Building Resilience

A rights-based approach to children and HIV/AIDS in Africa

Linda M. Richter and Sharmla Rama

Save the Children
Sweden

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For further information contact:
Save the Children Sweden
SE – 107 88 Stockholm, Sweden
Phone + 46 8 698 90 00
info@rb.se, www.rb.se

Save the Children Sweden
East and Central Africa Regional Office
Box 19423
202 KNH – Nairobi, Kenya
Phone + 254 20 386 5888/90
info@ecaf.savethechildren.se

Save the Children Sweden
Southern Africa Regional Office
SAQA House, Floor 3
1067 Arcadia Street
0028, Hatfield, Pretoria
South Africa
Phone + 27 12 342 0222
postmaster@za.rb.se

Save the Children Suède
West Africa Regional Office
BP 25934, Dakar-Fann, Senegal
Phone + 221 869 18 00
savedakar@sentoo.sn

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The photos in this report show children from different parts of Africa.
The children do not have any connection with the specific contents of the report.

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Project Leader: Professor Linda M. Richter (PhD)
Human Sciences Research Council (HSRC)
Child, Youth, Family and Social Development (CYFSD)
Private Bag X07, Dalbridge, 4014, South Africa
Phone: 27-31- 242-5544
Fax: 27-31- 242-5401
lrichter@hsrc.ac.sa

Graphic design: Annelie Rehnström
Photographer: Anna Kåri
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Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ARVs (ARV)	Anti-retrovirals
CABA	Children Affected by AIDS
CBO	Community Based Organisation
CLA	Children Living in Communities Affected by HIV/AIDS
CLHA	Children living with HIV/AIDS
COPE	Community-Based Options for Protection and Empowerment (Malawi)
CRC	Convention on the Rights of the Child
CYFSD	Child, Youth, Family and Social Development research program
DFID	Department for International Development (United Kingdom)
FBO	Faith-Based Organisation
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
HIV+	Human Immunodeficiency Virus- Positive
HSRC	Human Sciences Research Council
IGA	Organised Individual or Group Income-Generating Activity
KORDP	Kenya Orphans Rural Development Programme
MAP	World Bank's Multi-Country HIV and AIDS Programme for Africa
NEPAD	New Programme for Africa's Development
NGOs	Non-Governmental Organisations
NMCF	Nelson Mandela Children's Fund (South Africa)
NPAs	National Plans of Action (on vulnerable children)
NSPs	National Strategic HIV/AIDS Plans
OVC	Orphaned and Vulnerable Children
PLHA	People living with HIV/AIDS
PMTCT	Prevention of mother-to-child transmission of HIV
PRSPs	Poverty Reduction Strategy Papers
OVC-RAAAP	UNICEF-led Orphaned and Vulnerable Children Rapid Assessment, Analysis and Action Planning
SCS	Save the Children Sweden
SCUK	Save the Children United Kingdom
TAC	Treatment Action Campaign (South Africa)
UK	United Kingdom
UN	United Nations
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNCRC	United Nations Convention on the Rights of the Child
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
UNICEF	United Nations Children's Fund
UNICEF-ASARO	UNICEF Regional Office for East and South Asia
USA	United States of America
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

DOLPHIN

1. Executive Summary

HIV/AIDS has devastating effects on African children, their families and their societies

HIV/AIDS has impacted severely on Africa. The infection rate has risen rapidly and the scale of prevalence is largely unabated. Moreover, the epidemic compounds existing problems that children and families face resulting from decades of exploitation, poverty, civil and regional conflict, and natural disasters. UNAIDS data indicates that Sub-Saharan Africa remains the hardest hit region in the world, with a total of 25 million people living with HIV/AIDS.

Orphans are not the only ones feeling the impact

Many children in Sub-Saharan Africa, in addition to those who receive most media attention (i.e. orphans, child heads-of-household, and children living with HIV/AIDS), are affected by HIV/AIDS, poverty, and social instability. They include already vulnerable children, especially children with disabilities and children living outside of family care, as well as children living with chronically ill or disabled adults, children in homes that have become poorer as a result of fostering in children from the extended family, and children in communities suffering a high burden of illness, dependency, destitution, and death. In all of these situations, children's health, economic and food security, family life, connections to social institutions, opportunities to learn, human rights to development, and hopes for the future, are threatened.

Who is doing what?

As the vulnerability of children living in communities affected by HIV/AIDS becomes a clear challenge, governments, international agencies, civil society, neighbourhoods, and families have mobilised to try to tackle the issues these children face. This report provides a brief overview of the responses of the international community and governments in rising to these challenges, the roles of the private and civil society sectors, as well as the responses of families and communities dealing directly with the children.

The USAID Report in 1997: *Children on the Brink*, initiated a belated increase in the international community's engagement with the issue of children affected by HIV/AIDS. In 2004, the international community provided some direction for programming and funding through the endorsement of the UNAIDS/UNICEF framework for the protection, care, and support of children affected by HIV/AIDS. The framework outlined five strategies as follows: (i) strengthening the capacity of fam-

ilies; (ii) mobilising and supporting community-based responses; (iii) ensuring access to health, education and other services; (iv) promoting government protection of vulnerable children; and (v) raising awareness of the need for a supportive environment for children and families affected by HIV/AIDS. Following these developments, there has been a further increase in momentum within the international community, as they have provided guidance, resources, and continued research on many of the key issues faced by children living in communities affected by HIV/AIDS.

Governments have been the slowest to act. By 2003, only 13 per cent of the national policies of countries in Sub-Saharan Africa referred to orphans and vulnerable children. Mechanisms are emerging slowly, both to monitor and assist governments to respond to children affected by HIV/AIDS. Government interventions include national planning strategies, some limited social support schemes, and monitoring and evaluation systems. However, the crisis of children living in communities affected by HIV/AIDS is, for the most part, invisible to governments as such children tend to be dispersed in families and communities where their collective hardships (of both the children and their carers) are largely hidden from sight.

The emergence of community-based care initiatives has become a key reaction to the AIDS epidemic. These initiatives play a key role in easing the impacts of the epidemic, particularly on children. Although most of these efforts are operated by community organisations, religious groups or non-governmental organisations, their effectiveness often depends on the existence of formal health and education services and other government structures.

Families and communities were the first, and remain the vanguard, to take action against the worsening conditions of children, and they provide the greatest support system to vulnerable children. Out-of-pocket spending by households, most of whom are already very poor, is the largest single component of overall HIV/AIDS expenditure in African countries; a stark reminder that the economic burden of the disease is borne by those least able to cope. Less than 10 per cent of affected children are receiving assistance from agencies beyond their extended family, neighbours, church, and community.

Some useful approaches

There is no doubt that the adoption of the Convention on the Rights of the Child (CRC) and the African Charter on the Rights and Welfare of the Child, has resulted in policies, services, programmes, and adult behaviour being more focused on the best interest of the child. This focus on rights, and their enforcement, stems from a shift in developmental ethos away from the traditional trickle-down approach of external assistance from rich to poor, to an approach focusing on empowerment and participation. Rights-based programmes support rights-holders, who are often the poor, marginalised, and most vulnerable in society, to lay claim to their rights.

A Rights-based approach can rectify many of the distortions that have arisen from a crisis-driven response to children affected by HIV/AIDS, poverty, and conflict, and can provide a beacon for moving forward. The underlying principles of universality, indivisibility, responsibility, and participation provide a firm foundation for

framing priorities and responses to vulnerable children and families. Extensive experience and empirical research are being used to direct efforts to support children through the concentric circles of care and influence that surround children, i.e. through families, schools, and neighbourhoods, extending outwards to the media, legislative frameworks, and policies that all have a bearing on children's lives.

Substantial agreement exists amongst child-rights advocates that what is most needed is a set of collective governmental and community responses to strengthen the commitments of caregivers and households to the well-being of children. This should all be supported by constructive national policies and the mobilisation of resources. It is evident that the focus of programmes and strategic thinking must expand from the many small, unlinked initiatives to a coordinated approach aimed at long-term, universal benefits for all children.

Further, a continuum of responses is needed to assist children living in communities affected by HIV/AIDS. At one end of the continuum, specific assistance must be provided for the relatively small number of extremely vulnerable children, including children with severe disabilities, abused children, children without adult support, and children living in and out of the streets; at the other end of the continuum, all children in AIDS-affected countries must have increased access to government-provided social protection in all sectors, including health, education, and welfare provision. Only in this way will the health and well-being of all children, including those made vulnerable by HIV/AIDS, be improved.

Summary of the recommendations

Build Resilience: Responses to HIV/AIDS-related issues should be holistic, covering all aspects of prevention, treatment, and care, and strive to meet the rights of all children. These responses should lie along a 'response-continuum', and range from government interventions to the support of informal networks. Responses should also take into account the need to link into and learn from other HIV/AIDS and child protection programmes, and ensure that they address a wide range of vulnerable children.

Engage Government, Stakeholders, and the Children: Efforts to support children are best directed at the care networks and other influences that surround them. The role of government, communities, civil society, families, and the private sector is vital to ensuring a comprehensive and holistic approach to the challenge of HIV/AIDS. It is vital that children are consulted and participate in all decisions addressing them. Accordingly, interventions need to target all stakeholders to ensure that they address, in a pro-active manner, the issue of children living in communities affected by HIV/AIDS.

Analysis-Based Strategic Interventions: Programming should be based on an in-depth analysis of the situation, be strategic, and do no harm. It is imperative that stakeholders coordinate their responses, and that they are guided by a strong rights-based approach.

Address Discrimination: Responses should recognise root-causes to the spread and impact of HIV/AIDS, including gender inequality, as a source of vulnerability. Programmes must address both men and boys, and women and girls, and tackle issues of masculinity and sexual and reproductive health. The responses should also address children of different ages and in different settings of the HIV/AIDS pandemic.

Focus on Care Givers: All children need to be in a stable and caring relationship with adult caregivers. In this regard, family-based care initiatives should be supported and monitored while avoiding, as much as possible, residential and institutional care for children. Responses should focus on mitigating parental death and should enable caregivers to secure economic and social resources to provide for children's protection and care.

2. Scale and Nature of the Problems Affecting Children

2.1 The impact on children

The AIDS epidemic has, from the start, centred on adults rather than children, as if children were only an extension of adults. The difficulties experienced by children, caregivers, and families living in communities affected by HIV/AIDS are increasing dramatically as the epidemic matures and adult deaths mount. The worst affected children experience multiple losses, including the following:

- health and vitality, through infection, inadequate nutrition, and poor health care;
- economic support, through the constriction and collapse of livelihoods resulting from the illness and death of breadwinners and other adults in the extended family previously engaged in economic support and subsistence activities;
- parents and other primary caregivers to illness and death;
- families, as they are parted from caregivers and siblings because of distress, mobility, and migration;
- connections to social institutions, as a result of stigma in the community, and withdrawal from school because of poverty, as well as work and care obligations in the home;
- right to development in an environment that supports their basic needs and rights to health, education, care, and protection;
- opportunities to learn through participation and play because caregivers may be too ill to give them attention or they may be too ill to respond;
- their exclusion in family and/or community life through stigma and discrimination;
- hope and opportunities for the future because of demoralisation in the family environment due to depression, bereavement and multiple losses.

2.2 General situation

HIV/AIDS has impacted very severely on Africa, especially Southern Africa. The rapid rise in infection rate and the scale of relatively unabated prevalence, together with the compounding effect the epidemic has on existing problems faced by children and families following decades of exploitation, poverty, civic and regional conflict, and natural disasters, have contributed to the severity of the impact. In 2004, 25 million people were estimated to be living with HIV/AIDS in Sub-Saha-

In 2004, 25 million people were estimated to be living with HIV/AIDS in Sub-Saharan Africa. Although home to only 10 per cent of the world's population, two thirds of all people living with HIV/AIDS are resident in this region.

ran Africa. Although home to only 10 per cent of the world's population, two thirds of all people living with HIV/AIDS are resident in this region[1]. UNAIDS data indicate that Sub-Saharan Africa remains the hardest hit[2], as illustrated in Figures 1 and 2. Statistical analysis of the impact of HIV/AIDS on children shows that 2 million children in Sub-Saharan Africa are infected with HIV/AIDS and a further 12 million[3] are *"orphans due to AIDS"* (as defined by UNAIDS).

Figure 1: Regional HIV and AIDS statistics and features, end 2003 and 2005

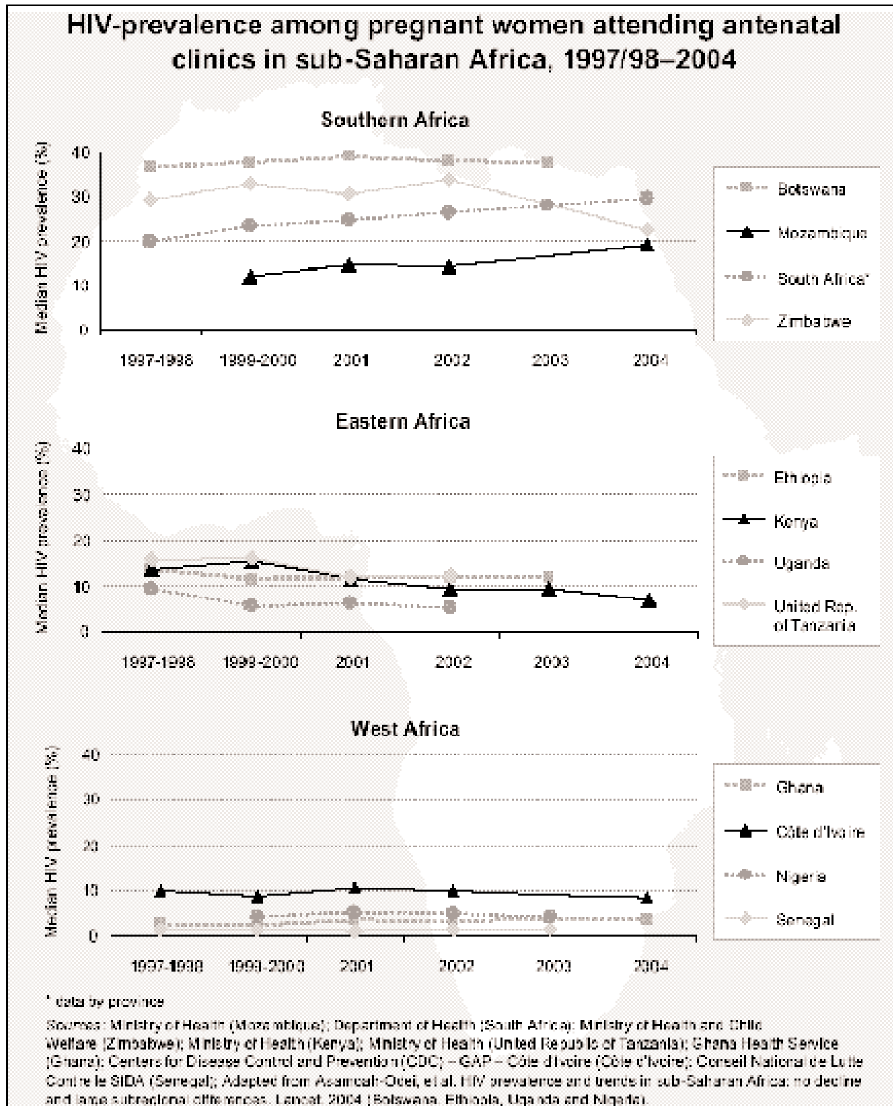
Regional HIV and AIDS statistics and features, 2003 and 2005

	Adults and children living with HIV	Adults and children newly infected with HIV	Adult prevalence (%)*	Adult and child deaths due to AIDS
Sub-Saharan Africa				
2005	25.8 million [23.8–28.9 million]	3.2 million [2.8–3.9 million]	7.2 [6.6–8.0]	2.4 million [2.1–2.7 million]
2003	24.9 million [23.0–27.9 million]	3.0 million [2.7–3.7 million]	7.3 [6.7–8.1]	2.1 million [1.9–2.4 million]
North Africa and Middle East				
2005	510 000 [230 000–1.4 million]	67 000 [35 000–200 000]	0.2 [0.1–0.7]	58 000 [25 000–145 000]
2003	500 000 [200 000–1.4 million]	62 000 [31 000–200 000]	0.2 [0.1–0.7]	55 000 [22 000–140 000]

Source: UNAIDS (2005). AIDS epidemic update. December 2005. Geneva: UNAIDS

There are several *AIDS epidemics* in Africa, arising from different clades of the virus in different parts of the continent, time of onset, virulence, enabling conditions, and prevention responses[4].Currently, adult prevalence is below 2 per cent in six countries (mostly in West and North Africa), while in another six countries it is above 20 per cent (mostly in Southern Africa). Prevalence rates in Central and East African countries fall between these two extremes. The epidemic had an early onset in the south-eastern part of the continent, affecting Uganda, Tanzania, Zambia, Malawi, and Zimbabwe first. These countries now show mature epidemics, with stable or declining incidence (new infections) but high rates of adult deaths and large numbers of adults sick with AIDS-related illnesses. Such debilitation has resulted in high levels of parental/caregiver deaths. Reports of HIV/AIDS appeared later in Southern Africa (South Africa, Botswana, Namibia, Lesotho and Swaziland). These countries all have explosive epidemics that show few signs of abating and, at the same time, the epidemic is maturing in these countries, with AIDS-related illness, adult deaths, and the numbers of new orphans on a steep incline. West Africa is showing a late onset epidemic, with varying prevalence between countries, determined largely by socio-cultural conditions that affect transmission[5].

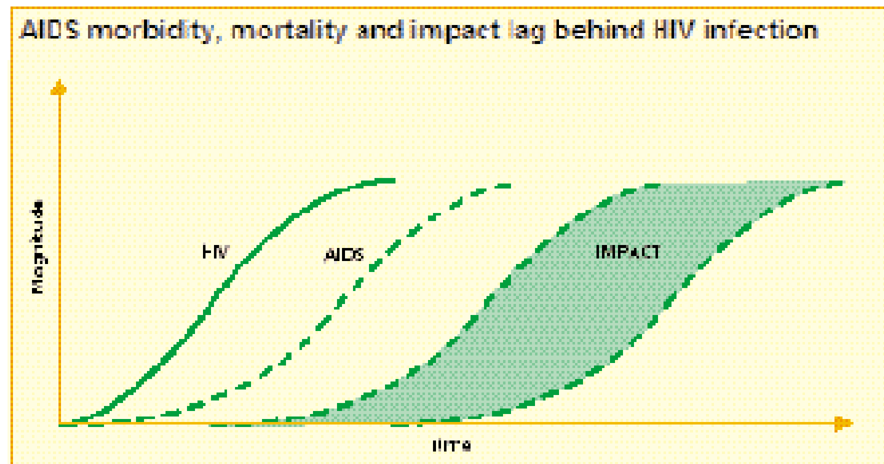
Figure 2: HIV-prevalence among pregnant women attending antenatal clinics in Sub-Saharan Africa, 1997/8-2004



Source: UNAIDS (2005). AIDS epidemic update. December 2005. Geneva: UNAIDS

The unique nature of the HIV/AIDS epidemic lies in its time delays[6] as illustrated in Figure 3 below. Years elapse between HIV infection and the onset of AIDS symptoms; meanwhile more people become infected with the virus. Consequently, more people progress from HIV-infection to AIDS and, without access to treatment and care, die. The full impact of this epidemic spans well into the future as families, economies, coping mechanism, cultures, and systems are affected in ways that are hard to predict[7]. The impact of the AIDS epidemic on children and families is frequently illustrated by the increase in orphaning, loss of work and livelihoods, deepening of poverty, and increased vulnerability of children.

Figure 3: Aids morbidity, mortality, and impact lag behind HIV infection



Source: Barnett & Whiteside (2002)

As reviewed here briefly, the problems facing children and their families living in communities affected by HIV/AIDS are many and varied. No single intervention, or type of intervention, will result in sufficient or sustained support for the well-being of the very large numbers of children affected by HIV/AIDS over the extended time-scale of the epidemic.

2.3 Who is vulnerable and why?

The terms used to speak about children affected by AIDS have evolved from *AIDS Orphans to Orphans and Vulnerable Children* (OVC) to *Children Affected by AIDS* (CABA) and most recently to *Children Living in Communities Affected by HIV/AIDS.* The categories OVC and CABA are both used as if there was wide agreement about the children included – when, in fact, there are often very different views about which children are vulnerable and even which children are orphans. The definition of Children Living in Communities Affected by HIV/AIDS is general and embraces the many different categories of children affected by HIV/AIDS. It includes the following identifiable groups of children:

There are often very different views about which children are vulnerable and even which children are orphans.

- Children indirectly affected by the AIDS pandemic
  In all countries with high HIV/AIDS prevalence, large numbers of children are indirectly affected by the epidemic because social institutions and services become overwhelmed and are further weakened when teachers, health service providers, civil servants and others become ill or are distracted by their responsibility for sick and dying relatives. For example, it is estimated that some 90 per cent of children in Zimbabwe and in other countries with severe HIV/AIDS epidemics have, in some way or other, suffered as a result of the impacts of HIV/AIDS[8].

- Vulnerable children affected by AIDS

  The term "children in especially difficult circumstances" was coined by UNICEF in the mid-1980s to describe the situations of particular groups of children that went beyond poverty. Children with disabilities, children living in and out of the streets, working children, children in institutions, children in conflict zones, and others, may all be considered to be vulnerable children living in especially difficult circumstances. Many of these children have very weak or no adult support at all. As a result of the HIV/AIDS pandemic, many of these children are doubly disadvantaged. Disabled children, for instance, are more likely to be infected with HIV, to live with HIV-infected parents, or to be orphaned through the death of their parents from AIDS, than other groups of children[9].

- Children in households that foster orphaned children

  The core response to orphaned and vulnerable children is through family fostering, a practice common in the Southern African region that pre-dates the AIDS epidemic[10]. Family fostering strengthens family ties by enabling children to live with aunts and uncles who they then regard as parents, and also by distributing social and economic assets and liabilities across extended families. Crisis fostering, by contrast, occurs when families, neighbours, or other guardians are obliged to take in children, instead of necessarily choosing to do so. This type of fostering, which is occurring more frequently in the context of the AIDS crisis, can be inappropriate or ill-matched, and often results in exacerbated poverty levels in many fostering households due to increased dependency ratios[11]. The standard of living of such households and the prospects of non-orphaned children are adversely affected by crisis-fostering. Neglect of children by inexperienced, unsupported, or frail caretakers exacerbates the problem. Children who live in households that foster orphans and other displaced children may suffer similar hardships to those experienced by orphaned children. Almost as many non-orphaned foster children as orphans have been reported to be living in households containing orphans in Uganda and Zimbabwe[12].

- Children living with HIV+ parents and sick adults

  Around 80 per cent of children born to HIV-positive mothers are uninfected at birth. Nonetheless, studies have found that uninfected children born to HIV-positive mothers have higher mortality rates than HIV-negative children in the community. In addition, it is reported that they have more attention, social adjustment, and behavioural problems than comparison children do. The mechanisms of effect are not yet clear, but they certainly involve deepening poverty resulting from the diversion of income and assets to pay for the treatment of sick adults. The loss of income, compromised parenting, childcare practices associated with maternal HIV infection, and the physical and psychological burden on children living with and caring for sick and dying parents are also contributing factors[13]. It is widely accepted that maternal and paternal depression, relationship breakdown, and bereavement affect parenting and child development[14]. One of the most poorly understood and neglected difficulties faced by children in poor countries living in communities affected by HIV/AIDS is the psychological and mental health impact of chronic

Studies have found that uninfected children born to HIV-positive mothers have higher mortality rates than HIV-negative children in the community.

parental illness. In high prevalence countries with mature epidemics, about five times more children are living with an infected or sick parent than have been orphaned as a result of the death of their parent.

- Children Living with HIV/AIDS (CLHA)

  The term "Children Living with HIV/AIDS" (CLHA) is preferred to "paediatric AIDS" or "infected children", because it links children to the rights-based PLHA (People Living with HIV/AIDS) movement. In eight Southern African countries CLHA represent between 2 and 4 per cent of the childhood population. In five high HIV-prevalence countries in Africa, between one third and one half of all deaths of children under five years old are from AIDS. However, most deaths among CLHA result from common diseases such as bacterial pneumonia, rotaviral and bacterial diarrhoea, malnutrition, and malaria, rather than from AIDS-related opportunistic infections[15]. Deaths from poverty-related diseases thus account, in the main, for the extremely low life expectancy of CLHA in Sub-Saharan Africa.

- Children orphaned by AIDS and other causes

  The definition of an orphan used by UNAIDS/UNICEF/USAID in their *Children on the Brink* 2004 report[16] refers to "any child under age 18 who has lost one or both parents". This is an unusual, even somewhat perverse, definition because in no other context are children with one surviving parent called orphans. Orphaning is increasing at a rapid rate, in parallel with increasing adult mortality due to AIDS, especially in Sub-Saharan Africa. Nevertheless, in most African countries, more children still become orphans due to causes other than AIDS, mainly as a result of wars and conflicts (see Figure 9 in Appendix). It is clear that all orphans must be treated as potentially vulnerable, and not only children who have lost parents to AIDS-related illnesses. The AIDS pandemic is leading to rapid increases in the number of orphans who have lost *both* parents. In Sub-Saharan Africa, it is predicted that, for the period 1990–2010, the number of double orphans will increase from 3.5 million to 9.6 million, representing 25 per cent of the child population in the region.

3. Overview of Major Responses

Descriptions of the impact of AIDS on children in Africa first appeared in conference and research papers in the late 1980s. The articles at that time provided estimates of the future scale of the orphan epidemic and described community-based assistance programmes. The World Health Organisation (WHO) and UNICEF were instrumental in disseminating research findings, documenting the problem, analysing responses, and proposing remedies. However, the early writings were not translated into concerted international action with the result that, during much of the 1990s, the problem of children affected by AIDS was given a low priority by United Nations (UN) agencies, development organisations, international NGOs, research bodies, and governments in affected countries. Instead, programmes to support vulnerable children were developed by local groups and organisations, and slowly attention was drawn to the worsening situation of children living in communities affected by AIDS[17].

3.1 International responses and recent developments

The 1997 *Children on the Brink Report* by the USAID catalysed a change in responses by the international community to children affected by AIDS. This report documented the scale of the impending orphan crisis and proposed intervention strategies[18]. During the past decade, international support for responses to the HIV/AIDS crisis has increased significantly, with some of the financial resources being earmarked to assist children and their families. These resources are being mobilised by USAID, the World Bank's Multi-Country HIV and AIDS Programme for Africa (MAP), the Global Fund, the British Government, and some of the larger international NGOs.

At the June 2001 *United Nations General Assembly Special Session (UNGASS) on HIV/AIDS,* governments from around the world drafted and endorsed the *Declaration of Commitment on HIV/AIDS: "Global Crisis – Global Action"*, to fight the epidemic. This Declaration included a set of national strategies and financing plans for combating HIV/AIDS and, with regard to children and HIV/AIDS, the following time-bound goals were agreed:

- Reduce HIV prevalence by 25 per cent among young people (aged 15 to 24) in the most affected countries by 2005 and by 25 per cent globally by 2010
- Ensure that by 2005 90 per cent, and by 2010 at least 95 per cent, of young people aged 15 to 24 have access to the knowledge, education, life skills, and services to reduce their vulnerability to HIV infection.

A review of these commitments in 2006 found government progress slow in rolling out treatment and care for people infected with HIV/AIDS, as well as a lack of political will from countries in setting clearly defined targets and timeframes. Although the

African Union in Abuja, Nigeria had drawn up a comprehensive programme with a number of goals, this was not reflected in the positions of African states in the review.

UNAIDS is the lead agency in the global fight against HIV/AIDS. Through consultative processes, it recently generated two frameworks:

- The "3 by 5" initiative was launched in 2003 together with the World Health Organisation. The aim of the initiative was to ensure that three million people living with HIV/AIDS were treated with anti-retroviral drugs in low- to middle-income countries by 2005. It was agreed that this was a step towards the goal of making universal access to HIV/AIDS prevention and treatment accessible for all who need them. While some countries have overshot their targets (for example, Botswana), others are lagging far behind, especially in the provision of ARVs for children[19].
- The *Three Ones*, a landmark agreement promoting universal coordination in the fight against AIDS, was adopted at a meeting co-hosted by UNAIDS, the UK and the USA in 2004 to strengthen national AIDS responses led by the affected countries themselves. The "Three Ones" principles endorsed are as follows:
    - One agreed HIV/AIDS Action Framework that provides the basis for coor dinating the work of all partners;
    - One National AIDS Coordinating Authority, with a broad-based multi-sectoral mandate; and
    - One agreed country-level Monitoring and Evaluation System.

The initiative was motivated by the fact that some AIDS programmes are developed in isolation by well-intentioned donors, non-governmental organisations and others. Governments of heavily-affected countries often have to deal with confusing demands to show progress. A recent UNAIDS report on the *Three Ones* outlines specific pointers to donors on how they can contribute to effective country-level and global responses[20].

Several international agencies commenced a consultative process in 2000 that led to the development of *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*, published in 2004 by UNAIDS, UNICEF, and USAID. The Framework, endorsed by more than 40 agencies, provides the broad range of stakeholders from all sectors of society with five overarching strategies to improve the care and protection of vulnerable children. This is the most significant and coherent strategic document to date, outlining a multi-sectoral approach to supporting children affected by AIDS. The five strategies aim to:

- 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;
- Mobilise and support community-based responses;

- Ensure access for orphans and vulnerable children to essential services, including education, health care, birth registration, and others;
- Ensure that governments protect the most vulnerable children through improved policy and legislation, and by channelling resources to families and communities;
- Raise awareness at all levels through advocacy and social mobilisation to create a supportive environment for children and families affected by HIV/AIDS.

In September 2005, UNICEF and UNAIDS launched a call to action: *Children – The missing face of AIDS*[21], advocating a four-point plan, the so-called 4 Ps, as follows:

1. Prevent mother-to-child transmission
2. Provide paediatric treatment
3. Prevent infection among adolescents and young people
4. Protect and support children affected by HIV/AIDS. The five strategies of *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* are included under this point.

Rapid developments are taking place on the international front. For example, more than 250 documents (published papers, reports, reviews, advocacy documents, etc) were produced during 2004 and 2005. In addition, new impetus has been given to activities in the field through meetings convened and the release of several key documents during the last year. Examples of initiatives taking place include the following:

- **Understanding the scale of the epidemic and appropriate actions** through consideration of the number of children affected, the nature of the impacts on children, and the long-term effects of orphaning and other forms of social distress occasioned by HIV/AIDS on children's growth, health and well-being[22]. The consultation of the Global Partners Forum in London 2006, led by UNICEF and SCUK, identified key actions required to eliminate barriers to taking to scale effective services and programming for children affected by HIV/AIDS. Recommendations were made in six priority areas: (i) elimination of school fees; (ii) birth registration; (iii) community mobilisation and capacity strengthening; (iv) family support; (v) widespread use of Cotrimoxasole; and (vi) monitoring and evaluation[23].
- **The importance of scaling up responses** to match the extent and severity of the problems affecting children[24]. In March 2006 Harvard University announced a two-year Joint Learning Initiative on AIDS and Children to bring together the required momentum, knowledge, and experience to scale-up responses to support children and their families. Several teams of multi-disciplinary experts, field managers, donors, government representatives, and others, drafted recommendations for action at the global and national levels on the following thematic issues: child survival and paediatric AIDS; family resilience, care-giving and demographics; health, education and social welfare; the economics of providing for children; and rights, protection and participation.

- **Prioritisation of interventions for infants** during their critical stages of growth, development, and socialisation, including uninfected children born to mothers living with HIV/AIDS[25]. The Bernard van Leer Foundation and UNICEF are instrumental in driving this initiative and area of focus forward.
- **Paediatric care** – Treatment for CLHA, including the effectiveness of Cotrimoxasole for opportunistic infections, the need for antiretroviral formulations for children, adherence to medication, and psychosocial care for children living with and receiving treatment for HIV/AIDS[26]. In November 2004, WHO and UNICEF convened a technical consultation on ARV formulations[27], whilst in January 2006 UNICEF hosted an international meeting on *Paediatric Care, Support and Treatment: Programming Framework Consultation.* The Global AIDS Alliance produced an advocacy report in 2006, entitled *Children left behind: Global stakeholders failing to adequately prevent or treat paediatric AIDS.*
- **Psychosocial care and support** for children and families affected by HIV/AIDS, and investigating commonalities with approaches used to address children affected by violence[28]; UNICEF and Bernard van Leer Foundation are active in supporting this area of focus. In March 2006, the Bernard van Leer Foundation hosted the 4th in a series of workshops on psychosocial issues inaugurated after the 2004 International AIDS conference held in Bangkok[29].
- **Supporting families and community-based initiatives** and getting additional resources to affected households and communities on the ground[30]. The Firelight Foundation has developed examples of good practice in supporting small community initiatives and their vision is articulated in *The Promise of a Future: Strengthening Family and Community Care for Orphans and Vulnerable Children in Sub-Saharan Africa*[31]. The importance of family-care, as opposed to institutional-care, for children without parental support has been described in several reports[32]. Efforts on this issue are being coordinated by the Better Care Network, an information hub moderated by UNICEF[33].
- **Rights-based approaches** and the important role of unencumbered access to education[34], health care, and civil registration in protecting the development of children affected by HIV/AIDS[35]. Research in this area has focused on access to education and research on entitlements to social security and health care provisions[36].
- **Social protection** – Economic strengthening of affected households and growing support for cash transfers in the form of pensions and grants, including conditional cash transfers[37], as a mechanism for addressing the combined impacts of HIV/AIDS and poverty[38]. UNICEF's Regional Office for East and South Asia commissioned papers on related topics, and UNICEF New York hosted a meeting in 2005 to consider the role of the state and social welfare in strengthening responses to children affected by AIDS. Conditional cash transfer programmes to assist children and families affected by AIDS are being piloted and/or planned in Malawi, Zambia, Kenya and South Africa[39].
- The critical need for **monitoring and evaluation** structures and systems to

ensure that the most promising models are extended and scarce funds are not spent on interventions with limited impact[40]. UNICEF, UNAIDS, USAID, the World Bank, Save the Children, and others have developed a country-level monitoring tool[41]. In February 2006, MEASURE hosted an expert meeting on targeted evaluations of programmes for orphaned and vulnerable children, and the HSRC, together with REPSSI, are piloting a child- and family-oriented community-level monitoring and evaluation system in South Africa.

3.2 Government responses

In many countries, with some notable exceptions[42], government response with respect to children affected by HIV/AIDS has been slow and ineffective. Poverty Reduction Strategy Papers (PRSPs) were introduced in 1999 to support national efforts to formulate effective growth and poverty reduction strategies. Together with National Strategic HIV/AIDS Plans (NSPs), PRSPs are intended to include links between HIV/AIDS and poverty, the role of communities, and the support of orphans and vulnerable children. However, the vulnerability of children is mentioned in a third of PRSPs and NSPs in Africa, with only Senegal including an intervention targeting this group. Not a single country budgeted resources for activities to care for and support children, suggesting that even where the issue was identified, there was high risk of policy slippage with interventions for children falling off poverty reduction agendas prior to their implementation[43].

The crisis of children living in communities affected by HIV/AIDS is largely invisible to governments because children are dispersed in families and communities where their hardships, and those who care for them, are mainly hidden from sight.

Governments in Sub-Saharan Africa have generally had limited involvement in the provision of services supporting vulnerable children, although South Africa, Namibia, and Botswana have developed statutory social support schemes that serve important safety net functions for children, including those affected by HIV/AIDS. Some governments, including Malawi, Namibia, South Africa, Zambia, and Zimbabwe, have conducted national situation analyses, established policies for orphans and vulnerable children, as well as establishing coordination mechanisms and legislation to protect and support orphans and vulnerable children, thus indirectly contributing to reducing stigma and discrimination and promoting children's well-being. However, despite being signatories to the Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child, there is little evidence that most states with significant epidemics are addressing the impacts of HIV/AIDS on children. Only 13 per cent of countries in Sub-Saharan Africa had a national policy on orphans and vulnerable children by 2003[44]. The recent UNICEF-led Rapid Assessment, Analysis and Action Planning (RAAAP) process assisted the development of multi-sectoral National Plans of Action on vulnerable children (NPAs) in 16 Sub-Saharan African countries.

The crisis of children living in communities affected by HIV/AIDS is largely invisible to governments because children are dispersed in families and communities where their hardships, and those who care for them, are mainly hidden from sight. Governmental action has been slow to emerge, partly because families and communities have shouldered most of the burden[45].

3.3 Donor responses

The *Three* Ones agreement advocated by UNAIDS draws attention to the disabling effects of a lack of coordination between donors (international and bilateral agencies) and governments, local organisations, and civil society. There is little concert of effort, and differences in goals, philosophies, work programmes, styles of interaction and cooperation, as well as favouritism in respect of implementing agencies, detracts from the support children and families require. This fragmentation may even damage children when decisions about funding, support, and collaboration are based on institutional priorities, i.e. with an emphasis on uniqueness and identity, rather than being guided by what is necessary on the ground. In addition, more effort should be expended to increase the authority, credibility, and effectiveness of designated government departments, initiatives, and committees to enable them to contribute to a more forceful response on behalf of children. Some of the problems identified by countries in the *Three Ones initiative*[46] with regard to donors and international agencies are outlined below:

- Donors are sometimes impatient with what they perceive to be failures of political commitment and leadership, weaknesses in organisational structure or technical incompetence in countries. Instead of helping to overcome these failures, they in some cases bypass national AIDS authorities and frameworks. In general, country teams are acutely aware of weaknesses at their end and think it would be more constructive if donors would help to address these weaknesses.
- Some major donors have their own institutional aims that do not accord with the aims identified by countries. When such donors are putting large sums of money into countries' AIDS programmes, they can over-ride the aims set by legitimately recognised national AIDS coordinating authorities and, in effect, steer countries in directions they may not wish to go. They often do this through vertical initiatives, where they provide direct funding to certain programmes and projects without reference to overall country efforts.
- Donors often collaborate with each other to insist on country transparency with regard to policies, expenditures, etc. when they, themselves, are not always transparent in their actions.
- When donors promise support, they do not always follow through with the timely release of funds. Instead, they leave countries (and programmes) hanging in expectation, which may eventually give way to frustration and disappointment.
- Donors often have "preferred" or "priority" countries (and programmes or districts) and some countries may find themselves far down on donors' lists or not on the lists at all, even though they are heavily hit by HIV/AIDS and have limited resources to respond to the crisis.

3.4 In-country NGO, CBO, and FBO responses

Large, in-country NGOs have evolved to provide assistance to children and families, some of them taking on the role of intermediaries for channeling international and national funds to smaller community-based organisations. Examples include the Family AIDS Caring Trust (FACT) in Zimbabwe, the Nelson Mandela Children's Fund (NMCF) in South Africa, the Kenya Orphans Rural Development Programme (KORDP) in Kenya, and Community-Based Options for Protection and Empowerment (COPE) in Malawi.

The emergence of community-based care initiatives has become one of the outstanding features of responses to the AIDS epidemic. These initiatives play a key role in easing the impacts of the epidemic, particularly on children. Although most of these efforts are operated by community-based organisations (CBOs), religious groups (FBOs) or non-governmental organisations (NGOs), their effectiveness often depends on the existence of formal health and education services and other government structures. Over the past decade, thousands of communities throughout Africa have recognised the increasing vulnerability of children and have reacted with ingenuity. As early as 1987, communities in Tanzania were responding to increasing numbers of orphans and families affected by HIV/AIDS by providing home-based care, food, educational support, and health care assistance[47].

The emergence of community-based care initiatives has become one of the outstanding features of responses to the AIDS epidemic.

Spontaneous community-based initiatives devised by local groups exist in all affected countries to help vulnerable children and families. These include: communal land and crop production; grain loan schemes; organised individual or group income generating activities (IGA), often involving small traders selling home-made food or vegetables; communal labour to repair houses and schools; home-based care for ill people and their families; labour-sharing to relieve caregivers and to enable children to attend school; community schools; orphan registration and home visiting programmes to provide relief, food, clothing, and school fees; social groups for vulnerable children; psychosocial activities to address the distress of affected children, and a variety of other efforts that give support to those worst affected by the epidemic.

Generally, civil society advocacy directed at government has been quite weak throughout Africa. The few advocacy initiatives that exist have been primarily led by international NGOs. The Treatment Action Campaign (TAC) in South Africa has been a notable exception that has successfully advocated for anti-retroviral roll-out.

3.5 The private sector

A significant gap exists with regard to attempts at bringing in the private sector and encouraging local philanthropy. The business sector is making progress partnering with government, multilateral organisations, and communities in establishing workplace prevention and education programmes that focus on their immediate workforce. Companies acknowledge that programmes should widen their focus to include community initiatives and that they should be increasingly strategic in how they contribute to interventions[48].

Notwithstanding the above, no models exist for international child agencies to work with corporate social investment programmes. Nor are there models to encourage local businesses (i.e. taxis, trading stores, traditional leaders and healers, successful hawkers, etc) to donate even small amounts of money or to share their organisational expertise with community groups trying to assist vulnerable children and families. Similarly, in South Africa, for example, none of the numerous child advocacy groups have attempted to address the private sector which, in the absence of clear guidance, tends to follow the well-trodden path of supporting orphanages and local projects instead of promoting holistic responses to HIV/AIDS.

3.6 Families and communities

Extended families, kin, and communities remain the principal supports for children affected by HIV/AIDS in Sub-Saharan Africa[49]. In rural Tanzania, for example, 95 per cent of orphans are cared for by relatives[50]. Studies in many countries in Africa and elsewhere find that families and communities absorb orphaned and affected children while their meagre resources hold out. Surviving mothers, grandmothers, and related women are the main care-providers for affected children. While surviving fathers are less likely to care for children than surviving mothers, this tendency seems to be changing[51]. However, in most circumstances, grandparents are the most common caregivers. The fact that families are absorbing the care of affected children does not mean that they are doing so without difficulty. Out-of-pocket spending by households, most of whom are already very poor, is the largest single component of overall HIV/AIDS expenditure in African countries: a stark reminder that the economic burden of the epidemic is borne by those least able to cope. Households are straining under this weight of sickness and death. It is clearly a case of the very poor helping the destitute. Despite the proliferation of resources ear-marked for HIV/AIDS, governmental[52] and international responses[53] to the HIV/AIDS crisis are not yet succeeding in getting significant resources to affected communities and families.

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Community-based approaches with a focus on assisting adult caregivers to support very vulnerable children, working on the assumption that children are dependent on adults and family caregivers, will continue to provide protection and care for children when donor-driven programmes come to an end. Challenges to family care include tackling inappropriate fostering, where children are pushed into households rather than being pulled, making them vulnerable to neglect, exploitation, and abuse[54]. In addition, older caregivers may have difficulties responding to the economic, health, and psychological needs of children. Child-headed households are reported to be increasing, but there are significant problems with available measurement and data, and current analyses indicate that they are transitory structures[55]. Where they endure, their existence is often testimony to community and neighbourhood assistance, because such households could not survive on their own[56].

4. Towards a Rights-Based Approach

There is no doubt that adoption of the Convention on the Rights of the Child (CRC) and the African Charter on the Rights and Welfare of the Child, has made policies, services, programmes, and adults more responsive to the best interest of the child. One indication of progress in this area is inclusion of child rights into the goals of the New Programme for Africa's Development (NEPAD) and the Millennium Development Goals (MDGs).

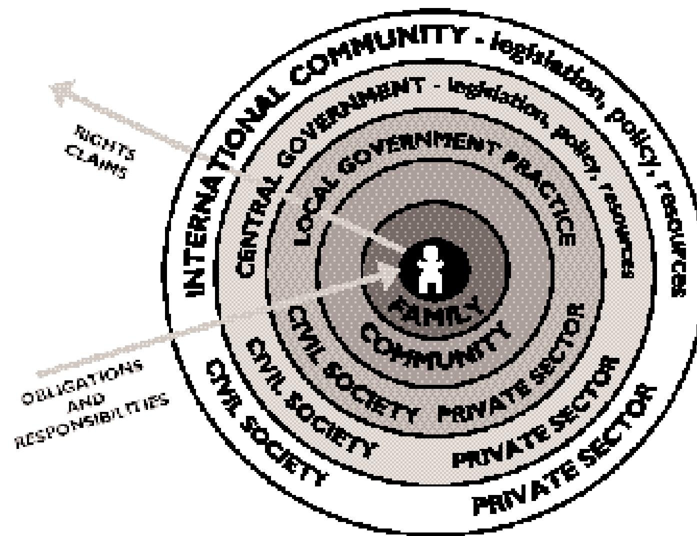
It is frequently asserted that the four underlying principles of rights-based programming, as highlighted in the CRC, are:

- *Universality* (that rights should be accessible to all people, including children)
- *Indivisibility* (rights cannot be separated from each other – they are all interdependent and inter-linked)
- *Responsibility* (there is a shared responsibility to ensure that rights are fulfilled and upheld and that duty bearers, especially, but not exclusively, governments, be held accountable for their responsibility)
- *Participation* (rights-holders, including children, must be actively involved in programmes aiming to fulfil their rights).

Article 3 of the CRC states: *"In all actions concerning children, whether undertaken by public or private welfare institutions, courts of law, administrative authorities or legislative authorities, the best interest of the child shall be the primary consideration"*. The CRC takes this further in its General Comment on HIV/AIDS and the rights of the child by asserting that children "should be put at the centre of the response to the pandemic, adapting strategies to children's rights and needs"[57]. Figure 4 below shows the different levels within society that impact on children's lives and the way in which the State, as the primary duty bearer, is responsible for fulfilling in a sustainable manner the rights of children, as outlined in the CRC and the African Charter. The State is positioned at a number of these levels, as is civil society and the private sector[58]. Some actors have clear moral and/or legal responsibilities towards children (for example, parents, caregivers, teachers, and social workers), with others supporting and facilitating the effectiveness of duty bearers.

"In all actions concerning children, whether undertaken by public or private welfare institutions, courts of law, administrative authorities or legislative authorities, the best interest of the child shall be the primary consideration".

Figure 4: Different levels within society which impact on children's lives



This focus on rights and their enforcement stems from a shift in developmental approaches away from the traditional trickle-down of external assistance from the rich to the poor, to an approach focusing on access, empowerment, and participation. Rights-based programmes support rights-holders, including the poor, marginalised, and most vulnerable in society, to claim their rights. This engagement has the potential to increase impact and strengthen sustainability[59].

Civil society does not bear the responsibilities of the State, but as an actor in the broader environment it is in a position to encourage and assist in meeting obligations toward fulfilling the best interest of the child. This can be undertaken in a variety of ways, such as: capacity building, provision of materials, institution building, policy development, advocacy, and lobbying.

Poor understanding or misunderstanding of children's rights has affected the fulfillment of the rights of children living with HIV/AIDS, as well as children living in communities affected by HIV/AIDS.

Poor understanding or misunderstanding of children's rights has affected the fulfillment of the rights of children living with HIV/AIDS, as well as children living in communities affected by HIV/AIDS. Early in the epidemic, the relationship between HIV/AIDS and human rights was particularised to people infected with HIV and living with AIDS and the discrimination to which they were subjected[60]. This relationship has been expanded[61], and a human rights approach is now accepted as necessary to guarantee the success of prevention, treatment, support, and care strategies. Within this approach, public welfare strategies and the protection of human rights are seen as mutually reinforcing.

Rights-based approaches to the AIDS epidemic have yielded results by[62]:

- Enhancing public health outcomes: **Protecting a person's right – particularly a person living with HIV – to achieve the highest attainable standard of physical and mental health can increase confidence in health systems.** In turn, this has led more people to seek and receive relevant information on HIV prevention, counselling, and care.

- Ensuring a participatory process **linking patients and care providers can improve the relevance and acceptability of public health strategies.**
- Fostering non-discriminatory programmes **can lead to the inclusion of marginalised groups that are more vulnerable to HIV infection.**
- Scaling up the AIDS response **through empowering people can enable them to claim their rights to gain access to HIV prevention and care services.**
- The accountability of states **can be enhanced through people seeking redress for the negative consequences of health policies. Legal action based on human rights has been a vehicle to enforce people's right to gain access to health care, including antiretroviral treatment.** For example, in South Africa, the Treatment Action Campaign won a court ruling that required the government to supply the antiretroviral drug Nevirapine at public health facilities to HIV-positive pregnant women, as part of a phased roll-out of a comprehensive national programme to prevent mother-to-child HIV transmission.

The UN Committee on the Rights of the Child (in its General Comment No. 3 of 2003) makes recommendations on children and HIV/AIDS and calls on State parties to[63]:

- Adopt and implement a children's rights-centered approach to HIV/AIDS in their national and local HIV/AIDS related policies;
- Allocate financial, technical and human resources to the maximum extent possible to support national and community-based action;
- Review existing laws or enact new legislation to implement fully Article 2 of the CRC, in particular to expressly prohibit discrimination based on real or perceived HIV status and to prevent mandatory HIV testing;
- To include HIV/AIDS plans of action in the work of national mechanisms responsible for monitoring and coordinating children's rights and to consider the establishment of review mechanism for complaints of neglect or violations of children's rights in relation to HIV/AIDS;
- Reassess their HIV-related data collection and evaluation to ensure children are adequately covered and disaggregated by age, gender, and as far as possible, belonging to vulnerable groups;
- Include in their reporting process information on national HIV/AIDS programmes with specific mention of those which explicitly recognise children and their rights.

The Committee's General Comment No. 3 of 2003 further acknowledges the roles that the international community and civil society play in the response to the HIV/AIDS pandemic. It also encourages State parties to ensure an enabling environment for participation by civil society groups, which includes collaboration and coordination amongst players[64].

UNICEF's Voices for Youth initiative, using the four guiding principles of the CRC, advocates the following relationships between the rights of children and HIV/AIDS[65]:

- **Survival, development, and protection:** AIDS is a deadly disease, so clearly it threatens children's rights to survive and develop into happy, healthy persons. According to Article 6 of the Convention on the Rights of the Child, governments must do everything they can to safeguard children's survival and development. This includes ensuring that children have access to basic health and education including the knowledge and skills needed to protect them and others from HIV, as well as appropriate treatment, counselling, and care.
- **Non-discrimination:** In terms of Article 2, rights should be protected without regard to "race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status". This includes being HIV-positive. Ignorance, fear, and prejudice cause children whose parents are infected with HIV, whether or not they are themselves infected with the virus, sometimes to be refused access to education, health or social services, and excluded from community life. HIV-positive children may even be abandoned by their families, communities, and societies. Discrimination against people who have HIV is not the only kind of discrimination that is relevant here. In many societies, gender discrimination places girls at a higher risk than boys of becoming infected with HIV. There are a number of reasons for this, including the fact that girls are less likely to access education than boys, making it less likely they will know how to protect themselves from infection. Even if girls are in school, traditional attitudes may exclude them from receiving sex-education or being taught about diseases such as AIDS, which are mainly spread through sex. Also, girls are more likely to be pressured into having sex and less likely to be able to control with whom, when, and how they have sex due to local and traditional attitudes and behaviour.
- **The best interests of the child:** Putting children's interests first (Article 3) is also relevant to HIV and AIDS. In many countries, HIV-related services such as HIV testing, counselling, treatment, and care have, until now, been designed primarily for adults, and may thus not be particularly welcoming or accessible to young people. For example, the service providers may lack information relevant to sexually active youth, they may not have specially trained health-care providers who know how to help and talk to children and youth, or the requirement for parents' or guardians' permission may pose a barrier to young people. As a result, youth may not use these services, which makes it harder for them to get the information they need to keep themselves safe and healthy. This relates directly to children's participation.
- **Participation:** The right to express views and have them taken into account (Article 12) is also relevant because it relates to young people's right to information aimed at raising awareness of HIV and AIDS, to ensure their ability to speak out about its impact on their lives, and to participate in the development of HIV

and AIDS policies, programmes, and products. The participation principle also applies to HIV testing and, if a child is old enough according to the laws of a country, being allowed to choose for themselves whether or not to have an HIV test.

There is growing realisation that the issues of children and HIV/AIDS extend beyond medical and health problems and that it involves a much wider range of other issues[66]. In this regard, the non-realisation of children's civil, political, economic, social, and cultural rights are important[67].

Various factors, such as the loss of a parent, an illness, migration of parent/s to find employment, financial difficulties, separation from siblings and family, and others, increase children's vulnerability and decrease their ability to access resources and support mechanisms. The lack of protection places children at risk of sexual abuse, exploitation, and discrimination. Children living in poverty are frequently denied many rights. In fact, the most common definitions of poverty refer to the inability to meet basic needs, including food, shelter, and clothing. Even with wholehearted political will, poor countries cannot fulfil many of the basic rights of their children. Given the difficult choices entailed in achieving even a minimal level of effectiveness in policy development, legislation, and implementation in resource-poor settings, a number of questions need to be addressed.

5. Analysis and Findings

The issues raised by international developments in respect of children living in communities affected by HIV/AIDS and from documents and reports of activities undertaken, can be discussed under a number of headings. Due to the inter-relation between the various elements involved in responding to children affected by HIV/AIDS, separating them inevitably leads to artificial divisions and a move away from the preferred holistic approach. This section highlights the issues and proposes ways to tackle them.

5.1 The need for a wider, long-term, holistic approach

From long-standing experience and empirical research, efforts to support children are best directed at the concentric circles of care and influence that surround children, i.e. families, schools, neighbourhoods, and extending outwards to the media, legislative frameworks, and policies that have a bearing on children's lives, as illustrated in Figure 4 above. Attempts by external programmes and projects to reach children directly are not sustainable, from either a financial or a socio-cultural perspective.

What is most needed is a set of collective community and programme responses to strengthen caregivers' and households' commitments to the well-being of children that are supported by constructive national policies and the mobilisation of resources. Within this mix of responses, it is accepted that activities to protect, support, and promote the psychosocial well-being of children and families are urgently needed.

Until now, most interventions to support children have been piecemeal and have not matched the size and expected duration of the problems experienced by children living in communities affected by HIV/AIDS. Williamson forcefully drew attention to this in 2000[68] when he cautioned that the aim of programmes by government and civil society was,

> *"not to save a few orphans in those rare communities in which external agencies operate, but to strengthen the capacity of families and communities to cope. Developing programmes that significantly improve the lives of individual children and families affected by HIV/AIDS is relatively easy with enough resources, organisational capacity and compassion. Vulnerable individuals and households can be identified, health services can be provided, school expenses of orphans can be paid, food can be distributed, and supportive counselling can be provided. Such interventions meet real needs, but the overwhelming majority of agencies and donors that have responded so far have paid too little attention to the massive scale of the problems that continue to increase with no end in sight. As programs to date have reached only a small fraction of the most vulnerable children in the countries hardest hit by AIDS, the fundamental challenge is to develop interventions that make a difference over the long haul in the lives of children and families affected by HIV/AIDS at a scale that approaches the magnitude of their needs"* (Williamson, J. 2000)

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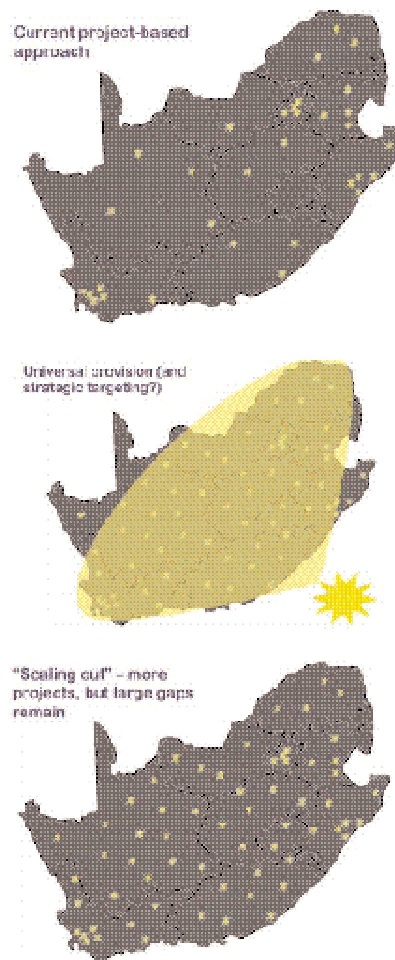
What is critically needed, in addition to community-based activities, are universal/comprehensive approaches, responding to the rights of citizens (including children), to receive essential services.

Project-based approaches are inherently limited. Even when they are scaled out (extended to other sites), they are unsustainable if dependent on external funding. They are also likely to leave large numbers of children out of the loop if not joined up by systemic strategies. What is critically needed, in addition to community-based activities, are universal/comprehensive approaches, responding to the rights of citizens (including children), to receive essential services. The incremental effects of these approaches are represented diagrammatically in Figure 5 below.

Figure 5: From projects to universal provision



Source: Richter, L. (2005). Going to scale[69].

Universal provisions have the potential to raise the level of care for all children, including the most vulnerable. These include social security, free health care, education, social welfare and early child development services, school feeding, legal provisions to protect property and prevent abuse, etc. Government is the primary duty bearer in the centre.

It is widely agreed that the two major challenges facing efforts by international and local governments, donors and philanthropic organisations to assist vulnerable children are:

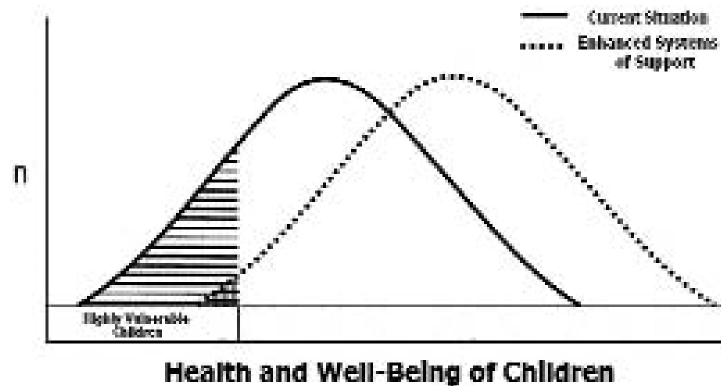
1) budget allocations, effective policy intervention, and successful implementation by national governments, and
2) the development of mechanisms for channelling resources to grassroots organisations and to destitute families.

Both of these challenges need to be addressed and improved upon, together with all the activities they involve. At the macro-level, government assistance is required in terms of social security provisions, as well as health, education, and other services that make up the social wage, together with efforts to scale-up promising community-based activities. At the micro-level, greater local philanthropy, mobilisation, and organisational capacity need to be drawn in, especially amongst better-off members of communities, such as shopkeepers, professionals, and entrepreneurs, to support the efforts of local volunteers to assist kith and kin.

Monitoring and evaluation, including estimates of cost and cost-effectiveness, are needed to guide investment in and expansion of services and programmes to support children living in communities affected by HIV/AIDS. Very few models exist that have been objectively evaluated with respect to the value they add to children's heath and well-being, their capacity to be taken to scale, the human resources and implementation logistics of scaling up, and anticipated costs and sources of sustainable financing.

Programmatically, there is a need for a continuum of responses to children living in communities affected by HIV/AIDS. At the one end of the continuum, specific assistance must be provided for the relatively small number of extremely vulnerable children, including children with severe disabilities, abused children, children without adult support, abandoned and children living in and out of the streets (the shaded portion of the curve on the left-hand side of the graph in Figure 6 below). In the main, though, improved access of all children in AIDS-affected countries to social security, health, education, and welfare provision is needed to shift the curve to the right, representing the health and well-being of the child population. As illustrated in this figure, such a shift improves the mean level of health and well-being of all children in the society and, simultaneously, reduces the number of extremely vulnerable children who may need individual assistance. This approach, when applied to other problems, is generally found to be more cost-effective in responding to the needs of vulnerable children than attempts to reach all such children through individualised services.

Figure 6: Universal curve shift to improve children's health and well-being



Source: Richter, L., & Foster, G. (2005)

Such a public health, or social development, response is justified by the very large numbers of children in severely AIDS-affected countries whose poor living circumstances and limited access to services compromise their health and well-being. Between a third and a half of all children are underweight in the regions worst affected by AIDS; by 2000, immunisation coverage, also a proxy for health service access, was just above 50 per cent in Sub-Saharan Africa, and less than 35 per cent in the 12 poorest countries. In the same region in 2002–2003, the net primary school enrolment and attendance rate was around 60 per cent (UNICEF ChildInfo)[70] and the prevalence of child labour in Africa is estimated to be between 20 and 50 per cent. These circumstances form the backdrop to any additional impacts that HIV/AIDS, specifically, has on children's health and development.

Not only is there a need for a focus on more universal programming, but there is a need for funding and programmes to be focused on the long term. Most externally-funded activities to support children living in communities affected by HIV/AIDS have not gone beyond the level of short-term, geographically limited projects for small numbers of children and families. This is as true of the work of very large donor and international agencies as it is of country-level funding institutions and organisations. There is, as yet, too little appreciation of the long-term nature and the size of the problems for children and families caused by the AIDS epidemic.

Initiating more projects in more communities may help but, by itself, is not the answer. Strengthening systems – ensuring children's access to health, education, social, police and legal services; increasing formal safety nets; and enabling and resourcing informal safety nets – has the potential for universal benefits at a scale that approximates the needs of all children, including children made vulnerable by HIV/AIDS and other causes. To date, however, too few international agencies have thrown their weight behind enhancing the capacity of governments and civil society to strengthen these approaches jointly. There is also too little interrogation of what projects are intending to achieve and where they are heading, ie are they pilots,

demonstrations, replacement services for lack of government provision, or something else? Also, questions have to be asked regarding the longer-term perspective that guides their form and development. Available money is not going far enough to yield benefits for children, and much of it is tied up in well-meaning projects without strategic intent and focus.

5.2 Approaches to children living in communities affected by HIV/AIDS

5.2.1 Inclusive terminology

The international debate and trends concerning children and HIV/AIDS are constantly evolving. However, a few areas still need advocacy to shift away from simple, catchy terms to appropriate language that does justice to the complexity of the debate.

Terminology itself is serving to increase stigmatisation and discrimination of groups of children. *AIDS-orphans and Orphaned and Vulnerable Children (OVC)* are both labels that can be used in ways that are harmful to vulnerable children, isolating children, imbuing them with difference, and creating prejudice towards them through differential targeting of programmes for them when many groups of children are visibly in need. Children are frequently referred to as *infected with HIV*, which separates them from the adult-led rights-based movements of People Living with HIV/AIDS (PLHA). In addition, OVC tends to direct attention on children in a way that focuses on the child as the cause of vulnerability, and the child as the appropriate site for intervention. Neither of these is necessarily useful, because the vulnerability and resilience of children is very dependent on the social and material conditions in which they live, and interventions to support children are often best directed at caregivers, families, communities, and services.

Using the terminology Children Living in Communities Affected by HIV/AIDS avoids labelling individual children, and contextualises children as part of families and communities.

For this reason, activists in the field encourage the term *children living with HIV/AIDS* (CLHA). Richter and Foster (2005) recommend that all categories of children affected by HIV/AIDS are best referred to as *Children Living in Communities Affected by HIV/AIDS;* this avoids labelling individual children, and contextualises children as part of families and communities. In addition, the term helps to direct interventions to the concentric circles of support around children upon which children's health and well-being depend. Lastly, the term provides for the fact that some children may be multi-disadvantaged in the context of HIV/AIDS – through, *inter alia*, poverty, disability, exposure to violence, destitution, and displacement[71].

5.2.2 Comprehensive well-being approach

Terminology has also dogged efforts to ensure that the response to children is comprehensive and takes account of their material, psychosocial and other needs. The term *psychosocial support* has become associated with a narrow counselling or therapeutic approach that may misdirect efforts to support children holistically. It is now

recognised that all efforts to serve children should attempt to improve *children's health and well-being* through a range of different forms of advocacy, legislation, services, programmes, and support and encouragement for caregivers.

Efforts to counter the impact of the AIDS epidemic have, from the start, *centred on adults rather than children,* as if children were only an extension of adults. One example concerns the sentiment that there is little point in allocating precious time and resources to prolong or improve the quality of life of infants living with HIV/AIDS, because there will be no-one to look after them when their mother dies. Donors, NGOs, international agencies and governments need to be constantly reminded of the importance to keep children in focus when discussing the HIV/AIDS pandemic.

Initially, the AIDS epidemic was approached from a narrow medical perspective; this has since widened to encompass human rights, legal, social, psychological, cultural, and other perspectives. With antiretroviral treatment becoming more widely available, *HIV/AIDS is being re-medicalised,* which is impacting on the approach taken towards children. The danger of this is twofold: firstly, ground could be lost in achieving holistic care and support for children, and secondly, disproportionate increases in resources for ARV services may detract from, rather than strengthen, primary health care for all children.

The separation of responses to children living in communities affected by HIV/AIDS from efforts to support children generally, has significantly handicapped this field.

The AIDS field has also given rise to a new group of experts, some with very little knowledge of children's development. In fact, the separation of responses to children living in communities affected by HIV/AIDS from efforts to support children generally, has significantly handicapped this field, and even given rise to some critical wrong-turns, such as the increased provision of residential or institutional care for children.

At a country and district level, there is also little coordination between programmes, even within the field of HIV/AIDS. For example, despite the fact that they largely service adults, most of whom are parents or responsible for the care of children, very few PMTCT, VCT or ARV programmes use the opportunity of contact and service provision to simultaneously support children, or to connect affected children to related service structures. Only recently has attention started to be given to children in home-based care programmes.

5.3 The role of governments

As already mentioned, governments are the primary duty bearer in the response to children living in communities affected by HIV/AIDS. They need to be encouraged to take on their responsibilities towards this group of children in particular, but also all their child citizens in general, particularly with regard to the following:

- **It is important to strengthen systems to support children.** Community responses and externally-driven programmes assist vulnerable children and, in most cases, attempt to fill the gap created by lack of government services. The required complement is strengthened state provision of health, education and social welfare services, and economic and community development. State pro-

vision is a necessary foundation to programmes assisting individual vulnerable children and their households, and will assist in shifting the curve to the benefit of children's health and well-being, as illustrated in Figure 6.

- **It is critical to enhance both the role and performance of government in supporting children living in communities affected by HIV/AIDS.** To date, most of the examples of best practice in relation to the care and protection of children living in communities affected by HIV/AIDS come from civil society. **Translating the National Plans of Action into actions that benefit vulnerable children will not happen without properly scaled implementation plans, together with the commitment of governments to prioritise vulnerable children and to provide additional resources.**
- Formal and informal safety nets protect children and families from the worst effects of poverty, HIV/AIDS, violence and natural disasters. When hard times hit, safety nets enable households to avert debt and destitution and avoid having to sell off productive assets. Formal safety nets are created by governments and NGOs through price subsidies, public works programmes, food or micro-credit programmes and cash transfers to targeted households through pensions, grants and allowances. Government intervention should cover the whole continuum from prevention to impact mitigation. Some countries, such as South Africa, have a functioning statutory social support scheme, providing old age pensions, child support grants, and foster grants for children legally placed in foster care. **Governments need to be encouraged to increase and improve the formal safety nets.**

5.4 Key issues while working with children living in communities affected by HIV/AIDS

5.4.1 Supporting children and their caregivers

All children need to be in a stable relationship with at least one caring and affectionate adult caregiver. Some children may have more than one caregiver, but all primary caregivers must fulfil two conditions. Firstly, they must care for and about the child in a way that motivates them to protect the child and provide for the child's needs in the best way possible under the circumstances. Secondly, the caregiver must have a long-term perspective of the child. That is, their care of the child must be guided, not only by the considerations of today or next week, but also by how this child will "turn out" as an adult. This latter perspective is what is missing fundamentally from all forms of paid care which are, by their nature, jobs, rather than relationships.

Where this form of care and commitment is not easily available to a child because their extended family is reluctant to take them in, because they have been abandoned, or because their kin network has been wiped out by war or natural disaster, alternative forms of adult-child relationships must be found or cultivated, as in adop-

tion and life-long fostering. Caregiver relationships with children are not replaceable by group or residential care in which paid caregivers come and go.

All caregivers must have opportunities to secure both economic and social resources sufficient to provide for a child's protection and care. Caregivers, in the meaning outlined above, will provide for and protect children only to the extent that they have the ability and the resources to do so. They cannot do so when they are destitute and isolated. In these circumstances, all efforts have to be directed at providing caregivers with opportunities to obtain or generate economic resources and to associate with others for social support and succour.

All caregivers and children need to participate in their community and society in ways that give meaning to their lives and provide them with hope and motivation for a shared future. This means having family, neighbours and friends, belonging to community associations and faith congregations, going to school, engaging in livelihood activities, and the like. Linking affected caregivers and children to groups, schools, and other social constellations is an important intervention in its own right.

An operations research study in Uganda looked at how to achieve maximal programme benefits for vulnerable children. The results drew attention to the fact that adult caregivers, parents and guardians, have needs of their own that must be addressed to enable and prolong their capacity to care for children living in communities affected by HIV/AIDS[72]. It was suggested that the following broad principles should be included in caregiver support programmes:

- Children living in communities affected by HIV/AIDS should be reached before they become orphans and caregivers living with AIDS enabled to address their concerns about the future welfare of their children.
- Community awareness and accountability about the asset and property rights of women and children should be increased, and efforts made to get relatives and community leaders to uphold these rights.
- The critical health needs of adult caregivers, including guardians, should be addressed. Care and support services enable caregivers to maintain their health and prolong their capacity to care for children.
- Adult-to-child communication should be improved and counselling provided on difficult issues, including parental illness, parental death, and sex education. Many parents and guardians express a need for support and advice on discussing difficult issues with children, including disclosure of their HIV status[73].
- The critical material needs of AIDS-affected households, including those headed by HIV-positive parents and guardians, must be addressed through access to social security, assistance with income-generation activities, provision of work opportunities, vocational training, food, clothing, home repairs, school fees and social support.
- The morale of children has to be improved by keeping them in school and offering sports and recreation facilities. School and other activities maintain the psy-

chological well-being of children and reduce the burden of childcare on stressed caregivers.

- Stigmatisation of and discrimination against AIDS-affected adults and children must be addressed. Fear of disclosure limits parents' ability to appoint guardians and to take other steps necessary to secure the future of their children. Strategies include communal monitoring to reduce mistreatment of children and AIDS-affected households, including teasing, gossip, neglect and abuse.

5.4.2 Support to communities

In the long run, affected communities are better placed to provide culturally-appropriate support and deal with the complex social issues surrounding children affected by HIV/AIDS than external agencies. However, these support activities are usually not sustainable in the long-term without additional assistance from external agencies and government. People who volunteer their time can only do so when the demands of their own households permit them to give assistance to others. Volunteers seldom have the resources to continue to provide material support to affected children and families except in crisis situations. For this reason, ensuring that manageable resources reach community-based groups, to enable them to continue to assist vulnerable children and their families, is the critical requirement of governments, assisted by international and local aid agencies.

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- **Recent analyses have demonstrated that too little of the money being allocated to HIV/AIDS initiatives is reaching affected families and communities. It has also been shown that international agencies, in particular, incur large costs to effect the transfer of funds to communities – to the detriment of benefits reaching the grassroots[74].** Efforts are also being made to ensure that international and local agencies support, rather than undermine, the emergence and sustainability of community-based activities. The importance of finding the right balance between direct external activities and local response is not unique to HIV/AIDS; however, the scale and urgency of the problem of the HIV/AIDS epidemic can lead to ill-planned or uncoordinated actions by external agencies with unanticipated negative consequences. For example, external agencies may divert the agenda of community actions; inappropriate targeting may leave vulnerable groups unsupported and cause resentment; material support from the outside may have the effect of disrupting community actions or relieving families and communities of a sense of responsibility; and communities may be left worse off when programmes are terminated because spontaneous initiatives did not develop or were suspended[75]. This does not mean that external support is not needed. Placing an emphasis on community-based initiatives should also not be interpreted as relieving governments of their responsibility to create an enabling environment for children and families (including unencumbered access to essential services and additional financial and infrastructural support where needed)[76].

- Informal safety nets are created from donations or exchanges of cash, food, clothing, informal loans, assistance with work or child-care, accommodation, as well as voluntary associations and solidarity groups who provide essential support to households affected by misfortune. These informal safety nets are woven through networks of kith and kin, created by relatives belonging to extended families and clans, and by community members acting either individually or together. Seeking relief from family, friends, and neighbours is a common response to economic and other crises, and families and neighbours provide for each other if they can – when asked for help – in the knowledge that, given the tenuous conditions in which they live, they may have to ask for help themselves in the near future. In Sub-Saharan Africa, the extended family, assisted by the community at large, is the most effective response for people facing household crises. Since state-administered support is generally non-existent in the region, social insurance for most people is provided through kinship ties that enable household members to access economic, social, psychological, and emotional support from their relatives and neighbours in times of need. **To date, however, insufficient effort has gone into supporting informal safety nets and in advocating for and pressurising governments to improve formal safety nets.**
- Very few internationally-funded projects are sustainable. This is compounded by insufficient effort being made through local community, civic, and government mobilisation to ensure their sustainability, which creates a stop-start approach at the community-level, discourages belief in projects and motivation to be involved, and encourages people to seek perverse gains from projects that they know will be of short duration. This can be extremely problematic for children. For example, many small orphanages are being established with external 'start-up' funds, but they rapidly run into difficulties two to three years later, at a time when children have already been separated from their families and communities, and it is even harder to find them placements in home environments. In several Southern African countries, such orphanages deteriorate into extremely depriving and abusive environments for children.
- As early as 1994, the importance of men's and boy's participation in the curbing of the spread of HIV/AIDS became apparent. For example, the Program of Action developed at the 1994 International Conference on Population and Development held in Cairo includes a statement on 'Male Responsibilities and Participation'[77]: **"Special efforts should be made to emphasize men's shared responsibility and promote their active involvement in responsible parenthood, sexual and reproductive behavior…"** The involvement of men and boys challenges constructions of masculinity and prompts changes in many commonly-held attitudes and behaviours, including the way boys are socialised to become men and how adult men approach sexuality and family responsibility[78]. It is therefore important to understand and examine the *contexts* in which gender is learnt[79]. Men need to take a greater role in caring for children and their family members and give greater consideration to HIV/AIDS as it affects the family. It is important for communities to accept and recognise the potential that men have to care for their children and families positively.

5.4.3 Support to vulnerable children

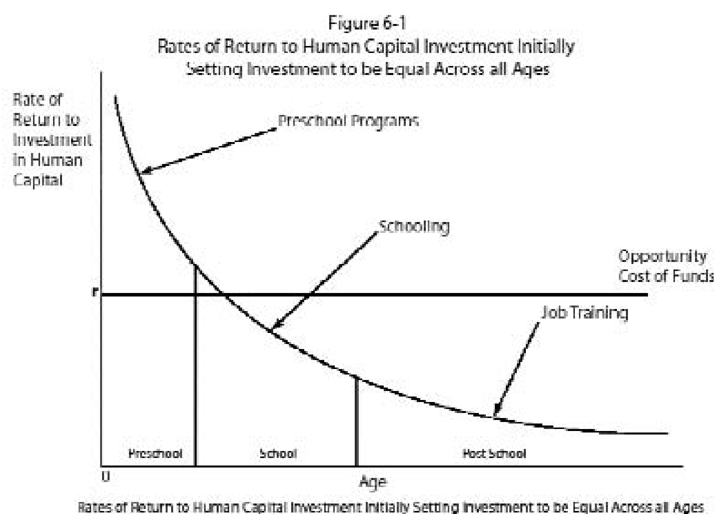
There have been significant developments in the field of HIV/AIDS and working with children living in communities affected by HIV/AIDS. The following points are not comprehensive, but it is helpful to bear them in mind when considering implementing or financing programs that specifically target children affected by HIV/AIDS.

A great deal is already known about how to support vulnerable children – from work done in the fields of poverty and livelihoods, malnutrition, violence, children living in and out of the streets, disability and the like. It is essential that the knowledge gained and lessons learned from other programmes working with other groups of vulnerable children are taken into consideration and used to guide thought and action in responses to children living in communities affected by HIV/AIDS[80].

It is essential that the knowledge gained and lessons learned from other programmes working with other groups of vulnerable children are taken into consideration and used to guide thought and action in responses to children living in communities affected by HIV/AIDS.

- Children are not one group. **There are significant differences in the challenges faced by boys and girls and by children of different ages.** While girls are, overall, more vulnerable than boys, studies of school drop-out, child labour, children's time-use, trafficking and sexual exploitation show that boys are also vulnerable and should not be neglected[81]. Moreover, neglect for boys' care may contribute later to the violence men perpetrate on women and children.
- The focus on orphans in the AIDS epidemic has biased attention towards older children, because the time lag between infection and death of a parent means that children are generally orphaned at ages 10 years and older. However, younger children are equally, if not more severely, affected by the crisis, though they are often neglected in programming. It is the younger children in the most formative period of their lives that are living with sick and dying parents, and in worsening household conditions as families divert their resources to the care of sick adults. **Individual and social dimensions of human development strongly point to the importance of protecting and investing in children during the pre-school period.** This is clearly illustrated in Figure 7, constructed by Nobel Laureate James Heckman on the basis of aggregated data. Investment in the early years entails: (i) supporting children's nutrition and growth and minimising childhood illnesses; (ii) promoting strong caregiver-child relationships to ensure children's nurture and protection; (iii) decreasing environmental threats to children's mortality and morbidity, including through exposure to abuse, toxins and injury; (iv) increasing access to early child development programmes for safety, stimulation and preparation for formal schooling; and (v) promoting educational access, retention and achievement.

Figure 7: Rates of return on human capital investment by age



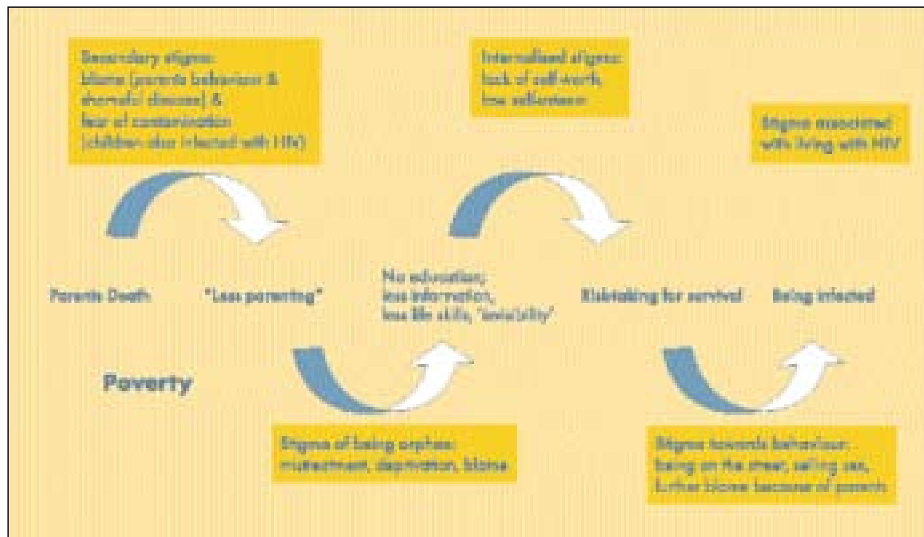
Source: James Heckman (2004)[82].

- Not all children who have a sick parent, whose parent has died, or who is being fostered are vulnerable. Most children and families cope with the life challenges that confront them. Children who are orphaned are not necessarily in need of external assistance, provided they receive stability, support, and care provided by affectionate caregivers, especially when this takes place in familiar surroundings and in a warm family environment. **Category-based approaches (for example, directed to orphans, child-headed households or fostered children) may be inappropriate, wasteful of resources, ignore the needs of other children, and may even undermine the coping capacity of children, families and communities[83].** Vulnerable children are those who are outside of parental care, are not thriving, excluded from education and social affiliations, forced to do heavy labour, etc.
- **Increasing residential and institutional care is not helpful for children.** Partly, this is resulting from a misunderstanding of the nature of orphanhood and family structure and functioning in Africa[84], as well as of the response to date to children living in communities affected by HIV/AIDS. It has been estimated that 95 per cent of the money, care and in-kind support provided to affected children and families comes from family, friends, neighbours, communities, and congregations. The proportion of external assistance effectively reaching children remains extremely small. Perversely, external assistance is effectively reaching communities through orphanages and other residential facilities that, on balance, do children more harm than good. Even in the United States and Europe, where resources are relatively unconstrained, family care is preferable to institutional care of all kinds[85].

- **Monitoring systems should be put in place to ensure that children are not abused and families are not suffering as a result of taking in child dependents.** Neglect of children by inexperienced, unsupported, or frail caretakers can result in abuse and neglect. Although foster care programmes are better than institutional care, if the caregivers are not properly supported and monitored, all children in the household can suffer.
- **Stand-alone interventions are less helpful to children and families than integrated approaches through which health and nutrition, economic and food security, legal aid, psychosocial and spiritual support, educational assistance, and other services are delivered.** Stand-alone approaches do not respond to the multiple needs of vulnerable children, and frequently duplicate the facilities and infrastructure existing in health services, schools and developmental programmes. Such stand-alone programmes also draw human resources and skills away from integrated programmes, they are expensive, and are unsustainable in the long-run. Similarly, once-off or short-term interventions, such as play groups, camps, etc, are more effective when integrated into ongoing services and activities, such as schools and faith-based groups, than when offered as a temporary provision for special children.
- Children living in communities affected by HIV/AIDS do not necessarily need psychological assistance. Most children, all over the world, affected by many different types of challenges, cope because they receive protection, care and support from affectionate and caring adults in their networks of kin and kith. In all instances, front-line support needs to be directed at adults in these networks to enable them to protect and care for children. **Efforts to normalise children's environments, routines, friendship groups, school attendance and daily activities has been found to be more helpful to children in their efforts to cope than being given opportunities by strangers to talk about their feelings.** Resumption of, and participation in, daily life with familiar adults and peers provides children with security and reassurance. It is sometimes necessary to support and advise adults to give children opportunities to ask questions and have them answered sensitively, honestly and in ways that are appropriate to a child's level of understanding. Involving children in efforts to help, and assigning them with appropriate tasks and responsibilities, also enable children to better manage their distress[86].
- Current information concerning the link between children's vulnerability and HIV indicates that orphans may be at particular risk of HIV infection due to an earlier onset of sexual activity, a higher likelihood of sexual exploitation and abuse, isolation and stigmatisation – all probably emanating from weak adult protection (see Figure 8 below)[87]. In particular, young girls and women may be more vulnerable to adverse reproductive health outcomes, and this risk is increased for girls and young women in poorer households and in situations of tenuous or reduced education[88], including out-of school children and youth[89].

While there are many programmes that link adolescent reproductive and sexual health, including HIV/AIDS, with broader youth development goals, there are no specific services and information directed towards communities, schools, caregivers and young people, to prevent all children, including orphaned and vulnerable children, from becoming infected. Issues of HIV/AIDS prevention are mainstreamed into adolescent reproductive and sexual health programmes and services[90]. In the same way, while violation of sexual and human rights are covered in OVC policies, the dissemination of information on sexual reproductive health and the implementation of legislation and practices to curb violence and sexual abuse of children is made in reference to all children[91].

Figure 8: Interactions between poverty, bereavement, stigma, and HIV risk



Source: Clay, Bond, & Nyblade. (2003)

6. Key Recommendations: Enacting rights-based programming for children living in communities affected by HIV/AIDS

Rights-based approaches can rectify many of the distortions that have arisen from a crisis-driven response to children living in communities affected by HIV/AIDS, poverty and conflict, and can provide a beacon for how to move forward. The underlying principles of universality, indivisibility, responsibility, and participation provide a firm foundation for framing priorities and responses to vulnerable children and families. However, direction and clarity need to be brought to rights-based programming for children, especially in the context of HIV/AIDS. The recommendations below highlight key principles and issues that should guide interventions aimed at the protection and care of children living in communities affected by HIV/AIDS.

6.1 Building Resilience:

Responses to HIV/AIDS should be holistic covering all aspects of prevention, treatment, and care, and strive to fulfil the rights of all children.

- Programmes should propose a continuum of responses to children living in communities affected by HIV/AIDS: at one end of the continuum, specific assistance must be provided for the relatively small number of extremely vulnerable children and their families, whilst at the other end, there is a need to advocate for strengthening of government systems that ensure children's access to health, education, social security and legal services.
- Responses should include support to safety nets. Formal and informal safety nets protect children and families from the worst effects of poverty, HIV/AIDS, violence, and natural disasters. Formal safety nets can be created by governments and NGOs through price subsidies, public works programmes, food or microcredit programmes, and cash transfers to targeted households. Informal safety nets are made up of donations or exchanges of cash, food, clothing, informal loans, assistance with work or child-care, accommodation, and voluntary associations and solidarity groups who provide essential support to vulnerable households. These informal safety nets are created by relatives belonging to extended families, and by community members acting either individually or corporately.
- Responses should prioritise efforts to normalise children's environment and rou-

tines. Going to school regularly, engaging with other children, and being actively involved in social life and family are key to building resilience.

- Expertise should be drawn from work already done with other vulnerable children, such as children living and working on the streets, trafficked children, child victims of sexual exploitation, and others. As these groups face many of the same issues, the lessons learned from work carried out to assist them can be a good guide for responses to children living in communities affected by HIV/AIDS.
- HIV/AIDS prevention and mitigation should be integrated into programmes for children such as basic education, primary health care and general child protection initiatives.
- Children should be considered in those HIV/AIDS services that have traditionally focused on adults, including provision for and access to prevention of mother-to-child transmission programmes, voluntary counselling and testing, and anti-retroviral treatment as well as home-based care and in post-test support clubs and services.
- Stand-alone and one-off interventions are less helpful to children and families than integrated approaches through which health and nutrition, economic and food security, legal aid, psychosocial and spiritual support, educational assistance and other services are delivered.

6.2 Engage Government, Stakeholders, and the Children:

Efforts to support children are best directed at the care networks and other influences that surround children – families, schools, neighbourhoods, media, legislative framework, and policies that impact on children's lives.

- Children should be encouraged and supported to participate in community and programme interventions in a meaningful and ethical way.
- Links should be established with the private sector to increase their awareness and response to the spread and impact of HIV/AIDS. This engagement should encourage the private sector to complement and support informed holistic interventions.
- The media and public discourse should be re-orientated to ensure that national and international agendas focus more on how to lessen children's vulnerability rather than focusing exclusively on HIV/AIDS.
- Civil society organisations, in their role as watchdogs, should advocate and lobby for governments to allocate resources and ensure the development and implementation of policies, plans, and interventions specifically addressing children's issues, including children living in communities affected by HIV/AIDS.

6.3 Analysis-Based Strategic Interventions:

Programming should be strategic and prioritise interventions to address the most critical child rights violations based on child rights situation analyses.

- Responses should be coordinated between donors, international agencies, bi-lateral agencies, civil society, and government. Networks and forums should be supported to ensure more harmonised interventions.
- Agencies and organisations need to conduct situation analyses to identify which children are vulnerable in communities affected by HIV/AIDS and target their programmes accordingly – as opposed to limiting interventions to particular categories of children, such as orphans or child-headed households.
- Responses should be guided by a rights-based approach that identifies rights holders and duty bearers and looks at the inherent causes of rights violations, promoting formal responses such as policies and practice that focus on bringing about change in a sustainable and participatory way.

6.4 Addressing Discrimination:

Responses should recognise root causes of the spread and impact of HIV/AIDS, including gender inequality as a source of vulnerability. Programmes should address both men and boys and women and girls and tackle issues of masculinity, and sexual and reproductive health. The responses should also address children of different ages and in different contexts of the HIV/AIDS pandemic.

- Fathers and other male family members should be supported and encouraged to care for and provide guidance to children living in communities affected by HIV/AIDS, contrary to traditional gender roles.
- Men and boys should be promoted and encouraged in their roles as partners to contribute positively to mitigating the spread and effects of HIV/AIDS.
- Sexual and reproductive health rights should be integrated into programmes, policies, and plans that address children living in communities affected by HIV/AIDS and especially vulnerable children.
- The term *Children Living in Communities Affected by HIV/AIDS* should be used in order to avoid the stigmatising and victimising effects of terms such as *AIDS orphans or Orphans and Vulnerable Children.* The term Children Living in Communities Affected by HIV/AIDS also focuses on society's role in causing children's vulnerability and in protecting and caring for children.

- Responses should provide for varying responses for children of different ages, including the need to cater for the special vulnerability of young children. Young children are particularly affected by changes in and loss of primary caregivers and by changes to their customary care environment and their daily routines.

6.5 Focus on Care Givers:

All children need to be in a stable and caring relationship with at least one adult caregiver. This calls for a set of collective community and programme responses to strengthen caregivers' and households' commitments to the well-being of children, supported by constructive national policies, strong state welfare systems and the mobilisation of resources.

- Interventions should recognise that caregivers must fulfil two conditions. Firstly, they must care for and about the child in a way that motivates them to protect the child and provide for the child's needs in the best way possible under the circumstances. Secondly, the caregiver must have a long-term perspective of the child; that is, their care of the child must be guided, not only by the considerations of today or next week, but also by how this child will "turn out" as an adult.
- Caregivers should have opportunities to secure economic and social resources to provide for children's protection and care. Responses should address the critical material needs of AIDS-affected households, including those headed by HIV-positive parents and guardians, through access to social security, income-generating activities, work opportunities, vocational training, food, clothing, home repairs, school fees, and social support.
- Research findings attest to the fact that residential and institutional care is not always helpful for children and that interventions should rather shift to supporting family-based care initiatives. Family, friends, neighbours, communities and congregations are often the best equipped to provide the necessary care for children living in communities affected by HIV/AIDS. These community-based responses should be supported and coupled with monitoring systems to ensure children are not abused and families do not suffer unduly as a result of taking in child dependents.
- Responses should focus on mitigating parental death, reaching children living in communities affected by HIV/AIDS before they become orphans, and enabling caregivers living with HIV/AIDS to address their concerns about the future welfare of their children.

7. Appendix

Figure 9: Orphan estimates by type and cause, 2003

Table 1: Sub-Saharan Africa: Orphan estimates by type and cause, 2003

Country	All children 0-17 (thousands)	Total orphans as a percent of all children	Total number of orphans	Total number of orphans due to AIDS	Orphans due to AIDS as a percent of all orphans	Maternal orphans			Paternal orphans			Double orphans			Children orphaned in 2003
						AIDS	Non-AIDS	Total	AIDS	Non-AIDS	Total	AIDS	Non-AIDS	Total	
Angola	7,000	15%	1,000,000	110,000	11%	66,000	450,000	510,000	79,000	620,000	700,000	47,000	130,000	180,000	110,000
Benin	4,000	9%	340,000	34,000	10%	22,000	130,000	150,000	21,000	210,000	230,000	11,000	38,000	49,000	39,000
Botswana	650	20%	160,000	120,000	77%	110,000	20,000	130,000	78,000	23,000	99,000	62,000	2,000	64,000	24,000
Burkina Faso	8,000	11%	830,000	260,000	31%	190,000	270,000	460,000	160,000	370,000	530,000	130,000	38,000	160,000	89,000
Burundi	4,000	16%	660,000	200,000	31%	140,000	230,000	370,000	130,000	310,000	430,000	70,000	54,000	140,000	71,000
Cameroon	8,000	12%	930,000	240,000	26%	140,000	310,000	470,000	140,000	470,000	600,000	63,000	64,000	130,000	120,000
Central African Republic	2,000	14%	280,000	110,000	39%	62,000	81,000	140,000	71,000	120,000	190,000	46,000	17,000	63,000	34,000
Chad	4,000	12%	500,000	96,000	19%	65,000	170,000	240,000	69,000	280,000	340,000	35,000	40,000	76,000	41,000
Congo	2,000	13%	260,000	97,000	37%	65,000	70,000	140,000	66,000	110,000	170,000	33,000	14,000	47,000	29,000
Congo, Democratic Rep. of	24,000	17%	4,200,000	770,000	18%	570,000	1,600,000	2,200,000	490,000	2,300,000	2,800,000	370,000	430,000	770,000	480,000
Côte d'Ivoire	7,000	13%	940,000	310,000	33%	230,000	260,000	490,000	180,000	460,000	640,000	120,000	62,000	180,000	110,000
Djibouti	300	11%	33,000	5,000	15%	3,000	12,000	15,000	3,000	19,000	23,000	1,000	3,000	4,000	4,000
Equatorial Guinea*	250	12%	24,000					13,000			16,000			3,000	3,000
Eritrea	2,000	10%	200,000	39,000	17%	24,000	79,000	100,000	21,000	130,000	160,000	9,000	14,000	23,000	26,000
Ethiopia	35,000	11%	3,900,000	720,000	18%	460,000	1,400,000	1,800,000	410,000	2,100,000	2,400,000	190,000	270,000	460,000	470,000
Gabon	600	11%	57,000	14,000	24%	9,000	18,000	27,000	8,000	30,000	38,000	4,000	3,000	7,000	7,000
Gambia	500	9%	46,000	2,000	5%	1,000	17,000	18,000	1,000	30,000	31,000	500	4,000	4,000	5,000
Ghana	10,000	10%	1,000,000	170,000	17%	130,000	370,000	490,000	94,000	540,000	640,000	49,000	73,000	120,000	110,000
Guinea	4,000	10%	420,000	35,000	8%	24,000	180,000	200,000	22,000	260,000	280,000	14,000	48,000	59,000	46,000
Guinea-Bissau*	650	11%	81,000					36,000			56,000			11,000	10,000
Kenya	16,000	11%	1,700,000	650,000	37%	560,000	590,000	1,100,000	350,000	750,000	1,100,000	330,000	110,000	450,000	230,000
Lesotho	1,000	19%	180,000	100,000	56%	71,000	45,000	120,000	64,000	47,000	110,000	49,000	7,000	56,000	30,000
Liberia	2,000	13%	230,000	36,000	15%	27,000	92,000	120,000	24,000	130,000	160,000	17,000	23,000	40,000	28,000
Madagascar	9,000	11%	1,000,000	30,000	3%	17,000	460,000	480,000	17,000	640,000	660,000	7,000	120,000	130,000	110,000
Malawi	7,000	14%	1,000,000	500,000	49%	360,000	260,000	610,000	310,000	330,000	640,000	190,000	47,000	240,000	150,000
Mali	8,000	10%	730,000	75,000	10%	49,000	290,000	330,000	43,000	430,000	470,000	21,000	69,000	90,000	86,000
Mauritania	1,000	9%	140,000	2,000	1%	900	67,000	68,000	500	96,000	96,000	300	14,000	14,000	16,000
Mozambique	10,000	15%	1,500,000	470,000	31%	330,000	480,000	810,000	280,000	690,000	980,000	170,000	110,000	290,000	200,000
Namibia	1,000	13%	130,000	57,000	43%	41,000	30,000	71,000	33,000	40,000	73,000	19,000	3,000	24,000	21,000
Niger	6,000	11%	680,000	24,000	4%	14,000	340,000	350,000	13,000	420,000	430,000	6,000	66,000	71,000	80,000
Nigeria	69,000	10%	7,000,000	1,800,000	26%	1,300,000	2,400,000	3,650,000	1,000,000	3,300,000	4,400,000	490,000	430,000	930,000	870,000
Rwanda	4,000	17%	810,000	160,000	20%	140,000	370,000	510,000	130,000	420,000	550,000	120,000	120,000	240,000	65,000
Senegal	6,000	9%	450,000	17,000	4%	11,000	180,000	190,000	10,000	310,000	320,000	4,000	50,000	54,000	51,000
Sierra Leone*	2,000	14%	330,000					140,000			230,000			60,000	40,000
Somalia*	7,000	11%	770,000					340,000			510,000			84,000	94,000
South Africa	17,000	13%	2,200,000	1,100,000	49%	740,000	440,000	1,200,000	570,000	830,000	1,400,000	290,000	74,000	360,000	370,000
Sudan	16,000	9%	1,300,000	91,000	7%	63,000	520,000	570,000	49,000	840,000	890,000	18,000	99,000	120,000	150,000
Swaziland	500	18%	100,000	65,000	63%	48,000	21,000	69,000	42,000	24,000	66,000	29,000	3,000	32,000	17,000
Tanzania, United Republic of	14,000	14%	2,500,000	980,000	40%	710,000	650,000	1,400,000	580,000	1,000,000	1,600,000	370,000	130,000	500,000	310,000
Togo	2,000	9%	240,000	54,000	23%	37,000	74,000	110,000	38,000	130,000	160,000	18,000	17,000	34,000	31,000
Uganda	13,000	14%	2,000,000	940,000	46%	700,000	480,000	1,100,000	570,000	700,000	1,300,000	380,000	87,000	470,000	190,000
Zambia	6,000	19%	1,100,000	630,000	57%	510,000	200,000	710,000	500,000	200,000	670,000	290,000	38,000	330,000	130,000
Zimbabwe	7,000	19%	1,300,000	980,000	78%	650,000	130,000	940,000	640,000	190,000	740,000	430,000	14,000	440,000	160,000
Total	388,000	12.3%	43,400,000	12,300,000	28%	8,700,000	14,100,000	20,000,000	7,300,000	23,100,000	28,700,000	4,600,000	3,100,000	7,700,000	8,200,000

Note: Due to rounding, totals may not equal sum of column or row figures.
*These countries have insufficient HIV prevalence information to make an estimate of orphans due to AIDS.

Source: UNAIDS, UNICEF and USAID (2004). Children on the Brink 2004

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FOCUS AFRICA
For lasting change

Focus Africa is a collaborative initiative among Save the Children Sweden's three regional offices in Africa and the Head Office in Stockholm. The aims of the initiative are to enhance awareness among people in Sweden regarding the situation of children living in Africa, increase advocacy on children's rights in Africa and Sweden and to build Save the Children's own capacity through experience- and knowledge-sharing among the three African regional offices.

Focus Africa has four thematic areas of focus: HIV/AIDS, children in armed conflict and disasters, poverty and children's rights. The initiative cooperates with local partners and organisations in order to strengthen civil society and achieve lasting improvements in children's lives.

Lasting change must come from within, not from outside.

Save the Children Sweden is part of the International Save the Children Alliance, the world's leading child rights organisation. Save the Children Sweden has been present in Africa since the 1960s and our regional offices in Kenya, Senegal and South Africa provide support to more than 100 partner organisation in 27 African nations.

In order to achieve lasting progress, Save the Children Sweden uses four different approaches in our work. We gather information, listen to children and analyse their everyday reality. We provide direct service to children in need. We disperse our knowledge and experience to those with influence over children's conditions. We also conduct advocacy work at all levels, to make children's rights a reality.

Welcome to visit our child rights bookshop on the Internet, www.rb.se/bookshop

For further information contact:
Save the Children Sweden
SE – 107 88 Stockholm, Sweden
Phone + 46 8 698 90 00
info@rb.se, www.rb.se

Save the Children Sweden
East and Central Africa Regional Office
Box 19423
202 KNH – Nairobi, Kenya
Phone + 254 20 386 5888/90
info@ecaf.savethechildren.se

Save the Children Sweden
Southern Africa Regional Office
SAQA House, Floor 3
1067 Arcadia Street
0028, Hatfield, Pretoria
South Africa
Phone + 27 12 342 0222
postmaster@za.rb.se

Save the Children Suède
West Africa Regional Office
BP 25934, Dakar-Fann, Senegal
Phone + 221 869 18 00
savedakar@sentoo.sn

Save the Children fights for children's rights.
We deliver immediate and lasting
improvements to children's lives worldwide.