, and communities.

Residential institutions are not the answer to the crisis of poverty and childcare in countries with severe HIV/AIDS epidemics. The same lesson was learnt with respect to children affected by armed conflict and war. Institutions are costly, harmful for children, and draw attention and resources away from efforts to support families – both families of origin and foster or adoptive families – to care for children.

Families may require assistance to care for children, especially when they are new, adoptive or foster parents, or when families are under stress. The inclination to establish institutions is misguided. Children themselves express a desire to be cared for in families.

The main focus of programmes for vulnerable children should be to strengthen family care and community support. Although institutional care is often justified as a temporary respite for the care of abandoned children until suitable family placements are found, more effort needs to go into setting up emergency and respite family care.

<b>Issue</b>	<b>Family care</b>	<b>Institutional care</b>
<b>Caregivers</b>	Family caregivers have a long-term perspective of a child and care of a child occurs in a network of inter-relationships that last a lifetime.	Paid child minders have a short-term perspective of a child, and their care is disconnected from the long-term of a child's life.
<b>Family, community and cultural connections</b>	Children remain connected to extended kin and the community and can be helped to maintain their lineage and inheritance.	Children have little, if any, connection with extended kin and the community, except through school, and are likely to lose their lineage and inheritance.
<b>Routines and rituals</b>	Families have rituals and routines in which individuals have culturally demarcated roles and responsibilities that help children participate meaningfully in their family and society.	The routines and rituals of residential care tend to serve the efficiency of the institution rather than the child or the wider society.
<b>Exploitation and abuse</b>	Vulnerable children in poorly chosen or unsupervised foster family care may be physically and sexually exploited or abused.	There are frequent reports of neglect, as well as physical and sexual abuse, of children in institutions. Children are especially vulnerable when institutions experience financial difficulties.
<b>Numbers supported</b>	The great majority of affected children are cared for and supported by relatives.	Only small numbers of affected children can be accommodated in institutions. Most children in institutions in resource-poor countries are there because their families are destitute and not because they are orphans.
<b>Cost of providing care</b>	Families provide care for children at relatively low cost, and even small amounts of income support for families benefit children.	Institutional care is consistently shown to be significantly more expensive than family care (see box: What about orphanages?)

Children in crisis are likely to be additionally stressed in an institutional environment. Established institutions need to be helped to address the psychosocial needs of resident children, and to increase their efforts to place children in supervised family care.

### **What about orphanages?**

While building more orphanages, children's villages or other group residential facilities would seem a possible response to caring for the growing number of orphans, this strategy is not a viable solution.

Care provided in institutional settings often fails to meet the developmental and long-term needs of children. Children need more than good physical care. They need the affection, attention, security and social connections that families and communities can provide. Countries with long-term experience with institutional care for children have seen the problems that emerge as children grow into young adults and have difficulty reintegrating into society. In Ethiopia, Rwanda and Uganda, for example, evaluations of children's long-term stays in orphanages led these governments to adopt policies of de-institutionalisation and support for family-based care.

Orphanages are more expensive to maintain than providing direct assistance to existing family and community structures. Institutional care would be prohibitively expensive for the vast majority of countries. The annual cost per child tends to be from \$500 upwards in Africa. Research by the World Bank in the United Republic of Tanzania, for example, found that institutional care was about six times more expensive than foster care. Cost comparisons conducted in Uganda showed the ratio of operating costs for an orphanage to be 14 times higher than those for community care. Other studies have found a ratio of 1:20 or even up to 1:100.

The magnitude of orphans due to HIV/AIDS is so large that an institutional response – besides not being in the best interests of the child – will never be the answer. Orphanages for more than 14 million orphans simply cannot be built and sustained.

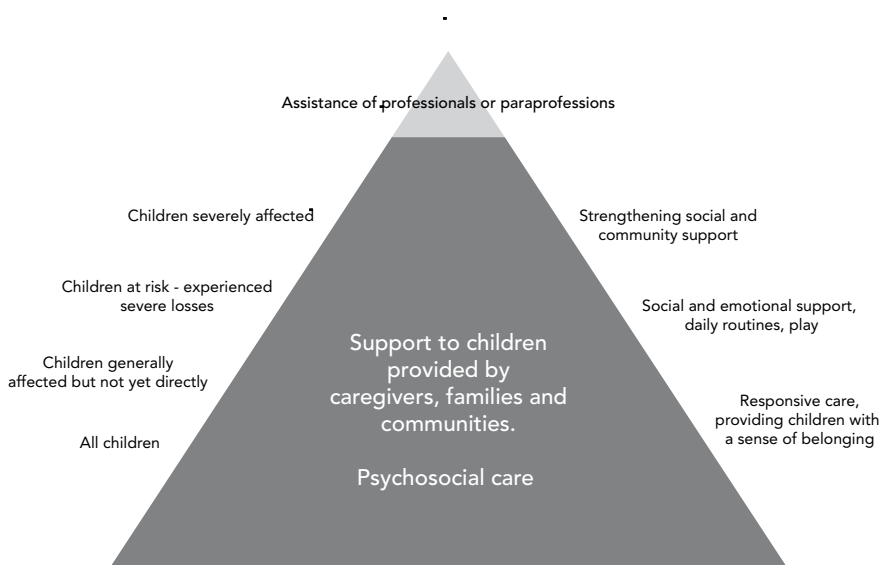
Source: Annex 3 from UNAIDS and UNICEF 2004

## **3.2 Integrated versus stand-alone interventions**

Children affected by HIV/AIDS have critical psychosocial needs. These are best addressed through supportive relationships and structures embedded in children's everyday lives. Stand-alone psychosocial interventions and programmes should reinforce, and not replace, the essential psychosocial care and support that children receive from caregivers, relatives and friends – support that occurs day-by-day and across the lifespan.

Most children affected by HIV/AIDS do not require stand-alone or specialised psychological assistance. Only a very small number of children need individual mental health interventions conducted by outside professionals or para-professionals. As shown in figure 6 (adapted from UNICEF's psychosocial cross-sectoral task team), most children need the sort of care and support that is provided by families and communities.

**Figure 6: The hierarchy of children's needs for psychosocial care, support and intervention**



Source: Adapted from figure shown by Patrice Engle, Senior Advisor, Early Child Development, Unicef, at the second "Road to Toronto" meeting, held in Cape Town, South Africa

Some caregivers need to be sensitised to the fact that children facing difficulties need additional love and reassurance, and they may require assistance with other aspects of caregiving, especially under conditions of great stress. When considered necessary, psychosocial interventions should therefore be directed at increasing the responsiveness to young children of caregivers, family networks, and social institutions such as preschool and school, and strengthening the social connectedness of young children to social groups including friends.

Integrated approaches that combine social and material support to caregivers and families are needed to improve the health and wellbeing of children in communities affected by AIDS. For example, malnourished children show better and faster recovery when, in addition to nutritional rehabilitation, their relationships with caregivers and their levels of cognitive stimulation are also improved. However, few caregivers are able to go on providing love and stimulation when they are destitute and socially isolated.



<b>Issue</b>	<b>Stand-alone material interventions</b>	<b>Stand-alone psychosocial interventions</b>	<b>Integrated interventions</b>
<b>Recognition of needs and impact</b>	Needs for protection, food, clothes and shelter are apparent and impact is immediate.	The psychosocial needs of vulnerable children and their caregivers are less frequently recognised.	Integrated interventions address the multiple needs of children and families in distress.
<b>Infrastructure</b>	There is infrastructure available for material provision, including through schools, health facilities and development programmes.	Very little infrastructure and few services exist for stand-alone psychosocial programmes. They are often project-based and donor-dependent.	Community organisations, schools, health and social services, development programmes and other opportunities can be used to provide integrated assistance to children and their families.
<b>Unintended consequences</b>	Material interventions may ignore the psychosocial needs of children and caregivers, and miss opportunities to build the capacity and resilience of children and families.	Psychosocial interventions may be seen to imply that families and communities cannot cope on their own. If this is so, it will erode rather than reinforce the resilience that psychosocial programmes aim to strengthen.	Integrated programmes can reinforce coping and resilience by addressing psychosocial needs in the course of providing other forms of assistance.
<b>Indigenous resources</b>	Material aid is often brought into communities from the outside, rather than supporting local capacity to provide for the material needs of communities.	In the AIDS field, many psychosocial programmes are foreign to the communities in which they are used. As yet, few programmes draw on indigenous coping and response strategies.	All efforts to give assistance should draw on indigenous resources to help provide a holistic response to the spiritual and other needs of children and families.
<b>Sustainability</b>	Material aid is sustainable if it is part of government provision or self-generated community initiatives.	Psychosocial programmes are generally not sustainable over the long term because they are resource-intensive and donor-dependent.	Integrated material and psychosocial assistance should be built into services for vulnerable children and families, including into health, education and social welfare and protection.

### **3.3 Brief interventions versus long-term investments**

The plight of children in difficulty, including those affected by HIV/AIDS, sometimes triggers quick-fix interventions. These interventions respond to the urgency of the situation, and often attract attention and funding. While short-term interventions may be ameliorative, they do not address the core problems of children's ongoing development and the needs of their families. They are additions to, rather than substitutes for, affectionate emotional care by stable caregivers in families that receive support from their communities and the state.

An afternoon of memory work, a drawing workshop, or a weekend at a camp, with little preparation and no follow up with caregivers and families, have limited – even if positive – impact on the lives of distressed children.

If delivered in isolation from efforts to ensure that children and families have access to essential services and social protection, and participate in socioeconomic development, brief interventions may draw attention, as well as human and financial resources, away from sustained longer-term support for children and their caregivers. They can do more harm than good if they attract staff away from existing services and provisions, and if they make everyday family support for children seem unimportant. Long-term, sustained services and provisions to strengthen families and communities, and to improve the quality and stability of care for children, are required – but this developmental approach is more difficult to fund and implement.

### **3.4 Even children who appear to be coping need support**

Many children experience enormous suffering in the face of the HIV/AIDS epidemic. As in other very difficult situations, the majority of children are coping with the challenges. A small number require the help of specialised services and external agencies to support them and their families to recover their bearings.

However, the fact that children are coping should not be taken to indicate that they do not need assistance. Child-supportive policies, a child-rights approach, provision of quality services, protection and social security, and a social and economic environment in which parents can garner resources to care for their children, are necessary for children to be able to grow up into resourceful, adaptable, productive and confident adults.

Long-term developmental support is necessary to provide an environment that is supportive of children and families.

Issue	Brief interventions	Long-term support
<b>Type</b>	Play groups, activity programmes, some memory approaches, and camps are sometimes delivered as brief interventions.	Long-term support is derived from poverty alleviation, community development, social security, access to health, education and social services or the integration of brief interventions into long-term planning.
<b>Needs addressed</b>	Address immediate needs, often in a crisis or in response to a problem with a child or in a family.	Addresses long-term needs for family security, quality of care, and children's development.
<b>Profile</b>	High profile and might be seen to be sufficient to address the problems of orphans and vulnerable children.	Low profile because they aim to build and reinforce the often invisible social fabric of caregiving, and family and community life.
<b>Appropriateness</b>	Short exposure to positive and enjoyable experiences or opportunities to be with others and receive social support may strengthen children's coping.	HIV/AIDS compounds the impacts of poverty, conflict, disasters and displacement. In these conditions, long-term systemic approaches are critical to support children's development and wellbeing.
<b>Source of the interventions</b>	Many short-term interventions are initiated and run by projects using donor funds.	Longer-term systemic interventions, such as free schooling, health care, and social security, require government commitment as well as NGO and community support.
<b>Funding and evaluation</b>	It has been easier to fund short-term project-based interventions. However, few of these interventions have been evaluated.	It is more difficult to generate sustained funding for socio-economic development. Nonetheless, poverty studies are increasingly attesting to the positive benefits of long-term systemic interventions

### 3.5 Getting it off your chest? Catharsis versus normalisation

It is important to normalise young children's lives when they are under stress and when they experience overwhelming sadness and problems. Normalisation involves helping a child feel safe in the context of their familiar surroundings and routines, receiving affection, nurturance and reassurance from supportive adults and older siblings, returning to school, and playing with friends.

Caregivers can be helped to understand the many ways in which children express themselves, and how to support children when they are distressed. They can also be helped to answer children's questions kindly and simply, and to reassure young children that they are safe and secure.

UNICEF has a responsibility to discourage any practices or interventions which rob the dignity or are known to be potentially harmful to children, their families and communities. These include:

- "debriefing" programmes, which aim to get children to recount their experiences, without any appropriate support mechanism in place;
- use of the post-traumatic stress disorder (PTSD) framework as a universal assessment tool, particularly in the immediate aftermath of a crisis;
- activities which cast children as victims;
- activities aimed exclusively at individual children in isolation from their community or environment;
- direct work with children by foreign professionals with no prior experience in the affected community;
- activities under the guise of PSS whose primary aim is research or information gathering.

Source: UNICEF programming for psychosocial support: Frequently asked questions. As presented by Sarah Norton-Staal at the fourth "Road to Toronto" meeting, held in The Hague, the Netherlands.

If young children do not talk about their stresses to their family, friends, teachers or other supportive people in their social environment, it should not be assumed that outsiders are needed to help the child "get these inner worries off their chest" through verbal expression, drama, story telling, or drawing. When cathartic activities are one-off and have no connection to the child's ongoing life and structures, they could do more harm than good. As reflected in the UNICEF box above, from experience gained in working with children in war and violence field, encouraging children to express themselves can lead to re-traumatisation.

Children should not be put in a position where they feel obliged to express their feelings about the illness or death of their parents, about their fears of what is to happen to them, or about their suffering at the hands of exploitative and abusive kin, neighbours and others. When children feel safe and reassured, they are more likely to speak to caring adults, spontaneously express their fears, and ask questions about issues that trouble them.

This approach is consistent with the position adopted by UNICEF and others.

Issue	Catharsis	Normalisation
<b>Programmatic activity</b>	Incorporated into self-expressive activities, such as debriefing, drawing and drama.	Incorporated into approaches that stress normality (such as opportunities to play) and participation (such as returning to school).
<b>Young children</b>	Young children seldom have the necessary ego strength (coping capacity) to talk about extremely stressful experiences.	It is often best for young children's coping to be immersed in supportive day-to-day activities.
<b>Older children and adolescents</b>	Older children, like adults, may wish to talk about their experiences, especially to gain perspective and mastery, share with people who have had similar experiences and receive social support.	Talking about experiences in safe and comforting circumstances is an important form of normalisation for older children and adolescents.
<b>Human resources</b>	Programme staff using cathartic approaches should be properly trained to recognise when they are subjecting a child to secondary traumatisation.	Advocacy and sensitisation can support families, care groups and schools to normalise the experiences and lives of children in distress.
<b>Cultural issues</b>	Expressing emotions in the form of talking or drawing is not a common way of coping with stressful experiences amongst young children.	There are other forms of expression, such as dancing, singing and performing rituals, that are part of the traditions of many non-Western cultures that help people, including young children, cope with extremely stressful conditions
<b>Good practice lessons from the violence field</b>	Prompting young children to talk about painful experiences with strangers from external programmes is now regarded as inappropriate.	It is recommended that discussions with children take place in a stable, supportive environment with the participation of affectionate caregivers.

What are the basic principles of psychosocial support for UNICEF?

Activities intended to provide psychosocial support, whether directly or indirectly, should aim to:

- reconnect children with family members, friends and neighbours;
- foster social connections and interactions, including in situations where children are separated from their family or community of origin;
- normalise daily life;
- promote a sense of competence and restoration of control over one's life;
- build on and encourage children's and community's innate resilience to crisis;
- respect the dignity of children, their caregivers and communities.

Source: UNICEF programming for psychosocial support: Frequently asked questions. As presented by Sarah Norton-Staal at the fourth "Road to Toronto" meeting, held in The Hague, the Netherlands.

# 4. What are the policy needs?

The UNAIDS/UNICEF/USAID *Framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS* (2004) sets out five key strategies for national policies and programmes.

## **1. Strengthen the capacity of families to protect and care for orphans and vulnerable children by prolonging the lives of parents and providing economic, psychosocial and other support**

Family relationships provide the most immediate and important source of support for children. The *Framework* notes that efforts to address psychosocial needs do not necessarily require separate programmes, and that they can be incorporated into other activities. Community ownership, engaging children and young people in planning and implementation, and tailoring activities to local cultural practices and beliefs are crucial to the success of interventions.

The *Framework* urges that “a particular emphasis must be placed on integrated early childhood development of children of preschool age, especially through efforts that focus on food and nutrition, health and development, psychosocial needs, daycare and other key areas”.

## **2. Mobilise and support community-based responses**

Given the scale and multidimensionality of the impact of the epidemic, leaders and community groups must take action to support and protect vulnerable children. The processes should begin with people being more open and accepting about HIV/AIDS, organising and assisting cooperative activities, and encouraging and supporting community care for children without family support.

## **3. Ensure access for orphans and vulnerable children to essential services, including education, health care, birth registration, and other services**

Services are necessary for children’s welfare and lack of access is a major cause of children’s vulnerability. The most vulnerable children have significant psychosocial needs and the capacity of services to support children’s development are generally weak. They may be non-existent in extreme cases of abandonment, war and natural disaster. A child-rights approach ensures access to essential services.

## **4. Ensure that governments protect the most vulnerable children through improved policy and legislation and by channeling resources to families and communities**

## **5. Raise awareness at all levels through advocacy and social mobilisation to create a supportive environment for children and families affected by HIV/AIDS**

While the *Framework* recognises that no ministry has sole jurisdiction over the issues affecting children living in communities affected by HIV/AIDS, it urges that “[g]overnments must find ways to bring together ministries of education, finance, health, social welfare and others to respond in a coordinated and effective way to the many needs of children”. Especially important are creative ways to strengthen social safety nets and to ensure that resources reach communities.

The *Framework* also draws attention to shortcomings in programming approaches to date:

- A much larger number of children than orphans are vulnerable to the impact of HIV/AIDS, as a result of poverty, armed conflict and child labour. For this reason, interventions should be directed to all vulnerable children. Targeting children living with HIV/AIDS or orphaned as a result of AIDS exacerbates the stigma and discrimination against them.
- Interventions to benefit vulnerable children should be integrated into other programmes to promote children's welfare and reduce poverty.
- Few resources are reaching families and communities who are in the front-line response to provide care and protection for children made vulnerable by the AIDS epidemic. This is especially true of households headed by women and the elderly, who are already on the edge of poverty and destitution.
- Little attention is given to vulnerable children in most national development agendas, and government leadership, coordination and facilitation has been weak.

## 4.1 Shifting the curve

Currently, the international and policy response to vulnerable children affected by HIV/AIDS is predominantly focused on orphans. While the loss of a parent entails terrible suffering for children, in terms of programmatic responses orphaned children may or may not be especially vulnerable, depending on their circumstances.

The emphasis on orphaning, which more often occurs amongst older children, has inadvertently drawn attention away from young children who are exposed to the damaging effects of deteriorating care and attention resulting from maternal illness, overwork or demoralisation, and deepening household poverty and insecurity.

To move forward, it is necessary to go beyond token remedies for children affected by HIV/AIDS. What is required are holistic, integrated responses to vulnerable children, rather than narrow HIV/AIDS-specific programmes that target so-called AIDS orphans, or provide for only one aspect of children's needs.

These include assistance to families who continue to cope, broad poverty reduction and empowerment strategies, food security, nutrition, access to health care and education, and early child care and development.

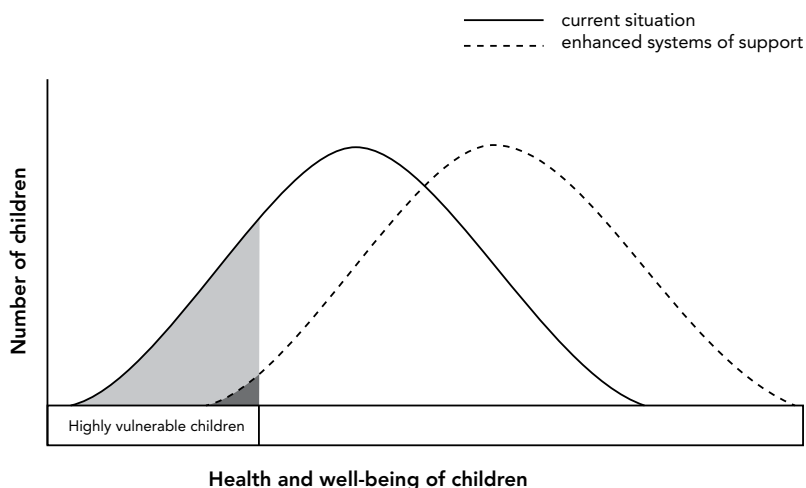
Systems-based responses are justified by the very large numbers of children in severely AIDS-affected countries whose poor living circumstances and limited access to services compromises their health and wellbeing.

The curve in figure 7 shows that most children, the high arc, are doing reasonably well in health and development, and relatively smaller numbers of children, on either side, are doing either very well or



very badly. As a result of the HIV/AIDS epidemic, the health and wellbeing of increasing numbers of children are threatened – the shaded portion of the curve on the left hand side. This group includes also very vulnerable children with severe disabilities, abused children, orphans without supportive family care, and abandoned and street children.

**Figure 7: Universal curve shift to improve children’s health and wellbeing**



Source: Adapted from Committee on Evaluation of Children’s Health, Board on Children Youth, and Families 2004.

In addition to efforts to help individual children, the main objective must be to shift the whole curve to the right, through improved access to health, education and social services for all children in AIDS-affected countries,

When the mean level of health and wellbeing of all children in the society is improved, the curve shifts to the right – and this, simultaneously, reduces the number of extremely vulnerable children who may need individual assistance (the cross-hatched section under the curve). If systems of care for all children are not improved, the shaded section of vulnerable children will increase, making it ever more difficult to support the development and wellbeing of young children.

This “public health” approach, when applied to other problems, is generally found to be more cost-effective for responding to vulnerable groups than attempts to reach all vulnerable children through individualised services.

A continued focus on individual children through crisis responses is a limited short-term strategy. Caution needs to be exercised to ensure that such crisis responses do not draw attention and resources away from strengthening the service systems to support children’s development over the long term. The dire needs of children evoke extreme emotions and prompt attempts to provide immediate assistance, but this must be balanced by investments in basic services and provision.

## 4.2 Strengthening systems to help individual children

Families and communities are systems of informal care and have, to date, been the most comprehensive and effective source of support for children affected by HIV/AIDS. More than 90% of all affected children are being cared for in extended families and communities (Urassa et al 1997). The majority of resources and efforts should be directed to strengthening these systems to enable them to continue to care for vulnerable children and to improve the care they are able to provide.

Community responses and externally driven programmes assist vulnerable children and, in most cases, their efforts are an attempt to fill a gap in government services. Neighbourhoods and programmes set up no-cost community schools or raise money to pay for fees and levies, uniforms and equipment, thus enabling poor children to attend government schools. Community groups and projects provide food, material and financial assistance, vocational training and help to pay for medicines or health service user-charges because of inadequate provision by governments. Community-run preschools provide child-minding facilities that enable caregivers to earn money in the absence of government-run crèches.

Though providing assistance to vulnerable children is critical to their wellbeing, the support that can be provided by relatives, communities and externally funded programmes is neither sufficient nor sustainable. It is also a response based on need rather than right.

The required complement is stronger state provision of health, education, social welfare and economic and community development. State provision is a sustainable and cost-effective approach to assisting individual vulnerable children and their households. Moreover, the universal provision of health, education, social welfare, and child care services are critical to the protection and promotion of the psychosocial wellbeing of the most vulnerable children.

<b>Issue</b>	<b>Assisting children</b>	<b>Strengthening systems</b>
<b>Perspective</b>	These are often short-term relief activities, though there are examples (e.g., fostering, payment of school fees) of longer-term development.	More focused on long-term socioeconomic development and improvement, though some systems approaches (e.g., food or income support) also provide short-term relief.
<b>Focus of interventions</b>	The most vulnerable children, based on need.	All children, based on rights.
<b>Sustainability</b>	Assistance is dependent on the availability of donor funds, community resources, and the workload of volunteers.	Functional systems provide services on a sustained basis, although access and quality may be problems that have to be continuously addressed by advocacy and demand.
<b>Number of beneficiary children</b>	Relatively small numbers of the most vulnerable children in areas where projects operate.	All children benefit from functional families and communities, as well as health, education, and social welfare services and community or economic development activities.
<b>Implementers</b>	Families, community groups, religious organisations, NGOs and some social assistance programmes.	Mainly government, with the support of international agencies, faith and non-governmental organisations.
<b>Cost-effectiveness</b>	Community-level activities are relatively cheap, though the cost is borne by community members. Support provided by external organisations such as international NGOs is expensive.	Generally good cost-benefit ratios especially if universal provision can be implemented or supplemented by NGOs.
<b>Programming trends</b>	There has been a proliferation of direct support activities with growing emphasis on psychosocial interventions and psychosocial support programming.	There is a new enthusiasm for universal primary education, health access and social protection, including social security*. There is, though, as yet little emphasis on improving the capacity of services to meet the psychosocial needs of vulnerable children.

\* For example, *The Livingstone call for action. Social protection – A transformative agenda* (March 2006). [www.helpage.org/News/Latestnews/@27954/main\\_content/Livingstone\\_call\\_for\\_action\\_March\\_2006.pdf](http://www.helpage.org/News/Latestnews/@27954/main_content/Livingstone_call_for_action_March_2006.pdf)

### 4.3 Hand-in-hand: Government and civil society

Most examples of best practice in relation to the care and protection of children living in communities affected by HIV/AIDS come from civil society. Community initiatives to assist vulnerable children generally result from the absence of government services. There are two main levels of civil society response to the crisis of children living in communities affected by HIV/AIDS:

#### **Community-based organisations**

CBOs include religious congregations, volunteer-driven CBOs and grassroots initiatives such as revolving savings and credit associations, burial societies, grain loan schemes, labour sharing initiatives, daycare crèches and home visiting programmes. There has been widespread and spontaneous emergence of community-level responses for children living in communities affected by HIV/AIDS, which often involve parenting, protection, and psychosocial and spiritual support, in addition to economic and material help. This mix of assistance appears to represent a culturally and situationally appropriate blend of material and psychosocial response to the situation.

#### **Non-governmental organisations**

NGOs employ staff to implement programmes to assist vulnerable children, though they are also often dependent on community volunteers. NGOs are more widely recognised and funded than CBOs. Local NGOs generally provide a broader range of responses, including psychosocial activities, than international NGOs.

Some governments have attempted to improve the psychosocial wellbeing of children affected by HIV/AIDS by addressing issues around stigma and marginalisation, as well as by supporting strong civil society responses to HIV/AIDS. In general, though, despite being signatories to the Convention on the Rights of the Child, there is little evidence that most states with significant epidemics have begun to seriously address the impacts of HIV/AIDS on children.

The crisis of young children living in communities affected by HIV/AIDS is largely invisible to governments because they are looked after in families and communities where their hardships, and those who care for them, are hidden from sight. Spending by households, most of whom are poor, is now the largest single component of overall HIV/AIDS expenditure in African countries – a stark reminder that the economic burden is borne by those least able to cope.

UN agencies and some donors have, from the outset, emphasised the important role to be played by government, despite the latter's lack of involvement with the issues affecting children. Because of the scale, duration and severity of the impact of HIV/AIDS on large numbers of young children, government action is critical because of its reach and the potential of system-based approaches to meet the rights of children.

Government and civil society must play complementary roles in supporting families and children. Attempts to displace roles and responsibilities from one sector to the other are counterproductive.

<b>Issue</b>	<b>Civil society</b>	<b>Government</b>
<b>Awareness of child vulnerability and psychosocial issues</b>	Community groups are often the first to respond to vulnerable children, followed by local NGOs and international agencies.	Government responses to orphans and vulnerable children have come late, and are still developing. It is important for support for children's psychosocial needs to be incorporated into health, education and social services.
<b>Main area of focus regarding children affected by HIV/AIDS</b>	Programming, direct service provision, and to some extent intermediary (technical) support.	Policy, standard setting and resourcing. Universal access to services is critical.
<b>Coverage of responses</b>	Selected areas have some services provided by civil society, but this is dispersed and unsystematic.	Universal access to state services will enable large numbers of children and families to be supported.
<b>Range of responses</b>	There is a broad range of responses including education, health, economic, child protection, psychosocial and spiritual support.	This could be extensive, with preschool activities, schools and health facilities that could also help to coordinate and facilitate a range of NGO and CBO responses.
<b>Psychosocial emphasis</b>	There is some emphasis by NGOs and CBOs on children's psychosocial wellbeing, but from a limited skills base.	There is, as yet, little appreciation of how health, education and social protection and social welfare services could be used to meet children's psychosocial needs.
<b>Potential for scaled response</b>	There is potential for "scaling out" (extension to other areas) to expand the scope and size of beneficiaries, but hard to "join up" such efforts with national, provincial or district coordination.	There is potential to achieve scale by supporting families and communities the establishment of a conducive environment for civil society, strengthening health, education and social services, and by funding the work of NGOs and CBOs.

## 4.4 Formal systems should supplement community safety nets

Social safety mechanisms, which generally transfer income in one way or another to needy people, protect them from the worst effects of poverty. When hard times hit, safety nets reduce the pressure on households to make hasty decisions to sell off productive assets or incur debt, and increase their likelihood of escaping destitution.

Both formal and informal safety nets provide support to households facing social and economic crises.

### **Formal safety nets**

NGOs and governments use mechanisms such as price subsidies, public works, micro-credit and food and cash transfers to targeted households through pensions and allowances. A few sub-Saharan countries have functioning statutory social support schemes, providing old-age pensions and child support grants.

However, the scale of the impact of AIDS on families and the increasing numbers of vulnerable children is of extreme concern to policymakers. States are challenged by the urgent need to transform social security systems to address child poverty and the increasing numbers of children living in AIDS-affected households. State-administered support for the destitute is generally non-existent in sub-Saharan Africa, but a new agenda for social protection is emerging.

### **Informal safety nets**

The extended family, assisted by the community at large, provides by far the most effective response for people facing household crises in low-income countries. Social insurance is provided through kinship ties that provide support in times of need. Relief from family, friends and neighbours is a common response to economic and other crises.

Informal safety net mechanisms involve donations or exchanges of cash, food or clothing, informal loans and assistance with work or child-care. Families and neighbours provide for one another if they can, when asked for help – in the knowledge that, under the tenuous conditions in which they live, they may have to ask for help themselves in the near future.

At times of distress such as bereavement, community members feel obliged to participate and contribute what they can towards funeral costs.

Though frequently unrecognised by governments and international agencies, vital safety net functions are performed by savings associations, cooperatives, loan-providers, support initiatives for vulnerable children and the chronically ill, and through the philanthropic work of faith-based groups and others.

Issue	Formal safety net programs	Informal safety nets
<b>Importance to households affected by HIV/AIDS</b>	Less than 10% of the financial outlay of households affected by AIDS comes from formal safety net programs (Foster 2004).	Kith and kin provide financial support to affected households. Community safety nets are important for households that fail to receive support from other sources.
<b>Flexibility</b>	These are frequently inflexible, sometimes with considerable opportunity costs for those seeking assistance and delays in provision of assistance.	Normally accessible and rapidly available at times of income and other shocks.
<b>Targeting</b>	Though designed to benefit the most vulnerable, most formal safety nets have difficulty reaching the poorest groups.	Because resources are administered on an individual basis, informal safety nets frequently respond to the most needy families.
<b>Extent and coverage</b>	Entitlement is intended to be universal, but lack of knowledge and opportunity costs can prevent many destitute people from accessing formal safety nets.	Safety nets are widespread, including in rural areas and informal settlements. Some households requiring assistance may fail to receive support due to family conflict or ethnic, religious and cultural exclusion.
<b>Effectiveness</b>	When operational, schemes provide assured and stable benefits to households meeting criteria for assistance.	These often provide small amounts of assistance sporadically that may keep households from destitution, but they cannot alleviate poverty or support asset building.
<b>Location</b>	These are better established in urban areas, but less accessible to the poorest people living in remote rural areas.	These are generally better established in rural areas, and may be weaker and less effective in informal urban settlements.
<b>Psychosocial impact</b>	These schemes are largely limited to material support, but this might significantly alleviate stress amongst the poorest families.	Informal safety net mechanisms almost always incorporate significant psychosocial care and support, together with material help.

# 5. What do we need to know?

In order to better address the rights and needs of children living in communities affected by HIV/AIDS, many questions still have to be asked and answered. Learning from experience gained in other fields of work with vulnerable children, evaluation of what is or isn't working in existing programmes and activities, and research are essential in order to respond appropriately and effectively to vulnerable children and their families.

## 5.1 Reinventing the wheel? Lessons from the field

In work on behalf of children affected by HIV/AIDS, we cannot afford to ignore the existing body of knowledge on children's development gained through more than a century of scholarship, as well as efforts to address the impact on children of poverty, natural disasters, political and civil conflict, displacement, and separation from parents as a result of work-related migration.

The resilience and adaptability of the family, kin networks, community initiatives, self-help organisations and faith affiliations are the main mechanisms through which parents and other caregivers deal with these threats to the survival and wellbeing of children. The challenge is to learn from, and apply, lessons learnt from other fields. These include:

### **Not all children are equally vulnerable to the effects of adverse environmental, social and material conditions**

A child's age, caregiving and family background, temperament and coping ability, and the supports available to the child at the time of the stress – especially closeness to trusted and familiar caregivers – are all known to lessen adverse effects on children. Vulnerability is not determined by social or other categorisation – not all street children, child soldiers, children in refugee camps, orphans or children with a disability are equally vulnerable.

In the context of ordinary life, single traumatic events will not necessarily have long-term detrimental effects on children. Support from families and communities, as well as from friends, enable children to cope with extremely difficult situations. Child vulnerability results from the absence of stable and affectionate adult care and protection, as well as from multiple risks or unabated stressful situations.

### **Children and their caregivers need services**

Few positive effects on children are achieved from single-focus interventions. Children's difficulties are intertwined with the difficulties and coping capacity of their caregivers. Support for caregivers can have strong knock-on effects for children, and it is unlikely that lasting effects will be achieved in ameliorating children's distress if efforts are not made to simultaneously alleviate the distress of their caregivers.

Child-directed interventions may have the unintended consequence of scapegoating the child, by making the child seem to be the one with problems. They can also cause resentment among other needy children, and may undermine a caregiver's motivation and efforts to support the child.



### **Supportive caregiver and family relationships are key to children's coping and their capacity to recover from severe stressors**

Emotionally responsive caregiving, confident parenting, and warm and supportive family relationships are fundamental to children's achievement, adjustment and wellbeing. The inner circle of proximal influences on children are so strong that, if these break down, they can cause problems for children independently of external stressors. Similarly, positive experiences outside of the family, while helpful to children, may have little long-term beneficial effect if countered by ongoing negative family relationships.

### **Prevention is better than cure and early intervention is more effective than intervention later in the chain of reactions**

In stressful environments, procedures can be put in place to prevent or reduce the impact of adversity. For example, if a home visiting programme for a sick adult also addresses children's additional workload and gives children social support, this may prevent or reduce the stressful effects of caring for a sick parent.

### **Holistic family health care is needed in HIV situations**

Medical and psychosocial treatment is important for children with HIV. This should be integrated into family care rather than separated into paediatric and adult services. All prevention, treatment and care initiatives that target adults, such as voluntary counseling and testing, ARV programmes and home-based care, should be used to extend the provision of previously unreachable and unaffordable care to children.

## **5.2 The importance of monitoring and evaluation**

All deliberate actions to assist children and families need to be evaluated – this is important to avoid unintentionally doing harm and to assess whether resources, human and financial, are being used in the most responsible and cost-effective way. Much of the programmatic work done to support children affected by HIV/AIDS has been based on commonsense and charity, rather than on careful study of inputs and relevant outcomes.

Nonetheless, a balance must be achieved between endless measurement and investigation on the one hand and unreflective action on the other. Programmes must have mechanisms that enable careful self-review about aims, approaches, costs and impact, with feedback from beneficiaries as to the appropriateness and effectiveness of the interventions offered.

The psychosocial wellbeing of children is difficult to measure for several reasons: it differs by age and stage and there is a wide range of appropriate behaviour and attainment at each level; it is culturally embedded and varies according to context, social norms and expectations; the measures used are complex and have to be validated for the settings in which they are applied; and there is disagreement, even at a disciplinary level, about the constructs to be measured and how they should be measured.

Nonetheless, there is available a range of qualitative and quantitative approaches that can be used in the assessment of children’s wellbeing.

Issue	Monitoring and evaluation (M&E)	Intervention without evaluation
<b>Learning</b>	M&E allows for effectiveness to be established and disseminated.	Harm may be done unintentionally, the programme may not adjust to recipient needs, and lessons learnt cannot be generalised to other programmes
<b>Orientation to work</b>	Incorporating a culture of feedback and evaluation allows for self-reflection and the evolution of approaches.	Evaluation is sometimes seen as alien, time-consuming and wasteful of resources. In addition, self-reflection and change in programmes can be difficult.
<b>Evidence base</b>	Interventions can be based on “what we know”.	Interventions are often based on anecdotal evidence, on “what we believe” (and hope!)
<b>Credibility</b>	Interventions that are evaluated are seen as more important than those that are not, and are more likely to be funded and/or scaled out and up.	Interventions to improve children’s psychosocial wellbeing are in danger of being devalued because there is as yet a limited evidence base to support them.
<b>Measurement</b>	M&E can use a range of designs and tools to give reliable and valid measurement.	Avoiding evaluation is a cheap and easy option in the short term, but with a price to pay in the long term.
<b>Ethics</b>	Ethical considerations are a prerequisite when working with children, especially in relation to consent and confidentiality of responsible adults and assent by children.	Concerns about ethics should not be used to avoid or abandon evaluation, especially where children and the use of valuable resources are concerned. Ethical issues can be addressed in work with children and families (Schenk and Williamson 2005).

# 6. Conclusion:

## Home is where the heart is

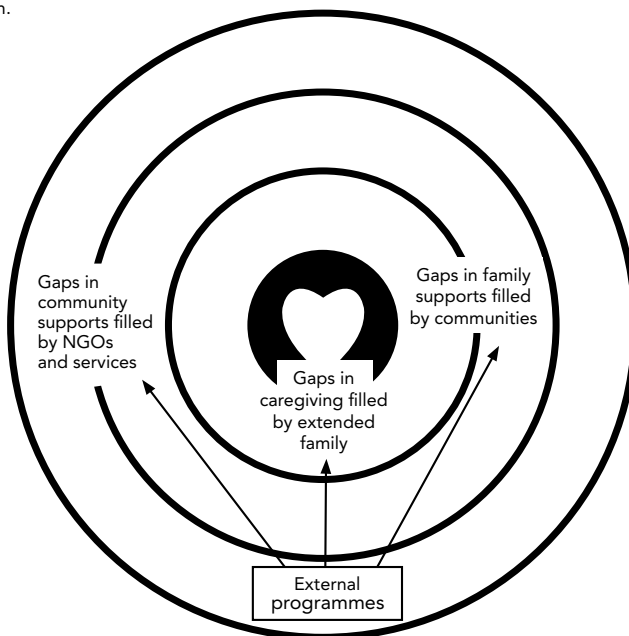
The heart of psychosocial care is to be found in the home and it is here that the main thrust of external efforts to improve the wellbeing of vulnerable children must be directed. The best way to support the wellbeing of young children affected by HIV/AIDS is to strengthen and reinforce the circles of care that surround children (see figure 8).

Some programmes and projects fail to appreciate the inter-dependence of these circles of care. This lack of recognition has led to the establishment of residential homes for vulnerable children and direct implementation of psychosocial interventions and programmes for children by external groups. These efforts, which are expensive, are not always necessary. Moreover, they run the risk of undermining family and community efforts to support children, and of diverting human and financial resources that should be directed to supporting families and communities to take in and provide quality care for vulnerable children.

Some children – especially those living outside families, on the streets or in institutions, with chronically ill caregivers, and orphans – are more vulnerable and especially require psychosocial care and support. However, this social support needs to be provided in family settings, with the same characteristics of commitment, stability, and individualised affectionate care. The primary aim of all psychosocial support programmes should be on encouraging and enabling family support, including foster care, and placing and maintaining young children in stable and affectionate family environments. Only secondarily should direct services be provided to affected children.

**Figure 8: Circles of care: Supporting the home to hold the heart of the child**

Supportive environment provided by government provision of services and protection.



Children are best cared for by committed and affectionate adults. When the caregiving circle is broken, for whatever reason, extended families must step into the breach. When the circle of care provided by kin is broken, community initiatives have to plug the gap. When the circle of care provided by community is broken, external agencies have a role to play. Embracing all efforts should be a strong and continuous circle of support provided by government provision and legislative protection.

The optimal use of the resources of external programmes is to support communities in supporting families who support children, because families are best placed to provide for the psychosocial needs of young children. When it is necessary for external agencies to provide direct services to children and to families, their touch should be light and, to be sustainable, balanced by appropriate actions to strengthen extended family and community supports.

## 6.1 Concluding recommendations

### **Focus on vulnerable children, not just on orphans**

Although orphaned children suffer greatly, a broader focus on vulnerability widens the base for the provision of psychosocial care and support for children. This rests on a comprehensive rights-based approach which also benefits orphaned and other groups of children in difficult circumstances.

### **Focus on children affected by HIV/AIDS, not just on children living with HIV/AIDS**

Although children living with HIV/AIDS require additional services, a narrow focus on only this group of children may reduce resources for other vulnerable children living in communities affected by HIV/AIDS, and will miss the opportunity to strengthen systems to support all vulnerable children.

### **Recognise that diverse children need diverse responses**

General statements about children affected by HIV/AIDS obscure differences between children, based on age, gender and other characteristics. It is important to take these difference into account in the provision of appropriate care and support for vulnerable children.

### **Family care is better than institutional care**

Positive psychosocial outcomes for young children are the result of affectionate, responsive and continuous care within a family. Institutionalisation is not an appropriate alternative, and every effort should be made to encourage family care, also through respite care, fostering and adoption. Caregivers and families need assistance to counter poverty, demoralisation and exclusion, all of which adversely affect their capacity to care for young children.

### **Integrated services are better than stand-alone interventions**

Integrated services are the most effective ways of meeting the multiple needs of affected children and their families. Stand-alone programmes address only some of the needs of children and families and are not likely to be sustained.

**Long term investments are better than time-limited interventions**

Because it takes many years, and even generations, for children to develop and fulfill their potential, sustained long-term provisions best serve the interests of children. Short-term crisis interventions may even disrupt long-term services, as has been evident in disaster responses.

Promoting young children's health and wellbeing now is better than reacting to problems in future. The promotion of wellbeing and resilience enables children to better deal with challenges, and can thus prevent future problems. Children's health and wellbeing also contribute to the prevention of HIV in the next generation.

**Normalisation is a more appropriate response to the distress of young children than approaches which encourage catharsis**

In order to be able to deal with stress and loss, children must feel safe, protected and loved, and to participate in the normal routines of their family and community.

**Strengthening systems will have greater benefits for all vulnerable children than efforts to help individual children**

Participation in functional families and communities, and universal access to education, health and social welfare systems support children's health and psychological wellbeing. This reduces the number of individual children who need additional assistance through special programmes.

**Governments must become more active, providing a foundation for civil society**

Governments must lead and resource a coordinated effort to protect and promote the health and wellbeing of children that matches the generally vigorous responses to vulnerable children being mounted by civil society.

**Formal safety nets must be strengthened to support informal ones under strain**

Formal safety nets must support affected households to provide security, and to supplement family and community assistance for vulnerable children.

**Other fields of experience can offer lessons for dealing with children in communities affected by HIV/AIDS**

We must learn from experience, and apply the lessons learnt from other fields, rather than treat HIV/AIDS as a special case in research, programming and policy.

**Monitoring and evaluation is necessary to guide action**

Evidence, from applied and basic research as well as programme evaluation, is crucial to guide and sustain appropriate and effective action.

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All young children require affection, stimulation, protection and nurture to grow and develop and to have a good foundation for coping with challenges and making positive contributions to society. Poverty and social upheaval negatively affect children's development by leading to stressed caregivers, instability, inadequate material supplies and lack of access to services.

HIV/AIDS exacerbates the negative effects of poverty on young children's development. Many children not living with the virus are affected by HIV/AIDS because they live with chronically ill or very aged caregivers who are unable to provide them with adequate care and support, or with extended families whose resources are over-stretched.

In addition to providing material support to HIV/AIDS-affected children, it is crucial to assist them in achieving psychosocial wellbeing – not only to enable them to be happier and cope better in the present, but also to enable them to deal with further hardships with more emotional and social resilience, and to provide them with hope and dreams for the future.

*Where the heart is: Meeting the psychosocial needs of young children in the context of HIV/AIDS* is an opinion piece developed through a series of four workshops convened by the Bernard van Leer Foundation in preparation of the XVI International AIDS Conference in Toronto in August 2006. A five-point "Call to action" prefaces *Where the heart is*, stressing the importance of family- and community-based care and government provision of universal integrated services.

Bernard van Leer  Foundation

Eisenhowerlaan 156, 2517 KP The Hague, The Netherlands

P.O. Box 82334, 2508 EH The Hague, The Netherlands

Tel: +31 (0)70 331 22 00, Fax: +31 (0)70 350 23 73

Email: [registry@bvleerf.nl](mailto:registry@bvleerf.nl) Web: [www.bernardvanleer.org](http://www.bernardvanleer.org)

