

**The role of the  
health sector in  
strengthening systems  
to support children's  
healthy development in  
communities affected  
by HIV/AIDS**

**A REVIEW**



World Health  
Organization

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## Preface

This document is a review of the scientific evidence and practice experience in providing what has come to be called psychosocial programming and support for children infected with and affected by HIV, and their caregivers. A great deal of attention is currently focused on psychosocial support programmes for children living in communities affected by HIV/AIDS. Psychosocial support programmes include a range of interventions such as awareness raising, counseling, group experiences for children, opportunities for recreation, and the like. However, several technical consultations, as well as the available evidence and experience, suggest that it is necessary, in the face of the combined effects of the HIV/AIDS epidemic and poverty, to support the psychosocial well-being of vulnerable children through as many avenues as possible. Efforts to promote the psychosocial well-being of vulnerable children require conditions and assistance that go beyond psychosocial support programmes, and there is now a strong call for integrated services to families and children affected by HIV/AIDS. Amongst these services, the health sector plays a critical role, in providing direct comprehensive services to affected children and families. However, health systems also have the potential to play a powerful indirect role by assisting and supporting community-based initiatives to provide assistance to the most affected children and their families.

This review covers the reasons for the shift in

focus from psychosocial support programmes to the psychosocial well-being of children, and from psychosocial support programmes to the need to strengthen services, especially health services. The psychological well-being of children is the outcome of many conditions and processes in addition to psychosocial support programmes. In addition, a broader and stronger response, emanating from and supported by the health sector has the potential to have a far greater impact on the psychosocial well-being of children than can be achieved with stand-alone psychosocial support programmes. Although the greatest wealth of research and experience comes from sub-Saharan Africa, because of the concentration of the epidemic in the region, the arguments made, evidence adduced and conclusions reached regarding the support of children are applicable to all contexts. The review takes as its starting point, the consensual strategies outlined in the *Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*. Access to services, including for health, is one of the five key strategies. Health services can assist vulnerable children and families, as well as provide the infrastructure, organizational capacity and integrative approaches needed to draw together the many efforts at the family and community level to respond to the hardships of children affected by HIV/AIDS, and their caregivers.

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## Executive summary

Children have not, to date, received due attention in the global effort to prevent, treat and ameliorate HIV/AIDS. The impact of the HIV/AIDS epidemic is experienced most severely at the household level because it severely exacerbates poverty and the supportive caregiving systems of families. The epidemic is having a progressive and cumulative effect on children by depleting their care resources through parental illness, death, destitution and an increased burden of care by families. This is occurring in a context of generally poor access to services and insufficient support from governments and the international community. In desperate attempts to be of assistance, uncoordinated and sometimes inappropriate actions are being taken to help vulnerable children. Much of the current effort is restricted to orphans, despite the fact that many other children are deeply affected by the epidemic and in very difficult circumstances. Under these conditions, there is widespread consensus that strengthening systems to support children living in communities affected by HIV/AIDS is the best option for achieving population-level improvements in children's health, psychosocial well-being, and educational development. The health sector is well placed, through its relatively systematic approach and infrastructure that reaches into most affected communities in developing countries, to lead multi-sectoral responses that facilitate the holistic care and protection of children living in communities affected by HIV/AIDS.

The lives of all children living in communities affected by HIV/AIDS are becoming difficult. Amongst these, sub-groups of children are affected in particular ways. These sub-groups include children infected with HIV, children living with chronically ill parents, orphaned children, and other categories of vulnerable children. Infected children, especially young children, have received little attention to date, and most children living with HIV/AIDS die prematurely from poverty-related diseases, as well as lack of access to appropriate treatment and support. The

greatest proportion of children born to parents living with HIV/AIDS are, themselves, uninfected. In general, though, the survival and development of these children is precarious. Most children will outlive their caregivers, bearing a large portion of the burden of care for a chronically ill parent, and/or suffering the resulting family deprivation. Children who have to care for ill parents or suffer neglect as a result of the incapacitation and disability of parental illness, and children in families which foster in affected children are themselves additionally prone to poverty and even destitution. However, many of these children remain invisible to the best resourced organizations, who limit the greatest part of their resources and intervention efforts to orphaned children, not all of whom are vulnerable. Because of the way orphans are identified in the context of the AIDS epidemic, as maternal, paternal or double orphans, the majority of orphans have, and are living with surviving parents; many others are in the care of close and affectionate family and need little additional assistance. Only time heals the terrible experience of losing a parent during childhood. The families that take them in, however, have to stretch their meagre resources among increasing dependents, and caregivers are often desperately in need of material, social and spiritual support. Many children are doubly disadvantaged by HIV/AIDS, co-occurring as it does with widespread poverty, as well as conflict and instability. There is a danger that programmes that target only orphans may inadvertently undermine spontaneous care by extended kin, misdirect resources to children who may not need additional external assistance, and overlook large numbers of extremely vulnerable children. In the main, what is needed is improved access of all children and families in AIDS-affected countries to health, education, social welfare, and economic strengthening to improve their health and psychosocial well-being.

Community initiatives and extended kin were the first to respond to the needs of affected



children, and continue to be in the front line. The emergence of community-based care programmes is one of the outstanding features among responses to the epidemic. These groups play a critical role in easing the impacts of the epidemic, particularly on children. Extended families absorb the largest portion of the economic costs of the epidemic on households, and effective mechanisms need to be developed to get additional resources to families and communities to enable them to continue to support the worst affected children. The fact that families are absorbing the care of affected children does not mean, however, that they are doing so without tremendous difficulty. The involvement of faith-based organizations has enormous potential to alleviate suffering and needs to be recognized, supported and expanded. International agencies and governments have been slower to generate responses, beyond policy, that match the size and time scale of the problems affecting children and families.

In 2004, an outstanding policy document was released, entitled the *Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*. The Framework, endorsed by 23 of the leading agencies in the field, built on several previous documents, under the title "Children on the Brink" (1997, 2000, 2004) The document is a consensual, authoritative statement of strategy that takes into account available knowledge and experience to date, and was developed through a consultative process that took place over several years. The Framework recommends a comprehensive approach to affected children, including efforts to support children's healthy development. In particular, the Framework draws attention to the importance of sustaining families and extended kin in their key roles of caring for and protecting children. Despite this strong conclusion, few resources are reaching families and communities, especially households that are already on the edge of destitution. One of the major challenges facing efforts by international and local governments, donors and philanthropic organizations, is the development of mechanisms for channeling resources to grassroots organizations and to deeply impoverished families.

The distress experienced by children is well recognized, as is the negative impact of the AIDS epidemic on their development, particularly as a result of unstable caregiving, inadequate nutrition, lack of access to health care, and exclusion from education. While efforts to support the healthy development of children in communi-

ties affected by HIV/AIDS are essential, separate programmes to address children's psychosocial needs may not be the optimum use of resources. Support from families and communities, and also from peers, enable children to cope with extremely difficult circumstances. A key strategy to support children's psychosocial well-being is to promote care as part of their everyday life. Parents and caregivers may need support to enable them to provide care and protection for children. Children have a multiplicity of needs, and there are age differences in the kind of support children require. The affectionate care of families and communities is the only effective and sustainable way of ensuring children's well-being. Stand-alone psychosocial interventions for children can be seen as foreign and may be experienced as an imposition. They may also be too narrowly focused to meet the needs of children identified as vulnerable. For these reasons, there is agreement that measures to support children's healthy growth and psychosocial well-being should be incorporated into other programmatic responses to the HIV/AIDS epidemic. The available evidence and experience strongly cautions against specialized psychosocial programmes for "AIDS orphans". Such efforts may increase isolation and stigmatization. Lessons learnt in other fields of intervention indicate that efforts to promote children's psychosocial well-being in the face of adversity require that care systems around the child be mobilized and strengthened in an integrated way. This is consistent with what is called a rights-based approach to children. It is especially important to counter the institutionalization of vulnerable children. Institutional care does not benefit children, and can harm especially young children. In addition, institutionalization is expensive and draws resources away from efforts to support families and communities who take in vulnerable children.

To date, the health sector has paid little attention to the situation of children living with, and affected by HIV/AIDS, especially young children. Both anti-retroviral and prevention of mother-to-child programmes must be expanded. These programmes have the potential to strengthen the health care system, in general, and services for children, in particular. Both need to be extended to promote the healthy development of young uninfected children who are living with HIV-positive parents, and appropriate care and treatment for children living with HIV/AIDS. In the current climate, there are clear advantages for the health sector to lead a comprehensive primary

care approach to children living in communities affected by HIV/AIDS. These advantages include a holistic view of health that accommodates a multi-sectoral response; a strong emphasis on children, especially young children; considerable infrastructure and reach relative to other services, as well as influence on national agendas. At a local level, health services, together with schools, could establish strong linkages with community-based initiatives to form Community Care Coalitions for children made vulnerable by the epidemic. Health services have a long history in programmes to strengthen health, school and community efforts to prevent and treat illness, support vulnerable children and promote their growth and development. In particular, the Integrated Management of Childhood Illness (IMCI) is a health facility and community initiative that fits well with several other approaches deemed to benefit vulnerable children, including Comprehensive Primary Health Care, the UNAIDS-led *Framework*, and the concept of Community Care Coalitions. What is needed is leadership from the health sector for the development of integrated models; tools

for assessment, implementation and evaluation; training programmes; and pilot projects, to take this forward.

The recommendations offered are that the health sector play the following roles in responding to children living in communities affected by HIV/AIDS:

1. Lead a holistic response to children in communities affected by AIDS that is founded on the UNAIDS/WHO *Framework*.
2. Use the *Framework* to promote integrated responses to children based on knowledge and experience gained within WHO, by partners and by countries.
3. Promote health centres as nodes of support, working together with community initiatives on the common agenda articulated by the *Framework* to support children and families.
4. Strengthen the community component of IMCI and ensure that it is used to organize and coordinate health sector responses to children in communities affected by HIV/AIDS.

# Chapter 1

## Introduction

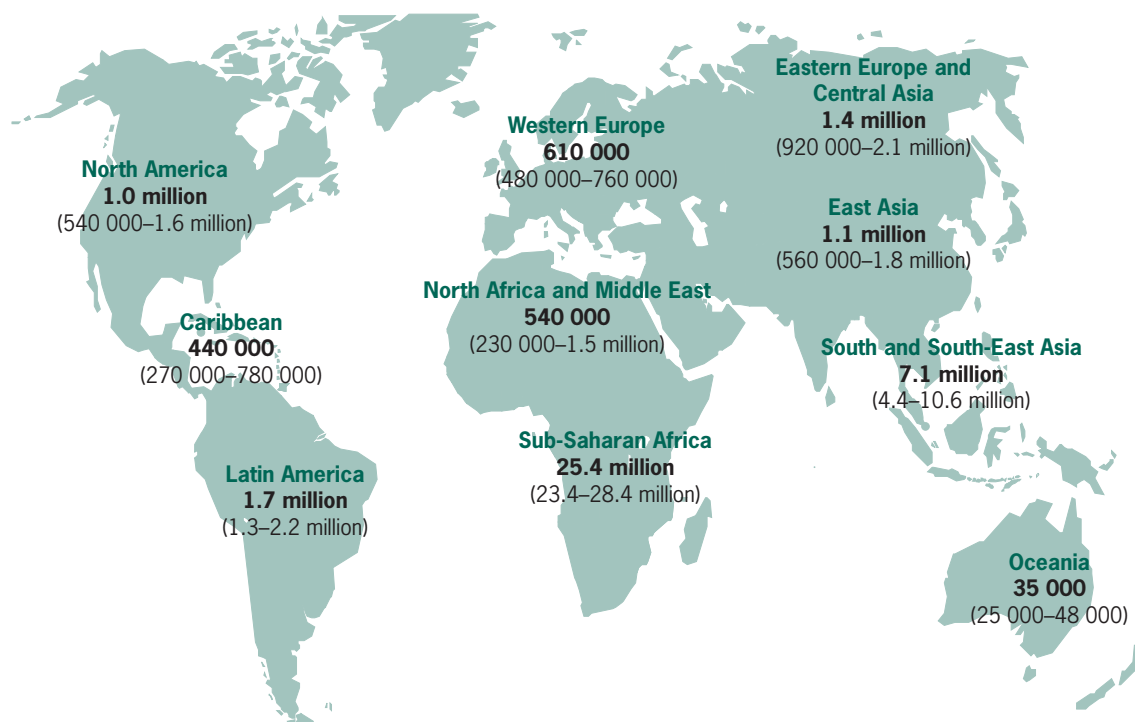
According to the annual *AIDS Epidemic Update*, published by UNAIDS/WHO in December 2004, close to 40 million people worldwide have been infected with HIV, and more than 3 million people died of AIDS during 2004 (see Figures 1 and 2). The vast majority of infections, serious illness and deaths occur in poor countries. Further, infections and deaths peak in adults during their most productive years, when they are most likely to have young children, and also responsibility for the care and support of dependent family members, including the aged. The impact of advanced epidemics is currently being most severely experienced as a crisis of care for children, sick people, aged and other vulnerable groups. Employment and livelihood activities are being lost, and social networks of support among families and communities are being weakened as disproportionately large numbers of middle-

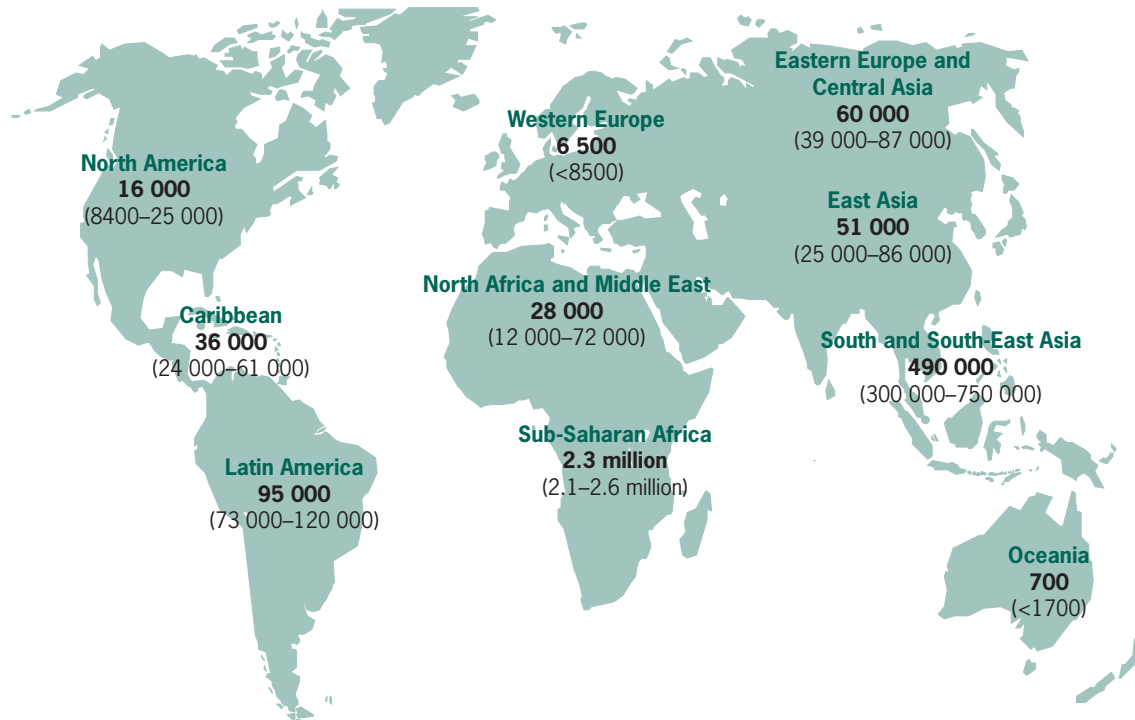
generation adults become ill and die (Marais, 2005). The impact of the epidemic is experienced most severely at the household level because it exacerbates poverty (Heywood, 2004). As noted in the 2004 UNAIDS Report, the living conditions of many poor communities were already on the decline when they began to experience illness and death due to AIDS. In these households, the major share of scarce resources is diverted to medical and funeral costs (Steinberg et al, 2002).

The difficulties experienced by children, caregivers and families living in communities affected by AIDS are increasing dramatically

The impact of the epidemic is experienced most severely at the household level because it severely exacerbates poverty.

Figure 1. Adults and children estimated to be living with HIV as of end 2004



**Figure 2. Estimated adult and child deaths from AIDS during 2004**

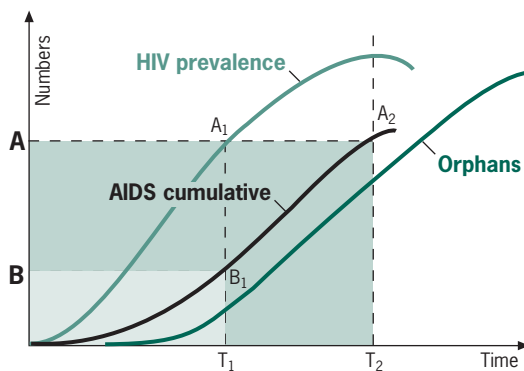
as the epidemic matures and deaths increase (Bedri et al, 1995; Nyambedha et al, 2001; Shetty & Powell, 2003). Under these conditions, the worst affected children experience multiple losses. They lose:

- their health and vitality, through infection, inadequate nutrition, and poor health care;
- their 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;
- their parents and other primary caregivers to illness and death;
- their families, as they are parted from caregivers and siblings because of distress mobility and migration;
- their connections to social institutions as a result of stigma in the community and withdrawal from school because of poverty, lack of supervision, and work obligations in the home, and
- their human right to development in an environment that meets their basic needs for health, education, care and protection (NEPAD et al, 2004).

The impact of the AIDS epidemic on children and families is frequently illustrated by the increase in orphaning, often referred to as the third wave of the epidemic, following infections and AIDS deaths (Foster & Williamson, 2000; World Bank & UNICEF, 2002). Orphaning, defined as a child under the age of 18 years who has lost one or both parents (UNAIDS, UNICEF, USAID, 2004), is one of the basic metrics by which the stage of the AIDS epidemic is visualised. Figure 3 shows three curves. The first curve represents HIV prevalence and, because of the long incubation period, AIDS cases lag behind by 5–10 years. People with AIDS illness need treatment and care, and will die unless dramatic changes in the effectiveness, availability and cost of treatment occur. The third curve represents AIDS impact. This includes the death of young adults, orphaning, loss of work and livelihoods, and the deepening of poverty. However, in considering the impact of HIV/AIDS on children, two points need to be taken into account – firstly, HIV/AIDS is not the only cause of orphaning in some of the worst affected countries and, secondly, a focus on orphaning is misleading because the impact of the epidemic on children goes beyond orphans.

An analysis of survey data in 40 countries concluded that “orphanhood is common in sub-Saharan Africa, irrespective of the AIDS epidemic”

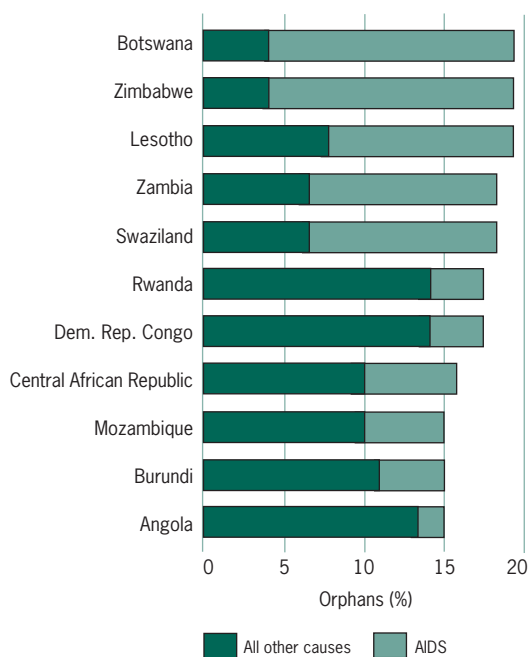
**Figure 3. Prevalence, case and impact curves of the epidemic**



(Monasch & Boerma, 2004, p. 565). Figure 4 shows the estimated proportion of orphaning among children attributable to AIDS as compared to other causes, in selected sub-Saharan countries. The figure illustrates the increase in orphaning due to AIDS, as well as the fact that large proportions of children in this region are also orphaned as a result of widespread conflict and endemic poverty.

As indicated above, the impact of HIV/AIDS goes beyond orphaning. Very large numbers of children are affected by the AIDS epidemic – greatly in excess of estimates of the numbers of

**Figure 4. Causes of orphaning in 11 countries in sub-Saharan Africa in which more than 15% of all children were orphans in 2003**



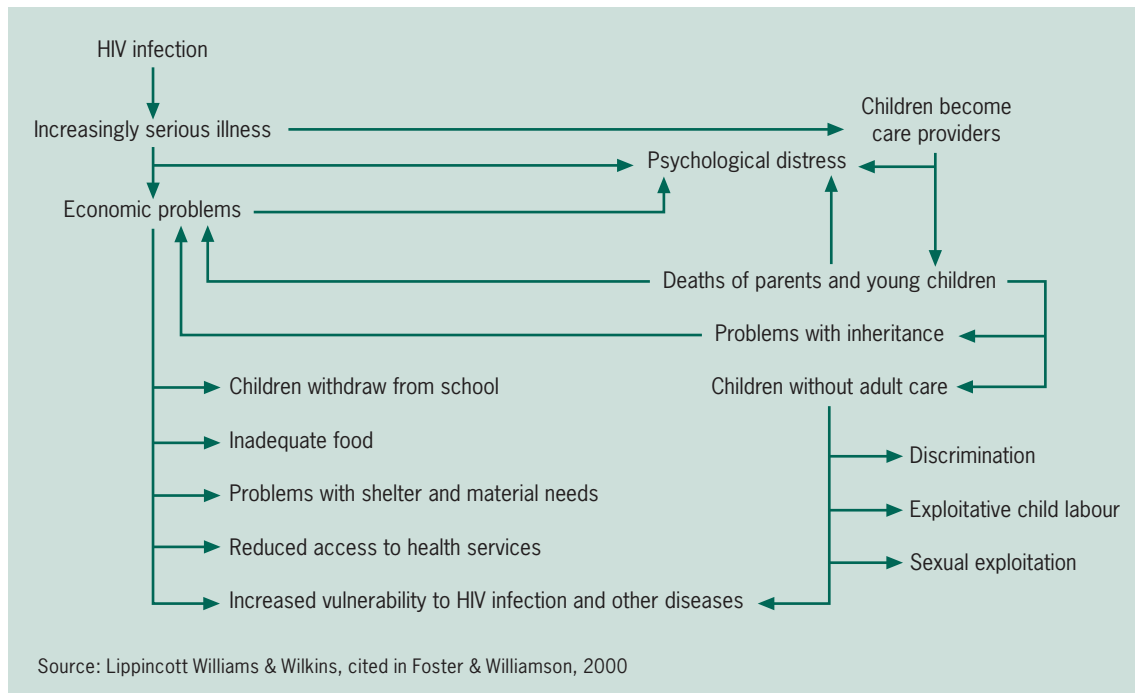
children orphaned. For example, in South Africa in 2001, just over 600 000 children were recorded in the Census as having lost both parents. However, given fertility and HIV prevalence rates at the time, it can be estimated that more than 2.5 million South African children had a mother who was alive, but infected with HIV. Without effective treatment, these children are at risk, in years to come, of a deteriorating quality of life as an increasing share of household resources, including emotional and social support, are directed to assisting one or more sick adults and eventually burying them, mostly at the expense of children’s nutrition, health and schooling. Other impacts of the epidemic on children, many of which are recurrent and progressive, are outlined in more detail in Chapter 2.

Catastrophic predictions of widespread pathology, violence and social disorder associated with high levels of orphaning have been tempered by sober analyses (Bray, 2003; Richter, 2004a). Nonetheless, many children in communities affected by HIV/AIDS suffer significant health, educational, social and personal disadvantages, including deepening poverty, premature termination of their education, residential instability and psychosocial distress (Dunn 2005a; Foster & Germann, 2002; Foster & Williamson, 2000; Richter et al, 2004; Sherr 2005a; Williamson, 2000). These effects, consequent on both caregiver/parent illness and death, are illustrated in Figure 5.

Children have not, to date, received due attention in the global effort to prevent, treat and ameliorate HIV/AIDS. The difficulties experienced by children are increasing as the epidemic matures. These are indexed by increasing child mortality, lower school attendance and achievement levels (Birdthistle, 2004), as well as the decline of human and social capital in families and communities. These trends indicate that country-level development goals are being severely compromised in the worst affected countries (Deininger, Garcia & Subbarao, 2003). It is also clear that the problems experienced by children and families are not one-dimensional. Children are affected by the epidemic in many ways, requiring the coordination of all sectors to ensure that children’s health and well-being are protected.

The impact of HIV/AIDS on children overlaps to a considerable degree with the known effects of poverty on children (Richter, 2004a; Richter et al, 2004). This is especially because HIV/AIDS impacts on household livelihoods, and because of a lack of essential services in resource-poor environments. Established measures of child

**Figure 5. Problems among children and families affected by HIV/AIDS**



vulnerability exist in other sectors outside the HIV/AIDS field that are strongly correlated with poverty. For example, a substantial number of children living in Africa lack access to health care, are malnourished, out-of-school or are involved in excessive forms of child labour. Such large numbers of vulnerable children provides the rationale for strengthening systems that improve the situation of all children living in communities affected by HIV and AIDS to complement programmes that support the most vulnerable children

There are also important lessons to be learnt from work done on the effects of war and vio-

lence on children (Tolfree, 2004). Nonetheless, the AIDS epidemic is unique in its effects on children in several respects. Firstly, HIV/AIDS illness and death accelerate poverty and occasion often multiple, compressed shocks to economic activities and livelihoods, family life and children. Secondly, children may experience sequential losses of caregivers as first one parent, another, other caregivers, and also aged grandparents die. This can lead to a high degree of instability in their residential circumstances and relationship with caregivers (Hosegood et al, 2004). Thirdly, AIDS remains a highly stigmatised condition that can result in social exclusion and rejection of surviving children. While the term *AIDS orphan* is frequently used as a rallying cry to mobilise resources for children affected by AIDS, it also labels children in inappropriate ways and forces young survivors to bear the brunt of widespread AIDS stigmatisation. Because of secondary, problematic effects of labelling individuals, rather

While the term *AIDS orphan* is frequently used as a rallying cry to mobilise resources for children affected by AIDS, it also labels children in inappropriate ways and forces young survivors to bear the brunt of widespread AIDS stigmatisation.

**Figure 6. Vulnerability of children in sub-Saharan Africa**

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

Source: The State of the World's Children, 2006

than their condition or circumstance, we advocate the use of the term *children living in communities affected by HIV/AIDS* (abbreviated as CCA) as a general term for all categories of children affected by the epidemic.

Throughout the world, the mainstay of assistance for children living in communities affected by AIDS comes from their families and communities (Foster, 2005a). Surviving parents, extended kin, especially grandmothers (Nyambedha et al, 2003a, 2003b), older siblings, neighbours, faith-based and other community care groups, are the primary source of support for almost all children and families living in communities affected by AIDS. Community-based, non-governmental organizations have adapted, and have been formed, to provide assistance for affected children and families. Beyond these, local, national and international governmental and non-governmental programmes have been developed to address one or more of the problems that affect children in particular. In the main though, these efforts are highly localised, with very wide gaps between programmes. The largest number of children and families receive no external help at all.

While innovative approaches have been developed and implemented to assist individual children and families, including to support children's psychosocial development (Richter et al, 2004), large scale, universal, interventions, underpinned by government policy together with international support, are needed to have any significant effect on the well-being of the very large number of affected children over the long haul of the epidemic (Williamson, 2000). Given the explosive and widespread nature of the HIV/AIDS epidemic, and its propensity to disrupt families, communities and developmental gains achieved through socio-economic development, interventions to respond to the psychosocial and educational needs of children have to match the scale and gravity of the challenges that confront children's development. There is widespread consensus that strengthening systems to support children living in communities affected by HIV/AIDS is the best option for achieving population

level improvements in children's health, their psychosocial well-being and their educational development (Richter, 2004a; Richter et al, 2004; UNAIDS, UNICEF, USAID, 2004).

The problems facing AIDS-affected children and their families are many and varied. Since a single kind of intervention is unlikely to produce significant, sustained improvements in their well-being, what is needed is a set of collective programme responses to strengthen affected households and communities, supported by constructive national policies and the mobilization of resources. The *Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* (UNAIDS, UNICEF & USAID, 2004) provides a broad range of stakeholders from all sectors of society with a set of strategies that can improve the care and protection of vulnerable children. Though the range of responses that are needed for children affected by HIV/AIDS are outlined in the Framework, there is, in general, a lack of strategic analysis of the ways in which such support can be mobilised and provided. Up to now, the health sector has played a very limited role in providing or facilitating care and support for increasing numbers of vulnerable children. However, the health sector is well placed – by utilizing its systems approach and an infrastructure that reaches into most affected communities in developing countries – to lead multi-sectoral responses that facilitate the holistic care and protection of children living in communities affected by HIV/AIDS.

... the health sector is well placed, by utilizing its systems approach and an infrastructure that reaches into most affected communities in developing countries, to lead multi-sectoral responses that facilitate the holistic care and protection of children living in communities affected by HIV/AIDS.

No child should be deprived of access to effective health services (Article 24) ... The child has the right to benefit from social security (Article 26) ... it is the State's duty to ensure that primary education is free and compulsory (Article 28).

There is widespread consensus that strengthening systems to support children living in communities affected by HIV/AIDS is the best option for achieving population level improvements in children's health, their psychosocial well-being and their educational development.

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cally address children's rights to essential services.

The HIV/AIDS pandemic provides an unparalleled opportunity to advance systems to promote the health and protection of vulnerable children in communities affected by HIV/AIDS. Increasing global and national resources are being made available to strengthen responses to children affected by HIV/AIDS. The current proliferation of grassroots initiatives in mitigation of the consequences of HIV/AIDS on children provides another window of opportunity. The health sector is uniquely placed to utilize HIV/AIDS resources to strengthen health, education and community efforts to improve the healthy development of all children, as envisaged in the definition of health advocated by the World Health Organization.<sup>1</sup> The health sector can play a critical role in supporting and strengthening policies and programmes to ensure that most vulnerable children have access to preventive, promotive and curative services, and that reinforce grassroots responses to the increasing numbers of orphans and vulnerable children in distressed families.

### Summary

The HIV/AIDS epidemic is at different stages around the world. In most sub-Saharan countries, the epidemic is fully into its third stage, most apparent in the increasing need for the care of sick and vulnerable individuals, including children. The way in which the epidemic has intensified poverty is experienced most severely at the household level and children are affected in multiple ways.

Orphaning, which is increasing very rapidly as parents and other caregivers die, is only one facet of the impact of HIV/AIDS on children. Children themselves living with HIV/AIDS or

with one or more chronically ill adults, or who take on adult responsibilities and who share their family's meagre resources with kin children taken into their household, are all affected by the epidemic. Many children in communities affected by HIV/AIDS suffer significant health, educational, social and personal disadvantages, including deepening poverty, premature termination of their education, residential instability and psychosocial distress. Under these conditions, programmes that specifically target orphans are in danger of stigmatising affected children and placing them at risk of community and family reprisal. In addition, very many other vulnerable children are likely to be overlooked.

Many affected families receive no formal assistance from external agencies, and their survival depends on the support they receive from kin, neighbours and community groups that have formed to give help to the worst affected households. It is a case of the poor helping the destitute, with little direct aid from governments, or international and national organizations. Deepening poverty is compromising national development achievements as well as any hope of meeting the Millennium Development Goals.

In the face of the scale and anticipated duration of the AIDS epidemic, there is widespread consensus that strengthening systems to support children is the best option for achieving population level improvements in children's health, their psychosocial wellbeing and their educational development. This is consistent with a right-based approach to child wellbeing. The health sector is well placed, by utilizing its systems approach and an infrastructure that reaches into most affected communities in developing countries, to lead multi-sectoral responses that facilitate the holistic care and protection of children living in communities affected by HIV/AIDS.

<sup>1</sup> World Health Organization (1948). Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19–22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.



## Chapter 2

# Impacts of HIV/AIDS on children

The AIDS epidemic is resulting in unprecedented welfare problems for massive numbers of families that affect children in a number of ways. Although potentially overlapping, several categories of children affected by the HIV/AIDS epidemic can be discerned. As indicated previously, though, these categories of children are best referred to collectively as children living in communities affected by HIV/AIDS (CCA).

### Children living with HIV/AIDS

Globally, there are 2.1 million children living with HIV/AIDS. The term “children living with HIV/AIDS” (CLHA) is recommended for this particular sub-group of children, because it conceptually links affected children with people living with HIV/AIDS (PLHA) and the rights-based PLHA movement. The term “HIV-infected children” is not used for the same reasons that led people living with HIV/AIDS to reject similar terminology – because it is stigmatizing. When used generally, the term “pediatric AIDS” leads to an over-emphasis on medical- and treatment-related issues at the expense of psychosocial and educational concerns in relation to children living with HIV/AIDS (Miller et al, 2005).

Children constitute 6 percent of people living with HIV worldwide, 13 percent of new HIV/AIDS infections and 17 percent of total HIV/AIDS deaths (UNAIDS, 2004b). In eight southern African countries between 2 and 4 percent of children under 15 years of age are HIV-positive (UNAIDS 2004b; UNICEF 2003). In five high HIV prevalence countries in

southern Africa, between one third and one half of deaths of children under five are from AIDS (Walker, 2002). Throughout the world, 10.8 mil-

lion children die each year before the age of five years, mostly from preventable causes and diseases that can be easily treated (Jones et al, 2003). Over half of deaths in children under five are associated with malnutrition (Jones et al, 2003). Similarly, 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 (ANECCA, 2004). At least 90% of HIV-infected children experience wasting and nutritional depletions during their course of illness (Bobat et al, 1998; Miller et al, 2005). Deaths from poverty-related diseases thus account for the extremely low life expectancy of CLHA in sub-Saharan Africa. In this severely affected region, most CLHA die before reaching the age of two years (Bobat et al, 1998; Newell et al, 2004). In comparison, the median survival time for CLHA in Western countries prior to the establishment of highly active anti-retroviral treatment was 11 years (Blanche et al, 1995; 1997). For this reason, public health measures to promote the health and well-being of all children in communities affected by HIV/AIDS is an important aspect of extending, and improving the quality of the lives of CLHA, together with paediatric antiretroviral treatment.

From the start of the epidemic, neuropsychological problems in HIV-infected and HIV-exposed children have been reported. These include developmental delays in one domain or another, cognitive anomalies, learning problems, and language difficulties (Armstrong et al, 1993; Sherr, 2005a, b). As with other biologically-triggered conditions in children, the severity of the manifestation and the degree of dysfunction the child shows is heavily dependent on the capacity of the care environment to provide counteractive influences. Where the developmental environment is supportive, as a consequence of material, social and personal resources, negative effects on behaviour and functioning are reduced (Coscia et al, 2001; Sameroff & Chandler, 1975).

Deaths from poverty-related diseases thus account for the extremely low life expectancy of children living with HIV/AIDS in sub-Saharan Africa

Only a few studies of neuropsychological functioning have been conducted among CLHA in severely AIDS-affected poor countries, and all have confirmed problems of one kind or another (Bell et al, 1997; Bobat et al, 2001; Boivin et al, 1995; Msellati et al, 1993). Given the strains on caregiving environments resulting from poverty as well as the impact of HIV/AIDS on families, it is likely that behavioural and cognitive impairments in CLHA will manifest. In turn, care for a sick, neurologically- or behaviourally-impaired child is likely to place very severe demands on caregivers

### Children living with HIV-positive parents

Around 80 percent of children born to HIV-positive mothers are uninfected at birth. Nonetheless, studies have found HIV-negative children born to HIV-positive mothers have higher mortality rates than other HIV-negative children in the community. Most children born to HIV-positive mothers reach five years of age or more before their mother dies (Nakiyingi et al, 2003). Uninfected children born to mothers with HIV infection are reported to have more attention, social adjustment and behaviour problems than comparison children (Nozyce, 1994; Kotchick et al, 1997; Peterson et al, 2001; Esposito et al, 1999). The mechanisms for the impact of maternal HIV infection on children remain to be elucidated. HIV infection may produce neuro-pathological dysfunctions in uninfected unborn children, directly as a result of the effects of human immunodeficiency virus or, indirectly, as a result of exposure to antiretroviral medications or to the mother's own psycho-neuro-immune responses to stress. Regardless of their cause, psycho-developmental effects on children are also likely to be mediated through compromised parenting and childcare practices associated with maternal HIV infection (Forsyth, 2003; Pelton & Forehand, 2005; Peterson et al, 2001). It is well established, in studies not involving HIV/AIDS, that maternal depression and lack of social support for caregivers have adverse effects on children's development, particularly in disadvantaged communities (Patel et al, 2004; Cooper & Murray, 1998). Increasing numbers of children of HIV-positive mothers also face challenges to the establishment of maternal-infant bonding and to their nutrition as a result of artificial feeding and early discontinuation of breastfeeding – both of which are among the recommended options in prevention of mother-to-child transmission pro-

grammes. In addition, large numbers of children both younger and older, are involved in caring for sick and dying parents, often with little outside help and in conditions of poverty, lacking water and sanitation (Keigher et al, 2005; Marcus, 1999; Sengendo & Nambi, 1997). The psychological and mental health impact of chronic parental illness is possibly one of the most poorly understood and neglected difficulties faced by children living in communities affected by HIV/AIDS in poor countries (Giese et al, 2003a).

The health and life situation of any woman is critical to the health and life chances of her children, not only during pregnancy, childbirth and the early months of life, but throughout childhood. A mother's capacity for child care, or that of another primary caregiver – the time and energy she can devote to her children, the conditions in the home, her material resources, her skills, knowledge and authority – all frame a child's passage from childhood to physical, social and emotional maturity. Whether or not an HIV-infected mother transmits the virus to one or more of her children, her infection, illness and early death from AIDS will have a profound impact on all of them. If she is the key provider of food, clothing and household amenities for her children, a mother's death has profound social and economic consequences for her orphaned children and for her husband if he survives, and her family. In addition to maternal effects, the presence of an HIV-positive sibling in the family may lead to parents' prioritising the needs of a chronically ill child to the neglect of their uninfected, relatively healthier, brothers and sisters.

The fact that there are in the region of 36 million prime-age adults worldwide living with HIV infection, is an indication that very large numbers of children live with HIV-positive parents. Around one-fifth of HIV-positive adults are urgently in need of antiretroviral treatment, suggesting that millions of children are living with one or both parents who are suffering from chronic illnesses in extremely difficult conditions with little help and support. Many children experience their first

**Around 80 percent of children born to HIV-positive mothers are uninfected at birth. Nonetheless, studies have found HIV-negative children born to HIV-positive mothers have higher mortality rates than other HIV-negative children in the community.**

impact of the epidemic with the onset of illness in their parent or caregiver. Children, very often girls, are forced to shoulder new responsibilities such as additional domestic chores, care of sick parents and relatives, income generating activities, and childcare duties for younger siblings. Educational, social, economic and psychological problems may increase during the terminal phases of parental illness and, for some children, ironically they may be relieved after the death of

their parent (Gilborn et al., 2001; Kelly, 2002; Sengendo & Nambi, 1997). It is therefore important to support children living with infected caregivers during the long period of suffering severe illness, as well as during their bereavement, and the many adjustments that will be

required of them thereafter. With the establishment of antiretroviral treatment (ART), the rate of increase in the number of orphans is likely to level off and decline, with a corresponding increase in the number of children living with HIV-positive parents.

### Children orphaned by HIV/AIDS:

The definition of an orphan used by UNAIDS/ UNICEF/USAID (2004) is a child under 18 years of age who has lost one or both parents. Because of widespread kinship care of children or fosterage, in many poor countries (Ainsworth, 1996; Madhavan, 2004; Monasch & Boerma, 2004), as well as father absence from households, this definition is frequently expanded to refer to a child less than 18 years of age who is without a living parent *available* to care for them. There is concern that the exclusion of fathers from some working definitions of orphaning reinforces the abdication of responsibility for their children's care by some men (World Bank & UNICEF, 2002) and underestimates the number of orphans (Foster & Williamson, 2000). Measuring orphaning in relation to biological parenthood simplifies the issue, but discounts the social reality of family and kin networks in many non-Western societies. In these societies, children are generally recognised and reared within a web of family obligations, as a result of which, care by a biological parent

may not have the same broad association with children's well-being as it does in the West (Hyde, 1993; Verhoef, 2002a). For example, Henderson (2003) notes that there isn't an African term for fostering because parenthood is understood to be potentially spread across a group of adults, rather than being confined to biological parenthood.

Orphaning is increasing at a rapid rate, in parallel with increasing adult mortality due to AIDS, especially in sub-Saharan Africa (Bicego et al, 2003). Overall, 12% of children in sub-Saharan Africa were orphans in 2003, with eleven countries in sub-Saharan Africa having orphan prevalence rates of 15 percent or more. In these countries, up to three-quarters of orphaning was the result of deaths of parents from AIDS. The pandemic is also leading to rapid increases in the number of orphans who have lost *both* parents, referred to as double orphans. During 1990 to 2010, the number of double orphans is expected to remain constant in Latin America and the Caribbean and will fall substantially in Asia. In the same period in sub-Saharan Africa, though, the number of double orphans will increase from 3.5 million to 9.6 million, representing 2.5% of the child population in the region (UNAIDS/ UNICEF/USAID, 2004).

As indicated before, children who are orphaned are not necessarily in need of additional assistance other than the stability, support and care provided by alternative caregivers, especially if this takes place in a close and affectionate family environment (Drew et al, 1998; Foster, 1996). A study in Malawi (Cook et al, 1998) found that community members did not view all orphans as vulnerable. Many praised the traditional support structures that enabled orphaned children to be taken in by the extended family. At the same time, however, they described how these traditional supports were being both overburdened and broken down with the increasing adult mortality rate caused by HIV/AIDS, as well as burgeoning poverty. The most common factors affecting an orphan's vulnerability described by participants in focus groups and ranked in order were, amongst others: children who have experienced multiple losses of people, especially over a short time;

The psychological and mental health impact of chronic parental illness is possibly one of the most poorly understood and neglected difficulties faced by children living in communities affected by HIV/AIDS in poor countries.

... children who are orphaned are not necessarily in need of additional assistance other than the stability, support and care provided by alternative caregivers, especially if this takes place in a close and affectionate family environment.

orphan-headed households; children who have lost their mother; girls; very young infants with no parents, and children with a disability.

A growing concern raised particularly in children's focus groups, is property grabbing following the death of a parent. Guardians and children feel victimized when relatives of the deceased person take all the valuables in the home (including the bricks and roof of the structure), sometimes immediately after the funeral (Roys, 1995). Teenagers were seen as being at risk due to the greater likelihood that they would drop out of school to care for younger siblings. Teenage girls were also identified as being at risk of becoming targets of sexual abuse from local adult males due to their emotional and economic vulnerability. Teenage orphaned boys, on the other hand, were described as being more likely to engage in risk-related behavior, including drug use, joining gangs, and attempting suicide (Cook et al, 1998). It is not known whether orphans are treated differently in families, and the research is equivocal on this point (Birdthistle, 2004; Case et al, 2004). However, several studies indicate that some orphans feel under stress, neglected and exploited (Atwine et al, 2005; Foster et al, 1997; Makame et al, 2002).

### Non-orphaned children living in households that foster orphans

The mainstay of the response to orphaned and vulnerable children is family fostering, a practice common in many countries predating the AIDS epidemic (Maharaj et al, 2000). Family fostering serves purposes of strengthening family ties by enabling children to live with aunts and uncles who are also regarded as parents, as well as distributing economic and other constraints and resources across the extended kin network (Verhoef, 2002a). HIV/AIDS has increased unplanned and sometimes inappropriate fostering (Nyambedha et al, 2001).

Poverty is exacerbated in many fostering households due to increased dependency ratios, and this affects the standard of living of the household, including the prospects of non-orphaned children (Deininger, Garcia & Subbarao, 2003; Madhavan, 2004). Children who live in households that foster orphans may suffer similar hardships to those experienced by orphaned children (Morgan, 2000). Studies suggest that it is only a minority of families that treat orphans significantly differently from their own biological children (Birdthistle, 2004). In general, relatives

go to considerable lengths to maintain children in school, borrowing through informal networks and selling assets where necessary, to keep fostered children in school (Foster 2002a; UNICEF Namibia, 2001). The number of non-orphaned children in households with orphaned children is difficult to calculate since few enumeration studies distinguish between orphan and non-orphan children living in the same household. In a predominantly urban area in Zimbabwe, a sample of 105 households was found to contain 221 orphans and 114 non-orphans under 15 years old (Foster et al, 1995). In a rural area of Uganda, 152 households contained 383 orphans and 342 other children (Monk, 2000). For every two orphans, one might therefore expect another one or two non-orphans to suffer from similar socio-economic deprivation.

### Other categories of vulnerable children

The term "children in especially difficult circumstances" was coined by UNICEF in the mid-1980's to describe the situation of particular groups of children that went beyond poverty – children with disabilities, children caught up in armed conflict and war, and exploited child labourers, as some examples. Since then, the term has been extended to other categories of vulnerable children, including orphans and children directly affected by HIV/AIDS. Children with disabilities, street children, children living in remote areas, working children, children in institutions, children living with chronically ill parents, and children in conflict zones may all be considered to be vulnerable children living in especially difficult circumstances. It is useful to consider all these groups together, because these conditions impact on children in similar ways and the appropriate programmatic responses to children in these conditions have a great deal in common. As a result of the HIV/AIDS pandemic, many of these children are doubly disadvantaged. A disproportionately high number of children in especially difficult circumstances are also being directly affected by HIV/AIDS. 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 (Save the Children, 2003; Foster 2005b). Street children and working children are often doubly affected in the same way (Mushingeh, 2002; FACT, 2000). The HIV/AIDS epidemic worsens the situation of

all children in affected communities, but children already vulnerable from other causes become especially vulnerable when affected by HIV/AIDS. These groups of vulnerable children may be exposed to additional disadvantage because the extraordinary levels of attention currently being given to so-called AIDS orphans is drawing resources away from interventions that support vulnerable children more generally.

### Children living in communities affected by HIV/AIDS

AIDS is affecting almost everyone in severely affected communities, even households without HIV-infected members (Goldenberg, 1996). Children in communities affected by HIV/AIDS experience changes to their quality of life when their teachers are absent from school (Baggaley et al, 1997), their parents provide money to support sick HIV-positive relatives, when their mother leaves home to provide care for AIDS-ill family members living elsewhere (Kelly, 2001), and when their household provides food, clothing or labour assistance to neighbours with chronically ill adults and orphans made destitute as a result of HIV/AIDS (Foster, 2005a). CCA also suffer the consequences of HIV/AIDS through other mechanisms – such as the weakening of social institutions and services as teachers, health service providers, civil servants and others become ill or are distracted by their responsibility for sick and dying relatives. As a result of these conditions, it is estimated that some 90 percent 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 (Catholic Relief Services, 2004).

While HIV/AIDS affects all children, it impacts girls and boys differently. This includes the patterns of HIV infection, school attendance, adoption, fostering, family responsibilities, economic inheritance, future prospects, coping and behaviour. The increased sensitivity to gender has drawn attention to the special needs of girls,

but the situation and vulnerabilities of boys are less often addressed. The age and maturity of a child also influences the way in which they are affected by the continuum of events occasioned by HIV/AIDS in families and households.

Currently, the international and policy response to vulnerable children affected by HIV/AIDS is predominantly focused on orphans. As previously argued, while the loss of a parent entails terrible suffering for children, in terms of programmatic responses, orphaned children may or may not be especially vulnerable compared to their peers. While some studies indicate that orphaning (loss of one or more biological parents), results in specific negative effects on children, such as a greater likelihood of not being in school, others suggest that deepening poverty associated with the loss of productive adults is the causal link between orphaning and disadvantage (Birdthistle, 2004; Lindblade et al, 2003). In a recent review of national surveys from 40 countries, no differences were found between orphans and non-orphans in terms of nutritional status and child work. Double orphans were less likely to be in school, but it wasn't possible to separate out the effects because they also lived in more disadvantaged households than other children (Monasch & Boerma, 2004).

In collective non-Western societies where there is family responsibility for the care of children, the term *orphan* literally translates to *a child who has no one to care for them* (Chirwa, 2002; Giese et al, 2003a). This is synonymous with an abandoned child without kin, a rare and shocking condition. Programmes that target orphans in the Western sense may inadvertently label children in potentially damaging ways, undermine spontaneous extended family care, misdirect resources to children who might not need external assistance, and overlook large numbers of vulnerable children who are not orphans. A focus on orphans, to the neglect of other vulnerable children, is known to be associated with the neglect and harassment of children who receive special treatment from external agencies, and this may be especially stigmatising when combined with the inappropriate identification of children as *AIDS orphans* (Stein, 2003; Urassa et al, 1997). The view that orphaning is the only, or even the major, problem of children affected by AIDS may also misdirect efforts towards individualistic interventions, such as the provision of alternative care for specific children. However, when it is appreciated that the AIDS epidemic impacts on the broader systems that constitutes children's caregiving niche,

Programmes that target orphans in the Western sense may inadvertently label children in damaging ways, undermine spontaneous extended family care, misdirect resources to children who might not need external assistance, and overlook large numbers of vulnerable children who are not orphans.

intervention efforts are more likely to be directed to support families and communities.

Changing terminology to refer to children affected by AIDS reflects an evolution in the understanding of the required programmatic responses to vulnerable children. The term *AIDS orphan* has been discarded internationally and it is unfortunate that it is maintained in the media and in some fundraising efforts. All authoritative organizations should strongly counter the use of the term. *Orphans and vulnerable children (OVC)* is also being less used in favour of more general terms such as *Children Affected by AIDS (CABA)*.

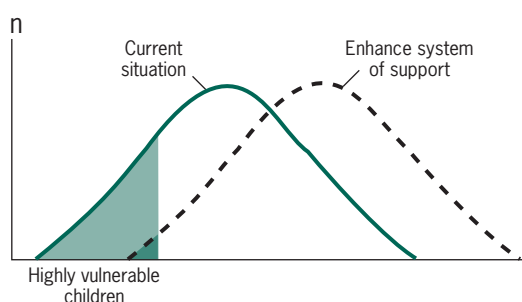
We recommend a collective term, not individualised to specific categories of children – *Children in Communities Affected by HIV/AIDS (CCA)*. The concept of children in communities affected by

HIV/AIDS helps to direct assistance to strengthening family and community systems, mainstream efforts to help, and justifies the integration of support work by different sectors.

What is needed is a continuum of responses to children living in communities affected by HIV/AIDS (see Figure 7). At the one end of the continuum, specific assistance must be provided for extremely vulnerable children, including children with severe disabilities, abused children, orphans without supportive extended family care, and abandoned and street children (the shaded portion of the curve on the left-hand side). In the main, though, improved access of all children in AIDS-affected countries to health, education and welfare provision is needed to shift the curve, representing the health and well-being of the child population, to the right (Committee on Evaluation of Children's Health, Board on Children Youth, and Families, 2004). As illustrated in Figure 7, this 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 for responding to the needs of vulnerable children than attempts to reach all such children through individualised services.

Such a “public health” response is justified by the very large numbers of children in severely AIDS-affected countries whose poor living

**Figure 7. Universal curve shift to improve children's health and well-being**



circumstances and limited access to services compromises their health and well-being. As indicated in Figure 7, large numbers of children are underweight, lack basic health care and are not immunized against disease, are not enrolled in school, and are engaged in child labour.<sup>1</sup> These circumstances form the backdrop to any additional impacts that HIV/AIDS, specifically, has on children's health and development.

### Summary

Children living in communities affected by AIDS – with CCA as the acronym – is a suggested umbrella term for several specific categories of children rendered especially vulnerable as a consequence of the epidemic.

Very large numbers of children in southern Africa are living with HIV/AIDS. Despite this, there is, as yet, little urgency in the response to calls for antiretroviral treatment for children. Deaths attributable to poverty-related diseases account for the extremely low life expectancy of children living with HIV/AIDS in sub-Saharan Africa. Children with HIV infection are also likely to suffer a number of difficulties and developmental delays that increase the burden of care provided by families.

Most children born to parents living with AIDS are uninfected. Nonetheless, these children suffer significant disadvantages. Preoccupation and ill-health negatively affects parenting. In addition,

<sup>1</sup> Between a third and a half of all children are underweight in the regions worst affected by AIDS; by 2000, immunization coverage, also as 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); the prevalence of child labour in Africa is estimated to be between 20 and 50 per cent (Andvig, 2003; Hope, 2005; UNICEF, 1997a; Rau, 2002).

All authoritative organizations, including within the health sector, should strongly counter the use of the term *AIDS orphan*.

tion, children are frequently forced to shoulder new responsibilities such as additional domestic chores, care giving responsibilities for sick parents and relatives, income generating activities and childcare duties for younger siblings. The psychological and mental health impact of chronic parental illness is possibly one of the most poorly understood and neglected difficulties faced by children living in communities affected by HIV/AIDS in poor countries.

Orphaning is increasing at a rapid rate, in parallel with increasing adult mortality due to AIDS, especially in sub-Saharan Africa. Children orphaned as a result of HIV/AIDS and/or other diseases and injuries – frequently poverty-related – suffer the pain of losing their parents. However, they are not necessarily in need of more assistance than other groups of vulnerable children. What is important is that they are afforded stability, support and care provided by alternative caregivers, especially in close and affectionate family environments.

The mainstay of the response to orphaned and vulnerable children is family fostering, a practice common in the southern African region, long predating the AIDS epidemic. Poverty is exacerbated in many fostering households due to increased dependency ratios. Children who live in households that foster orphans may suffer similar hardships to those experienced by orphaned children.

Other groups of children especially affected by the epidemic include children with disabilities, street children, children living in remote areas, working children, children in institutions, children living with ill or disabled caregivers, and children in conflict zones. Children living in communities with high HIV/AIDS prevalence, as a result of which services and community morale suffer, are also disadvantaged.

Currently, the international and policy response to vulnerable children affected by HIV/AIDS is predominantly focused on orphans. Programmes that target orphans may inadvertently undermine spontaneous family care by extended kin, misdirect resources to children who might not need external assistance, overlook large numbers of vulnerable children who are not orphans, and prompt the neglect and harassment of children who receive special treatment from external agencies, especially when combined with the inappropriate categorisation of children as *AIDS orphans*.

What is needed is a continuum of responses to children living in communities affected by HIV/AIDS, which includes both specific assistance for the relatively small number of extremely vulnerable children, and improved access of all children in AIDS-affected countries to health, education and welfare provision. This is the optimum combination of rights-based and targeted approaches to children.

## Chapter 3

# Responses to children in communities affected by HIV/AIDS

Descriptions of the impact of AIDS on children in Africa first appeared in conference and research papers in the late 1980's (Beers et al, 1988; Ankrah, 1993; Barnett & Blaikie, 1992; Hunter, 1990; Preble, 1990a; 1990b; UNICEF, 1990). Academic articles provided estimates of the future scale of the orphan epidemic and described community-based assistance programmes (Bos, 1991; Chin, 1990; Hunter, 1990; Preble, 1990a, b). WHO and UNICEF were instrumental in disseminating research, documenting the problem, analysing responses and proposing remedies (UNICEF, 1990; WHO, 1990; WHO/UNICEF, 1994). However, these early writings did not translate into concerted international action. During the 1990's, the problem of children affected by AIDS had a low priority in UN agencies, development organisations, international NGOs and research bodies. Rather, it was local groups and organizations that developed programmes to support vulnerable children, and who called attention to the worsening situation of children living in communities affected by AIDS (Foster, 2002a).

### International responses to children in communities affected by HIV/AIDS

International responses to children affected by AIDS started to change with the publication of *Children on the Brink* by the US Agency for International Development. Hunter and Williamson documented the scale of the impending orphan crisis and proposed intervention strategies (1997). In 1998, the United States administration committed additional resources for an expanded international HIV/AIDS response, singling out the impact of AIDS on children for special attention.

During the past decade, international support for HIV/AIDS responses has significantly increased, with financial resources being earmarked to assist children and their families. HIV/AIDS funding for poorer countries totalled

\$300 million in 1996, increasing to \$1.7 billion in 2002 and \$4.7 billion in 2003 (UNAIDS, 2004b). In 2003, funding for orphans and vulnerable children (OVC) in severely affected African countries was \$200-\$300 million, whilst resources needed for a response to children were estimated to be \$600 million in 2004, increasing to \$2 billion by 2007 (Gutierrez & Bertozzi, 2004). The World Bank initiated its Multi-Country HIV and AIDS Programme for Africa (MAP) in 2000 and, by 2004, had approved projects worth \$1 billion. One half of funds were for non-government use. It is stated that MAP works with 30,000 community-based organizations and has built financial systems to enable one half of its resources to go directly to the community (Cashel, 2003; Wolfensohn, 2004).

The Global Fund, established in 2002, approved proposals totalling \$3 billion and made disbursements worth \$700 million, with 56 per cent allocated for HIV/AIDS. Some 16 of 82 proposals identified vulnerable children as a target group but only eight provided a strategy for providing support to vulnerable children. In 2004, the Global Fund recognized that children affected by AIDS were not receiving the attention they deserved and announced that one million orphans would be targeted through its funding systems (Save the Children, 2004a). In 2003, the United States government announced a five-year plan to provide care for ten million people affected by HIV/AIDS. Of the \$15 billion budget, ten percent was intended to help children affected by HIV/AIDS, with half the allocation to be channelled through non-profit and faith-based organizations (Otterman, 2003). In 2004, the British Government increased its funding for HIV/AIDS to £1.5 billion (about \$2.8 billion) over three years, with ten per cent to be spent on responses to the needs of orphans and other children made vulnerable by HIV/AIDS (DFID, 2004).

Based on *Children on the Brink*, several international agencies commenced a consultative process in 2000 that led to the publication of *The*



*Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* (UNAIDS/UNICEF/USAID, 2004). The Framework provides a broad range of stakeholders from all sectors of society with a set of strategies to improve the care and protection of vulnerable children, and it is adopted as a central aspect of the analyses and recommendations of this review.

Poverty Reduction Strategy Papers (PRSPs) and National Strategic HIV/AIDS Plans (NSPs) provide indications of the importance national policy makers attach to issues such as the relationship between HIV/AIDS and poverty, the role of communities, and the support of orphans and vulnerable children. PRSPs were introduced in 1999 to support national efforts to formulate effective growth and poverty reduction strategies. By mid-2004, PRSPs were implemented in 42 countries including 21 in sub-Saharan Africa. Most PRSP countries also have NSPs. An analysis of African PRSPs found that only Tanzania and Madagascar considered HIV/AIDS interventions as a key element in the fight against poverty. Around half of NSPs, and hardly any PRSPs, mentioned funding mechanisms. This is an important shortcoming in view of the need to provide resources for vulnerable children at the community level. The vulnerability of children was mentioned in only one-third of PRSPs and NSPs in Africa, with

**Until now, most interventions to support children have been piecemeal and have not matched the size of the problem. Urgent steps to scale up and replicate successful interventions are needed.**

only Senegal including an intervention targeting this group. No countries budgeted 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 (Bonnell et al., 2004).

Until now, most interventions to support children have been piecemeal and have not matched the size of the problem. Urgent steps to scale up and replicate successful interventions are needed. To do this, a number of steps are required, including conducting a participatory situation analysis, implementing a national policy for vulnerable children, establishing a national coordination mechanism to respond to the chal-

lenge of children affected by AIDS, implementing a national action plan for vulnerable children, and instituting monitoring activities based on indicators measuring the well-being of orphans and vulnerable children (UNAIDS, 2004b). Only a minority of countries with significant HIV epidemics have national policies for the protection of orphans and vulnerable children. By 2003, among the 21 countries in east and southern Africa, only Malawi, Rwanda and Zimbabwe had national OVC policies, though policy development was in progress in four other countries (UNICEF, 2003). 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. Translating the NPAs into actions that benefit vulnerable children will be difficult without properly scaled implementation plans, as well as the commitment of government to prioritise vulnerable children and to provide additional resources. In several countries, the RAAAP initiatives were limited by the lack of involvement of civil society organizations, the main implementers of OVC activities.

### **The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS**

As described earlier, a consultative process, begun in 2000, culminated in the publication of *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* (UNAIDS/WHO/ UNICEF/ USAID, 2004). The Framework, which builds on a series of reports entitled *Children on the Brink* (Hunter & Williamson, 1997; 2000; UNAIDS, WHO, UNICEF, USAID, 2004) provides a broad range of stakeholders from all sectors of society with a set of prioritised strategies to improve the care and protection of vulnerable children. The Framework is advanced against the background of what is known about efforts to provide care and protection to vulnerable children, and is based on lessons learned over nearly two decades of experience in the field of HIV/AIDS. The strategies proposed were subject to numerous consultations, and the publication is a consensual document, endorsed by 32 of the major agencies and organizations working in the field of HIV/AIDS, and widely accepted by groups working with vulnerable children. As a whole, the programmatic implications of the Framework are intended

to benefit children's health and psychosocial well-being. The Framework is the authoritative document on responses to children living in communities affected by HIV/AIDS, and the health

sector should use the Framework to structure its approach to supporting the healthy development of children living in communities affected by HIV/AIDS.

In June 2001, at the United Nations Special Session on

HIV/AIDS, countries resolved that, together with partners, they would:

By 2003, develop and by 2005 implement national policies and strategies to: build and strengthen government, family and community capacities to provide a supportive environment for orphans and boys and girls infected and affected by HIV/AIDS, including by providing appropriate counselling and psychosocial support; ensuring their enrolment in school and access to shelter, good nutrition, health and social services on an equal basis with other children; to protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance.

The UN General Assembly Special Session on Children ('A World Fit for Children') reaffirmed both the Millennium Development Goals and the 2001 Special Session goals specifically established for children affected by HIV/AIDS. While the international community appreciates the depth of the problem, responding to the crisis of children living in communities affected by HIV/AIDS is not yet seen as a global priority. The Framework is an attempt to take these declarations one step further and to lay out a common set of strategies to be achieved by the concerted effort of all partners.

The Framework draws attention to a number of shortcomings in programming approaches to date:

- Little attention is given to vulnerable children in most national development agendas, and government leadership, coordination and facilitation has, to date, been weak.
- Few resources are reaching families and communities who are providing the front-line response to provide care and protection for

children made vulnerable by the AIDS epidemic. This is especially true of households headed by women and the elderly, who are already on the edge of poverty;

- Interventions to benefit vulnerable children should be integrated into other programmes to promote children's welfare and reduce poverty;
- A much larger number of children than orphans are vulnerable to the impact of HIV/AIDS, as a result of poverty, armed conflict and child labour. For this reason, interventions should be directed to all vulnerable children. Targeting children living with HIV/AIDS or orphaned as a result of AIDS exacerbates the stigma and discrimination against them.

The Framework sets out five key strategies:

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

The rationale for this is that family relationships provide the most immediate source of support for children, and even street children tend to retain links with their families. "Families are the best hope for vulnerable children" (p. 15). The Framework notes, in accordance with the recommendation made in this review, that efforts to address psychosocial needs do not necessarily require separate programmes, but can be incorporated into other activities. In addition, the Framework urges that "a particular emphasis must be placed on integrated early development of children of preschool age, especially through efforts that focus on food and nutrition, health and development, psychosocial needs, day care and other key areas" (p. 17).

**2. Mobilize and support community-based responses.**

Given the scale and multidimensionality of the response needed, leaders and community groups

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need to take action to support and protect vulnerable children. The processes begin with people being more open and accepting about HIV/AIDS, organizing and assisting cooperative activities, and encouraging and supporting community care for children without family support.

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

Essential services are necessary for children's welfare and lack of access is a key component of children's vulnerability. Article 65 of the Declaration of Commitment of the UN Special Session on HIV/AIDS specifically calls for increased access to essential services for children living in communities affected by HIV/AIDS. Comprehensive local action plans are necessary to meet the service delivery needs of families and communities.

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

While the Framework recognises that no ministry has sole jurisdiction over the issues surrounding children living in communities affected by HIV/AIDS, it urges that "Governments must find ways to bring together ministries of education, finance, health, social welfare and others to respond in a coordinated and effective way to the many needs of children" (p. 24). Especially important are creative ways to strengthen social safety nets and to ensure that resources reach communities. "Governments need to establish more coherent systems and mechanisms that enable funds from multiple donors and sources to be channelled to affected communities" (p. 25).

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

This is especially important to reduce fear, ignorance, denial and stigmatisation of those most affected by the epidemic.

**Non-governmental and community-based organizations**

*International organizations*

Well before multinational agencies became involved in programmes to support children in

communities affected by HIV/AIDS, local activities began to emerge to assist vulnerable children and their families. Some of these arose spontaneously as concerned community members acted together in faith-based and other social groups to provide help to affected neighbours, while others were prompted by professionals working in the field. Community-based organizations were formed to organize, fund and extend these responses, and international humanitarian agencies, including Redd Barna, Save the Children (UK), World Vision and Terre des hommes supported these early initiatives.

In 1994 WHO and UNICEF pulled together lessons learnt from promising programmes around the world, noting that the pandemic was giving rise to a host of problems for children, and that responses would have to take account of the fact that the countries most affected by HIV/AIDS were also those simultaneously challenged by poverty, war and conflict, and natural disasters. Since that time, a number of international organizations, including AXIOS (2001), Family Health International (2001), the Interagency Coalition on AIDS and Development (2002), the International HIV/AIDS Alliance (2000), Save the Children (2003, 2004b), UNAIDS/UNICEF/USAID (2004), UNICEF (2004), USAID (2000, 2001, 2002, 2003, 2005), the World Bank (1999), World Bank/UNICEF, (2004) and World Vision (2002) have drawn together programming experience and research findings to enable lessons to be learnt, progress to be made, and the scale of the response expanded to rise to the enormity of the effects and the long duration of the impact of the AIDS epidemic on children..

Concern, however, has been growing around the role of external organizations, and the need to find ways to ensure that these 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, but the scale and urgency of the problems generated by the HIV/AIDS epidemic can lead to ill-planned actions by external agencies with unanticipated negative consequences. 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

### Community-based Options for Protection and Empowerment (COPE)

COPE, a community mobilization programme to ameliorate the impact of the AIDS pandemic on the lives and welfare of children and families, was established in 1995 with assistance from Save the Children (US) and, in 1997, from the US Agency for International Development (USAID)/Displaced Children and Orphans Fund (DCOF).

COPE began its efforts by sensitizing religious, business and political leaders to the reality of the impact of AIDS on the community, and to initiate the formation of community care alliances. These alliances jointly assume responsibility for addressing the broad range of problems experienced by communities. Part of COPE's approach was to strengthen the capacity of partnerships, to mobilise internal resources, to access external resources and to organise community involvement. Area AIDS Committees mobilised action at the village level by bringing people together to address their concerns.

COPE was reviewed by DCOF in 1996, 1998 and 1999 with a range of recommended changes proposed on each occasion. Initially COPE's focus was on problem solving and service provision, but this proved to be too costly. COPE considered their initial programme activities to be community-based because volunteers carried out many of the activities. However, ongoing participation of volunteers depended on continuing involvement of a large number of NGO staff and material benefits from the programme. Once COPE staff moved on to work in another part of the district, volunteers did not always continue their work. In addition, COPE employed a complex information gathering and monitoring system that was thorough, but very labour intensive and expensive. After the first evaluation, COPE cut costs by reducing staff, and by redirecting efforts into community mobilization. Its principal activities were seen in a positive light by communities, their leaders, government personnel and NGO staff. For example, patients in homes with trained care-givers were found to be receiving better care, to be more comfortable, and to live in greater dignity. However, because the COPE activities appeared to be too costly to maintain, alternative approaches were introduced. COPE started to use the Community AIDS Committee (CAC) concept, an idea that was initially devised

by the Malawian Government and UNICEF, as the *modus operandi* for implementing their programmatic strategy. CAC's co-ordinate both HIV/AIDS care and prevention activities at sub-district level and these, in turn, are supported and monitored by the District AIDS Coordinating Committee (DACC). CACs are responsible for the mobilization, monitoring and support of Village AIDS committees (VAC's) in all villages in the CAC catchment area. Through committees, COPE implemented a broad range of interventions. They identified orphans, ill people and other vulnerable people; assisted the return and reintegration of orphans to school; trained caregivers in the skills required for home-based care; started youth Anti-AIDS clubs; planned and organised recreation activities to address the psychosocial needs of orphans, and developed community gardens to produce food and income for the benefit of vulnerable households. Chiefs and well-to-do members of the community donated land for cultivation, and COPE staff assisted the committees with training in agricultural practices.

In 1997, COPE expanded from 16 VACs to 208 VACs with 4 420 members. More than 12 600 enumerated orphans received material assistance and food; more than 150 woman heads of households were in enterprise networks, 735 youth received vocational skills training, more than 11 000 families benefited from agricultural inputs. In terms of training, 449 people were trained in caregiving and community-based child care, 807 people received home-based care training, and 6 577 people received HIV/AIDS prevention training. A total of 248 967 people benefited directly or indirectly from the COPE programme at an annual cost of \$317 000.

A significant lesson learned by COPE is that fragmented and compartmentalised programmes are less effective in assisting families affected by HIV/AIDS than programmes that are integrated. HIV prevention efforts also appear to be more effective if integrated with activities to care for those living with AIDS, orphans and other groups affected by the pandemic. The integration of programmes through community mobilisation increases social cohesion, which is believed also to reduce infection rates.

because spontaneous initiatives did not develop or were suspended (Grainger, Webb & Elliott, 2001). This does not mean that external support is not needed. Also, these cautions do not mean that an emphasis on community-based initiatives relieves governments of the responsibility to create an enabling environment for children and families, including unencumbered access to essential services, as well as additional financial and infrastructural support where needed (Foster, 2005a).

**Local organizations**

Large, in-country NGOs now also exist to provide assistance to children and families, and some of them have become intermediaries for channeling international and national funds to smaller community-based organizations. For example, 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 epidemic. They play a key role in easing the impacts of the epidemic, particularly on children. Although most initiatives are operated by community organizations, religious groups or non-governmental organisations,

their effectiveness often depends on the existence of formal health and education services and other government structures.

In the past, there was no special need to consciously respond to vulnerable children. Instead, families looked after the children of kin

and support was provided to households caring for vulnerable children through existing community safety net mechanisms (Foster, 2005a). During the 1990s, though, a completely new component of the community safety net developed in response to the impact of HIV/AIDS. Over the past decade, thousands of communities throughout Africa have recognized the increasing vulnerability of children and have

responded with ingenuity. Community groups in Africa do not commonly establish children’s homes or institutions for vulnerable children, if this is not prompted by external influence. African communities view what is happening to children as one of the most important impacts of the AIDS epidemic (Bolton & Wilk 2004). As early as 1987-91, communities in Tanzania were noted to be responding to increasing numbers of orphans and families affected by HIV/AIDS. Those affected were provided with home-based care, food, educational support and health care assistance (Mutangadura et al., 1999; World Bank, University of Dar es Salaam, 1993).

In all affected countries there are spontaneous community-based initiatives, devised by local communities to help vulnerable children and families. These initiatives include: communal land and crop production; grain loan schemes; organized individual or group income generating activities (IGA), often involving small trade 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 carers 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

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**Community Grain Banks in Burkino Faso**

In Burkina Faso, community grain banks have become popular, providing a village-based solution in times of food shortage. Communities must decide to establish a grain bank themselves and elect a committee to manage it. They build their own grain banks and are provided with credit and training in purchasing, managing money and record keeping, to enable them to control their own food security. After harvest time, community groups buy grain at best prices in nearby markets and stock the bank, which then makes food supplies available at the hardest times of year at carefully controlled prices to the most needy households. Management by women’s committees appears to be the most successful, because women tend to be more transparent in financial affairs and have better skills in management of food supplies, especially in times of crisis. (Yameogo, 1997).

for vulnerable children; activities to address the psychological distress of affected children, and a variety of other efforts that give succour and support to those who are worst affected by the epidemic.

These activities may be driven by local groups, such as faith-based communities but frequently also by the charismatic leadership of one or more concerned individuals. The cumulative impact of large numbers of local initiatives is significant. In the long run, affected communities are better placed to directly provide appropriate support and deal with complex social issues of children

### Support Groups for People Living with HIV/AIDS in Zimbabwe

A study from Zimbabwe provides an overview of what is fairly typical of HIV/AIDS support groups elsewhere in Africa. The study surveyed 150 support groups with 2 509 members. Two-thirds of the groups were in rural areas and over a third were formed in the previous year. Two-thirds of the groups were small, with 5-15 members, and there was no difference in size between newly formed and older groups. Most groups were actively recruiting new members. Though membership was open to everyone in the community affected by HIV/AIDS, most support groups consisted of women and nearly half required a membership fee. About one-third of the groups were hosted by an NGO or a hospital, mostly faith-based organizations. The majority of the groups (90%) were affiliated, most of them with ZNNP+, the national network body for PLHA, and the survey probably under-represented independent support groups. The main source of revenue for support groups was membership fees; only five groups received external funding. Two-thirds of groups had an annual budget and this was under Z\$10,000 (US\$250). All relied exclusively on volunteers and the main aim of the groups was to serve group members and help them live positively. The commonest reason for joining a group was participation in income generating activities, followed by access to counselling, participation in public education, access to material support and home care. The failure rate of income generating projects was high, most commonly because of lack of access to capital (Southern African AIDS Trust, 1999).

affected by AIDS than external agencies such as NGOs, and even government. The multitude of initiatives that continue to spring up runs contrary to the oft reported assertion that families and communities with severe epidemics are breaking up. However, these activities are usually not sustainable in the long-term without additional assistance. While people volunteer their time, they can only do so when the demands of their own households permit them to give assistance to others, and they seldom have the resources to continue to provide material support to affected children and families except in crisis situations. For this reason, getting manageable resources to community-based groups to enable them to continue to assist vulnerable children and their families is the critical requirement of governments, as well as international and local aid agencies.

Subbarao and Coury (2003) have summarised approaches to community-based interventions and note a number of challenges faced by these programmes.

To date, most initiatives have been sporadic and piecemeal, rather than well-funded national

programmes; there are few well-documented success stories to inform the sustainability of programmes; most programmes are run by volunteers without the expertise to evaluate their efforts or to conceive their activities on a larger scale; and there have been few developmental interventions (for example, that focus on income generating activities) in comparison to the large number of programmes which attempt to provide direct assistance to orphans and vulnerable children. This means that few community-based efforts have been thought through to scale. What is needed is for efforts at the two extremes of the continuum to be strengthened. Firstly, this needs to be done at a macro-level with government assistance through health, education and other services generally thought of as the social wage, together with efforts to scale up promising community-based activities. At the other extreme, greater local philanthropy, mobilisation and organizational capacity needs 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.

One of the major challenges facing efforts by international and local governments, donors and

The cumulative impact of large numbers of local initiatives is significant.

**Mutual self-help groups in Uganda**

*Munno Mukabi* refers to informal mutual self-help groups, a traditional practice that is seeing renewed popularity as a result of the impact of AIDS. One such group helped look after 102 orphans staying with very elderly relatives or on their own; the groups enable participants to engage in social and economic support activities as well as recreation. These associations are particularly useful in responding to periodic but unpredictable risks related to death, sickness, and celebrations that can impose significant financial pressure on households (Wright et al. 1999; Moyo et al. 2002). Informal women's counselling groups and impromptu meetings have sprung up, where women assist each other in the plantations, caring for the sick and relieving caregivers. Neighbourhood women appear unannounced to weed and trim the banana gardens of a woman who is ill. The women have persuaded local Resistance Councils to solicit outside help for orphans and some have assumed the responsibility of caring for children in their homes. Informal counselling sessions enable women to share their experiences and concerns (Barnett & Blaikie, 1992). In some districts in Uganda, village residents' mutual assistance groups are compulsory for all adults. These groups are currently the most widespread and effective of all groups, though they are plagued with poor management and a low capital base (Kasente et al., 2002).

philanthropic organizations in their attempts to assist vulnerable children, is the development of mechanisms for channelling resources to grassroots organizations and to destitute families. Large-scale international assistance often has had disappointing results and, increasingly, donors are recognising that the most sustainable and cost-effective efforts to protect, support and assist orphans and other children made vulnerable by AIDS are those that are carried out by grassroots community groups (Williamson et al, 2001). Grassroots organizations can be overwhelmed when they receive too much funding too quickly without parallel increases in management capacity. On the other hand, donors have no mechanisms for channelling small amounts of money in keeping with the needs and capacity of CBOs

and informal community initiatives. Based on a recent review of funding approaches, Foster (2005a) identified a number of bottlenecks at several levels of disbursement and recommended that mechanisms be put in place to direct manageable amounts of money to small organizations and community groups, as well as to track what proportion of the large tranches of available HIV/AIDS funding reaches communities and directly benefits vulnerable children and their families. As Alison Dunn notes (2005b), "Most advocacy and campaigning effort goes into boosting the amount of HIV/AIDS money made available. Yet little effort goes into deeper questioning and analysis of how funding is currently being spent and whether it is effective (p. v).

**One of the major challenges facing efforts by international and local governments, donors and philanthropic organizations to assist vulnerable children is the development of mechanisms for channelling resources to grassroots organizations and to destitute families.**

**Faith-based organizations**

During the late 1990's, community responses to vulnerable children proliferated, especially amongst faith-based organizations (FBOs). In 2002 and 2003, research teams in Kenya, Malawi, Mozambique, Namibia, Swaziland and Uganda surveyed what religious groups were doing to meet the needs of orphans and vulnerable children (see Table 1). Interviews were conducted with 690 faith-based organizations, mostly churches, mosques and religious coordinating bodies. The scale of the response was staggering – over 90 per cent of surveyed religious groups engaged in activities to support orphaned and vulnerable children. Over 9 000 volunteers supported more than 157 000 vulnerable children in 397 faith-based initiatives. More than half of the initiatives established by congregations were started in the preceding four years. These responses were prompted by the growing numbers of children going hungry, without adequate clothing, not attending school, lacking spiritual or parental guidance, or subject to exploitation, abuse, rape or unwanted pregnancy. Though the precipitating factor for most community responses is the growing number of orphaned children, around one half of the children supported by

**Table 1. Community-based child and family support activities of faith-based organizations**

Type of response	% FBOs	Description of responses
Religious education and spiritual support	90+%	Spiritual support to families and children through scripture reading, religious instruction, prayers, singing and encouragement to attend worship.
School assistance	73%	School fees, levies, uniforms, equipment, books and boarding fees
Material support	62%	Essential material support such as food and clothing to individual children from destitute households
HIV prevention	51%	Increased awareness of HIV and moral guidance for children.
Visiting / home care	39%	Identification of needy households, regular visits, parenting, advice, household supervision, meal preparation, dwelling maintenance, assistance in household agriculture or income generation, and home care supervision for HIV/AIDS patients
Psychosocial support	32%	Counselling to children; psychosocial support group activities, experiential learning
Medical care	30%	Facilitate children's access essential medical support through the provision of medical fees, medicines and transport costs.
Income support and generation	19%	income-generating projects to produce food and cash; preparation and distribution of school uniforms; agricultural projects at various levels to increase output; labour sharing; credit schemes for funeral benefits
Vocational training	15%	Apprenticeship and training in marketable skills for orphaned adolescents; nutrition gardens, husbandry projects, manufacturing co-operatives, buying-and-selling initiatives, carpentry, dressmaking.
Day care centres	11%	Care and food during the day for pre-school children, often whilst caregivers are working to enable women to work in or outside the home
Community schools	5%	Non-formal education facilities for out-of-school children.
Fostering promotion.	3%	Encourage fostering and adoption by non-relatives of orphans

religious congregations were vulnerable children other than orphans, most of them destitute. Many faith-based programmes are small-scale, supporting fewer than 100 vulnerable children, although some groups support over 1,000 children and most initiatives were expanding (Foster, 2004; 2005a).

The organizational capacity of congregations in terms of governance and financial accountability was on a par with many larger NGOs. But few received significant external technical or financial support and, of necessity, were forced to rely on their own resources and skills. Many congregations indicated their only source of support was contributions by members of their congregations. This reflects the motivation of religious groups who commit their own time and resources to ensure the future well being of vulnerable children in their communities.

The success and effectiveness of numerous faith-based projects operating in Africa is attributed to the fact that care and compassion for vulnerable people is intrinsic to religious doctrines. Religious bodies are an integral part of community infrastructure, and provide a coherent social network within which projects can be

initiated and sustained. There is also a rationale, beyond lack of resources, for volunteer work. Lynette Mudekunya (2002) points out that FBOs have a number of inherent qualities that make them particularly effective conduits for community based care interventions. For example, FBO's are able to identify vulnerable and needy children through their members in communities; refer children on to other services, and assist in the distribution of emergency relief to children; play a significant role in reducing stigma and discrimination through a spirit of acceptance of those who are infected and affected by HIV/AIDS; offer support to caregivers (who are generally female, elderly or very young, poor, and/or ill); and FBO members can visit children and families, and actively discourage abuse by caregivers and neighbours. They can also act as significant adults in children's lives.

The potential of the religious sector in supporting orphans and vulnerable children has not been fully realized. One reason is an anxiety amongst funders about the conservative agenda of right-wing religious groups in the United States. However, the potential for expansion is enormous. There are some quarter of a million congregations



**Families, Orphans and Children Under Stress (FOCUS)**

FOCUS is a project working with church groups in Zimbabwe initiated by FACT (Family AIDS Caring Trust), Zimbabwe's oldest and longest running AIDS service organization. The main aim of FOCUS is to assist communities to care for orphans by identifying orphaned children; assessing and prioritizing those in greatest need (children living without adult supervision, withdrawn children, children being cared for by a terminally ill caregiver, children in rags, children in homes where there is clearly no food, or no sign of food preparation, etc); visiting the most needy; establishing partnership and co-operation with other community groups, leaders and organizations; increasing sustainability by limiting provision of material support, and encouraging maximizing community resources where possible.

FOCUS has been found to be a low cost project with high levels of community ownership, requiring a minimum of external support, effective in reaching the poorest of orphan households, and replicable. An evaluation and best practice analysis found that in 1999, seven FOCUS sites reported having made 93 000 visits to 2 170 households with a population of about 6 500 orphans and vulnerable children, and 992 children's were able to attend primary school because their school levies (between \$2 and \$4) were being paid (Lee et al, 2002).

in the AIDS belt of east and southern Africa (Foster, 2005c). In spite of the crisis, a majority of congregations have probably not yet established any responses to vulnerable children.

**Family responses to children in communities affected by HIV/AIDS**

Extended families, kin and communities remain the principal supports for children affected by HIV/AIDS in sub-Saharan Africa (Foster, 2005b; Masmus et al, 2004; Ntozi et al, 1999; Webb, 1996). In rural Tanzania, for example, 95% of orphans are taken care of by relatives (Urassa et al, 1997). Studies in many countries in Africa and elsewhere find that families and communities

absorb orphaned and affected children as long as their meagre resources hold up (Family Health International, 2001). In the main, surviving mothers and related women provide most of the care for affected children. While surviving fathers are less likely to care for children than surviving mothers, this tendency seems to be changing (Case et al, 2002). In most settings, grandparents are the most common caregivers.

Community-based approaches focus on assisting adult caregivers to support very vulnerable children on the assumption that children are dependent on adults, and family caregivers will continue to provide protection and care for children when programmes fail or pull out. However, more family or informal fosterage is occurring as a result

of necessity and children are often pushed into households, rather than being pulled, and this makes children vulnerable (Subbarao & Coury, 2003). In addition, older caregivers may have difficulties responding to the economic, health and psychological needs of children, and households in which very old caregivers have responsibility for children may suffer severe resource constraints. In addition, grandparents themselves will die, leaving children who have already experienced multiple losses. Child-headed households are reported to be increasing, but there are significant problems with available measurement and data (Desmond et al, 2003). While child-headed households are often referred to as a sign of community and family disintegration, closer examination of these households frequently indicates that their existence is testimony to community and neighbourhood assistance, as such households could not survive on their own (Germann, 2005).

Family structure and function is changing as a result of the HIV/AIDS epidemic (Ankrah, 1993; Caldwell et al, 1993). Emerging family forms include families with fostered children of kin; elderly household heads with young children; large families with unrelated (fostered or adopted) children; single-parent households; child-headed households; formal or informal cluster foster care; and itinerant or homeless families (Hunter & Williamson, 2000). All these family forms need to be supported because they provide care for vulnerable children and other dependent members.

The fact that families are absorbing the care

**Extended families, kin and communities remain the principal supports for children affected by HIV/AIDS in sub-Saharan Africa.**

**The fact that families are absorbing the care of affected children, does not mean that they are doing so without difficulty.**

of affected children, does not mean that they are doing so without difficulty (Rutayuga, 1992). In private, observes Susan Hunter, some guardians express dismay at having to

restart families late in their lives, both in terms of their loss of personal freedom and in their anxiety about meeting the needs of small children financially, physically, and emotionally. They are also frustrated by the behaviour problems of children and young people who have been traumatised by the sequence of events surrounding their parents' deaths. The adults may be traumatised themselves by repeated deaths within their families (Hunter & Williamson, 2000).

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 affected by HIV/AIDS (Gilborn et al, 2001). This study recommended the following broad principles to include in caregiver support programmes:

- Reach children affected by AIDS before they become orphans and enable people living with AIDS to discuss and address their concerns about the future welfare of their children.
- Increase community awareness and accountability about the property rights of women and children. This is especially important because most surviving caregivers are women, and a substantial proportion is young. Efforts to promote the writing of wills must be accompanied by commitments by relatives and community leaders to uphold property rights. Community groups and local leaders (government, traditional and spiritual) must be mobilised to help enforce property rights.
- Address the critical health needs of adult caregivers, including guardians (Linsk & Mason, 2004). Care and support services need to be provided to caregivers to maintain their health and prolong their capacity to care for children. This minimises the toll of illness and death on children, improves their well-being and access to school, and delays their primary, secondary or tertiary orphaning.

- Improve adult-to-child communication and provide counselling 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 the adult's HIV status (Faithfull, 1997; Gewirtz & Gossart-Walker, 2000; Thorne, Newell & Peckham, 2000).
- Address the critical material needs of AIDS-affected households, including those headed by HIV-positive parents and guardians. This can be done through income-generation activities, vocational training, food, clothing, home repairs, and school fees.
- Improve the morale of children affected by HIV/AIDS by keeping children in school and offering sports and recreation facilities. School and other activities maintain the psychological well-being of children and reduce the burden of childcare on stressed caregivers.
- Address stigmatisation of and discrimination against AIDS-affected adults and children. Fear of disclosure limits parents' ability to appoint guardians and to take other steps 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.

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 is borne by those least able to cope. Households are straining under this weight of sickness and death, with extended families and community members taking up the responsibility to support children made vulnerable by HIV/AIDS (Seeley et al, 1993). It is clearly a case of the very poor helping the destitute. Despite the proliferation of HIV/AIDS resources, international responses to the HIV/AIDS crisis are failing to get resources to affected communities and families. It is imperative that new ways be found to reduce the share of total AIDS spending by the poor. The priority question for govern-

**School and other activities maintain the psychological well-being of children and reduce the burden of childcare on stressed caregivers.**

ments, international agencies and others is how to ensure that available and new resources for HIV/AIDS, including for children, can best be disbursed in order to build the capacity of affected communities and households and directly benefit vulnerable children (Foster, 2005a, b).

### Summary

International responses to children affected by HIV/AIDS have been late in development. Notable publications such as *Children on the Brink* in 1998 and the *Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* in 2004 have drawn attention to the: the lack of attention given to vulnerable children in most national development plans; the very low level of resources reaching families and communities supporting children made vulnerable by HIV/AIDS; the large numbers of other children, in addition to orphans, that are made vulnerable by HIV/AIDS through poverty, armed conflict and child labour; and the need to integrate interventions to benefit vulnerable

children with other programmes to promote children's welfare and reduce poverty

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

Until now, most interventions to support children have been piecemeal and have not matched the size of the problem. Urgent steps to scale up and replicate successful interventions are needed. One of the major challenges facing efforts by international and local governments, donors and philanthropic organizations to assist vulnerable children is the development of mechanisms for channelling resources to grassroots organizations and to destitute families.

## Psychosocial interventions and psychosocial well-being

The literature on protecting and promoting children's development under conditions of adversity is huge, and encompasses children living in poverty (Fitzgerald et al, 1995; McLoyd, 1995; Save the Children, 2005), childhood malnutrition (Pelto et al, 1999; Richter & Griesel, 1994; Zeitlin et al, 1990), abuse and neglect (Bartlett, 2002), street children (Grootaert & Kanburn, 1998; Jacob et al, 2004), the impact of natural disasters (Pynoos et al, 1998), and children affected by armed conflict and displacement (Machel, 2000; Psychosocial Working Group, 2003). Much is already known about interventions to support the psychosocial development of children that can be generalised to children living in communities affected by HIV/AIDS.

The problems facing children and their families living in communities affected by AIDS are many and varied. No single intervention can produce significant, sustained improvement in the well-being of the very large numbers of children affected by HIV/AIDS over the extended time scale

of the epidemic. Instead, what is needed is a set of collective community and programme responses to strengthen caregivers' and households' commitments to the well-being of children, which are supported by constructive national policies and the mobilization 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 (Foster, 2002b; UNAIDS, UNICEF, USAID, 2004).

Despite agreement about the importance of children's *psychosocial* needs in the face of the AIDS epidemic, considerable confusion surrounds the use of the concept *psychosocial* in this field (Robinson, 2005). Definitional issues have been addressed at several meetings, and in a number

of publications – all of which stress the inter-relationship between emotions, thoughts and behaviour (psychological aspects) and social experience (Psychosocial Working Group, 2003).

The Bernard van Leer Foundation has led two consultations<sup>1</sup> to clarify what is meant by the concept *psychosocial* in relation to children living in communities affected by AIDS. At the Johannesburg meeting, the following description was agreed.

*Psychosocial well-being is essential for children's survival and development, especially in enduringly difficult circumstances.*

*Children affected by HIV/AIDS endure the loss of caregivers, livelihoods, and health. Many suffer deprivation, overwhelming loss and grief, upheaval, discrimination and social exclusion.*

*Psychosocial care and support includes interventions that assist children and families to cope. They enable children to experience love, protection and support that allow them to have a sense of self-worth and belonging. These are essential in order for children to learn, to develop life skills, to participate fully, and to have faith for the future.*

*Support for children's psychosocial well-being is a key investment in human capital because it underpins all other processes for the long-term development and stability of societies.*

The description stresses the fact that children's psychosocial resources, mainly derived from their relationships with others, especially with primary caregivers, their sense of belonging, and their hope (Garmezy, 1991; Werner & Smith, 1989; 1992), enable them to cope with hardship, including going hungry, being cold and uncomfortable, and other privations of poverty and loss. It also stresses the importance of children's psychosocial well-being, not only in the short term, as a focus

<sup>1</sup> Johannesburg 28–29 November 2004; Cape Town, 1–5 April 2005.

... activities to protect, support and promote the psychosocial well-being of children and families are urgently needed.

of recovery from and adjustment to parental illness, death and related stressful situations, but as a longer term investment in socioeconomic national and human development (Young, 2002; Keating & Herzman, 1999).

In the literature on children affected by violence, and more recently by HIV/AIDS, the term psychosocial is frequently used to refer to a range of intervention tools, processes and programmes to address non-material, especially the social and emotional, needs of children in difficult circumstances. This use of the concept evolved to prioritise interventions for children of a different kind and purpose to emergency and material aid, economic and livelihood activities, health care and the like. However, broad agreement is growing that the focus should shift from *psychosocial interventions to children's psychosocial well-being*. That is, the recommendation is that work in this field should concentrate on the environmental and relationship conditions and interventions needed for children to grow well, including emotionally and socially (Williamson & Robinson, 2005). In addition, interventions intended to support children's healthy development should be community-based, building on and mobilising the strengths and capacities of individuals, families and communities, and they should be appropriate to local social and cultural frameworks (Salole, 1992).

### Psychosocial interventions

As indicated above, the term psychosocial is applied to a range of interventions and activities. At the one extreme, psychosocial interventions, responsive to the need for reconstruction and reconciliation in the context of conflict and war, are increasingly regarded as a core aspect of humanitarian and developmental aid (Loughry & Eyber, 2003; Robinson, 2005). At the other extreme, psychosocial interventions to counter the psychological and social distress of children affected by violence and AIDS frequently take the form of counselling and other interpersonal and group activities. In a review of psychosocial interventions in the context of long-standing ethnic conflict and violence in Sri Lanka, Galappatti (2003) identified a number of different kinds of activities to which the term psychosocial intervention is applied. Examples of these include:

- *The provision of explicitly psychological or medical therapeutic services* such as counselling, befriending (supportive listening for catharsis),

and activities to enable children to express feelings and explore problems and their potential solutions. Memory boxes and memory books are illustrative of this category of interventions (Denis & Makiwane, 2003; Morgan, 2004).

- *Awareness raising and education* through, for example the dissemination of information about trauma and bereavement and methods for coping with distress. The Journey of Life, produced by the Regional Psychosocial Support Initiative (REPSSI),<sup>1</sup> is a structured workshop process to raise awareness of the needs of children in communities affected by AIDS (Madorin, 1999).
- *Social activities to support the expression of feelings, fears and other thoughts* through meetings, theatre and other opportunities for interpersonal interaction.
- *Activities to support and stimulate children's development* through play activities, resources to improve children's social and physical environments, and the provision of early child development (ECD) services.
- *Skills training* to improve communication, conflict mediation, lay counselling services for affected people, as well as skills to improve socioeconomic conditions, community relations and the like.
- *Mobilisation of social networks* such as children's clubs, women's support groups, and other communal activities.
- *Advocacy and publicity campaigns* to improve access to services, remove threats to well-being and to implement programmes to address the needs of children and families.
- *Strengthening of people's spiritual resources* through participation in religious activities and involvement in spiritual education.

Given the diversity of activities included under its rubric, the Psychosocial Working Group (2003) concluded that the term psychosocial intervention "has come to refer to any programme that aims to improve the psychosocial well-being of people" and means "anything from peace-building and conflict resolution to individual psychotherapy to advocacy projects for human rights" (p. 2)

Very few of these kinds of interventions have been systematically evaluated when applied to alleviating the distress experience by children living

<sup>1</sup> <http://www.repssi.org>

in communities affected by HIV/AIDS, though all have strong face validity, and many have emerged spontaneously as part of community responses to affected children and families. It is important that lessons about psychosocial interventions for children in communities affected by AIDS are learnt from other fields, particularly from efforts to assist children in poverty and children affected by armed conflict (Richter et al, 2004a; Robinson, 2005). For example, the concepts of trauma and post-traumatic stress disorder were rejected in the violence field because many children who experienced severe losses and witnessed frightening events did not develop psychopathology and did not require specialised psychiatric and psychotherapeutic services (Bracken & Petty, 1998; Summerfield, 1999). Support from families and communities, and also from their peers, enable children to cope with extremely difficult situations. This lesson is particularly important in the HIV/AIDS field, where bereavement suffered by a child when a parent or primary caregiver dies is frequently viewed as a trauma, with many of the same fault lines that emerged in relation to the effects of war on children. There is no doubt that the death of a parent causes a child immense psychological pain and distress (Dane, 1993); however, a psychiatric approach to bereavement is inappropriate for most children (Sengendo & Nambi, 1997). In the same vein, prompting children to talk about painful experiences to strangers from external programmes is now regarded as inappropriate. Instead, it is recommended that such discussions with children should only take place “in a stable, supportive environment with the participation of caregivers who have a solid and continuing relationship with the child”

**Support from families and communities, and also from their peers, enable children to cope with extremely difficult situations.**

(Working Group on Children Affected by Armed Conflict and Displacement, 1996; p. 9).

What, to date, has not been made clear in writings about *psychosocial interventions* and children’s

*psychosocial well-being* is the nature of the interaction between interventions and well-being. For example, it has long been known that positive emotional states and psychosocial supports contribute to good health and improve recovery and/or adjustment to ill-health (Kiecolt-Glaser et al, 2002). That is, what are commonly thought of as psychosocial interventions have effects on

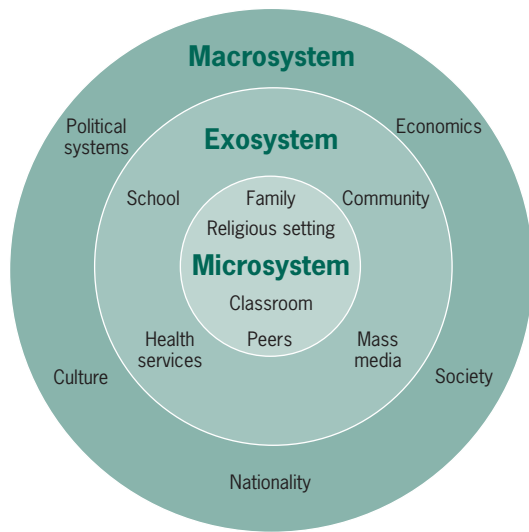
health and related aspects of human functioning that are not psychosocial. Similarly, better nutrition, which is not usually regarded as a psychosocial intervention, has been shown to positively affect children’s attention and learning – that is, it improves psychosocial well-being (Pelto et al, 1999). The functioning of children, like all human beings, is integrated, as is their experience of the conditions of their lives. Viewed in this way, the distinction between psychosocial and non-psychosocial interventions and well-being is artificial and retained, for the most, for advocacy purposes to ensure that children’s psychosocial needs receive attention. While it has been necessary in the past to draw a sharp distinction between psychosocial interventions and material aid in advocacy, this review emphasises the necessity for integrated approaches to improve the health and well-being of children in communities affected by AIDS.

### Psychosocial well-being of children

The approach taken in the field of interventions to support children affected by violence and war has been to define psychosocial well-being in children and then to design and implement specific activities to promote these outcomes. For example, Duncan and Arntson (2004) provide a summary of psychosocial well-being that includes the following: secure attachments with caregivers; meaningful peer relationships and social ties; social competence; a sense of belonging; self-worth and self-esteem; trust in others; hope, optimism and a belief in the future. These characteristics of well-being are clearly age-dependent, and apply variably to toddlers, preschool children, children in middle childhood, and adolescents.

From the broader child development literature, a wide range of factors are known to influence children’s psychosocial well-being, and the ecological or systemic model of Uri Bronfenbrenner (1977) is generally adopted to visualise these influences (see Figure 8). In this approach, the aim is to improve the caregiving environments in which children spend their days, as well as the affectionate and mediational (teaching-learning) qualities of caregiver-child relationships (Hundeide, 1991; Richter, 2004b). An advantage of a focus on the quality of caregiving can avoid many of the ethnocentricities that characterise psychosocial interventions when Western cultural perspectives are imposed on other cultural groups. Stand-alone psychosocial interventions for children can sometimes be seen as foreign

**Figure 8. Ecological model of human behaviour in the context of development**



and experienced as an imposition, and often are too narrowly focused to meet the needs of children identified by families and communities (Robinson, 2005; Verhoef, 2002b).

Ecological models represent dynamic systems in which influences at all levels exert bi-directional effects. For example, while caregiving relationships undoubtedly influence children's development, children's reactions and behaviour also strongly influence their caregiving environment (Bell, 1979; Sameroff & Friese, 1990). For example, disobedient children are often regarded as difficult to care for and frequently elicit

parental anger (Verhoef, 2002a). In the bioecological systems in which children live, proximal influences, those that occur in children's day-to-day relationships and experiences at home and school, especially their close relationships with affectionate caregivers, exert the strongest influence on children's development and well-being (Bradley & Caldwell, 1995). The quality and stability of caregiving relationships, be they with parents, other adults or older siblings, have a strong protective effect on children, including in the face of adversity (Richter, 2004b). Children have been

observed to cope extraordinarily well in conditions of extreme hardship when accompanied by familiar and supportive caregivers (Freud & Burlingham, 1943; Rutter, 1990). For this reason, only a very small number of children, including those that experience very high levels of stress, develop emotional, social and behavioural problems that may require specialised help (Garmezy, 1983). As a consequence, efforts to assist children and families should primarily be directed at strengthening the bonds between caregivers and children.

The majority of children will cope and thrive if stable and affectionate relationships with caregivers and friends are maintained or restored, and the daily routines and patterns of their lives are continued. A key strategy to support children's psychosocial well-being is thus to strengthen primary caregiving relationships and to "promote normal family and everyday life to as to reinforce children's natural resilience" (Working Group on Children Affected by Armed Conflict and Displacement, 1996; p.7). The elements that contribute to children's resilience are: safety and security, affectionate caregivers, familiar routines and tasks (such as schooling provides), and interaction with friends. Further, "one of the most important contributions that can be made to improve children's psychosocial well-being is to help adults in a family re-establish their capacity for good parenting. A particularly risk combination is a deeply depressed and isolated young mother [or an aged grandparent] with small children" (Ibid; p. 8).

The Working Group on Children Affected by Armed Conflict and Displacement (1996), which brought together experts in the field, offers the following basic principles and approaches in programmes involving war-

**The quality and stability of caregiving relationships, be they with parents, other adults or older siblings, have a strong protective effect on children, including in the face of adversity.**

**Stand-alone psychosocial interventions for children can sometimes be seen as foreign and experienced as an imposition, and often are too narrowly focused to meet the needs of children identified by families and communities.**

**A key strategy to support children's psychosocial well-being is to strengthen primary caregiving relationships and to promote normal family and everyday life to as to reinforce children's natural resilience. Parents and others can be helped to promote the care of children.**

affected children. All of their recommendations are applicable to children in communities affected by AIDS:

- Apply a long-term perspective that incorporates the psychosocial well-being of children.
- Adopt a community-based approach that encourages self-help and builds on local cultures, realities and perceptions of child development (Robinson, 2005; Salole, 1992).
- Promote normal family and everyday life so as to reinforce a child's natural resilience (Coscia et al, 2001).
- Focus on primary care and prevention of further harm in the healing of children's psychological wounds.
- Provide support as well as training for parents, other adults and personnel who care for children.
- Ensure clarity of ethical issues in order to protect children (for example, from being labelled as an *AIDS orphan*).
- Advocate for the fulfilment of children's human rights.

This approach is also consistent with what is called a rights-based orientation to programming (Robinson, 2005). For example, the preamble to the

Convention on the Rights of the Child states that "Convinced that the family, as the fundamental group of society and the natural environment for the growth and well-being of all

its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community" (Cook, 2001).

In addition to the above, many programmes have a strong commitment to include children actively in social networks and activities, as well as their participation in efforts to address the problems that they and their families experience (Laws & Mann, 2004). Children's agency, their active engagement and participation, is an essential aspect of building children's resilience (Apfel & Simon, 1996; Grover, 2005, enabling children to deal with hardships that are inevitable in conditions of poverty, war and HIV/AIDS (Hart, 2004). In this sense, the active engagement

of children in solving problems that affect them and their families promotes better psychosocial coping and adjustment by countering hopelessness and despair and reinforcing children's sense of competence.

Based on experience derived from programmes to support children affected by violence in southern Africa, Duncan and Arnston (2004) conclude that there are four main aims to so-called psychosocial programming:

1. Restoring the normal flow of development;
2. Protecting children from the accumulation of distressful and harmful events;
3. Enhancing the capacity of families to care for their children, and
4. Enabling children to be active agents in rebuilding their communities and in actualising positive futures.

Many interventions have been developed to support the healthy development of children living in conditions of poverty, stress, war and conflict, and in communities affected by HIV/AIDS. These interventions focus on a variety of domains of children's development, such as learning and adjustment, and may be delivered through a variety of mechanisms. Some programmes provide inputs, such as stimulation or support, directly to children (Grantham-McGregor et al 1994, while others attempt to build the confidence and competence of caregivers (Spiker et al, 1993). Some are centre-based and others are built around home visits or community groups (Olds et al, 2002). At the core of most programmes are efforts to strengthen caregiver-child relationships. Evaluations of these programmes, either as pilot projects, or when taken to scale, have demonstrated their effectiveness, especially when properly implemented and initiated early in the lives of children (Glass, 1999; Guralnick, 1998; Schweinhart & Weikart, 1993; Shonkoff & Meisels, 2000). Reviews by the World Bank and others have laid out the economic arguments for investing in children's healthy development, especially under conditions of deprivation, dislocation and stress (Karloly et al, 1998; Keating & Herzman, 1999; Young, 2002; 2004). In addition to these, a

... many programmes have a strong commitment to include children actively in social networks and activities, as well as their participation in efforts to address the problems that they and their families experience.

Provide support as well as training for parents, other adults and personnel who care for children.



number of manuals and materials have also been developed for a range of psychosocial interventions in the context of poverty, armed conflict and HIV/AIDS (Arntson & Knudsen, 2004; Baingana & Bannon, 2004; Baron, 2002; Colling, 1998; Cook, 1998; 2001; International HIV/AIDS Alliance 2000; Killian, 2004; Loughry & Eyber, 2003; Madorin, 1999; Mallmann, 2003; Scope & Family Health International, 2001; Simonsen & Reyes, 2003; Strang & Ager, 2004).

In 1998, the Programme on Mental Health in the WHO supported an intervention package for *Improving Mother-Child Interaction to Promote Better Psychosocial Development in Children (PEIMAC)*. The programme is based on two fundamental principles of child development, well supported by empirical evidence. These principles are, firstly, the importance for young children's healthy development of close affectionate relationships with adults and, secondly, the critical role of mediated learning for children's cognitive and language development (Hundeide, 1991; Klein, 2001).<sup>1</sup>

The programme advances a practical set of guidelines for promoting caregiver-child relationships that is easily incorporated into programmatic work.

As will be set out in the remainder of the review, the available evidence and experience strongly cautions against narrow specialised psychosocial programmes for identifiable groups of children, such as

orphans (Robinson, 2005). Practitioners are well aware of the stigmatisation and isolation that can develop around children who are labelled "lucky orphans" because of the attention they receive from external agencies (Robnson, 2005).

Most children cope with difficult circumstances

with the love and support of affectionate caregivers and peers. Their needs for support differ by age and maturity and this must be taken into account. Some children require additional attention and understanding from adults around them to help them adjust to and cope with difficulties, most importantly from parents, family members and teachers. A few children need outside help, either to assist them directly because they are demonstrating psychopathological symptoms, or to advise and counsel their caregivers on how best to interact with them to assist the child to recover (see Figure 9).

Narrow psychosocial programmes are not sustainable, and also not likely to be effective, given the broad range of problems experienced by children living in communities affected by HIV/AIDS. In addition, targeting orphans may add significantly to their existing social marginalisation (UNAIDS, UNICEF, USAID, 2004; World Bank & UNICEF, 2002). Lessons learnt in other fields of intervention to improve the care and protection of children indicate that efforts to promote children's psychosocial well-being in the face of adversity, including among children in communities affected by AIDS, require that care systems around the child, especially in the family, be mobilised in an integrated way (Psychosocial Working Group, 2003; Robinson, 2005). Under extremely difficult circumstances, the coping capacity of caregivers comes under strain and is best addressed by support group activities that counter isolation and assist with the family's most pressing concerns.

### Focus on early child development

While efforts to support children in communities affected by AIDS should attempt to reach the most vulnerable children, it is important that all interventions be consistent with the broad goals of human and social development. Two clear principles are available to frame interventions within this perspective.

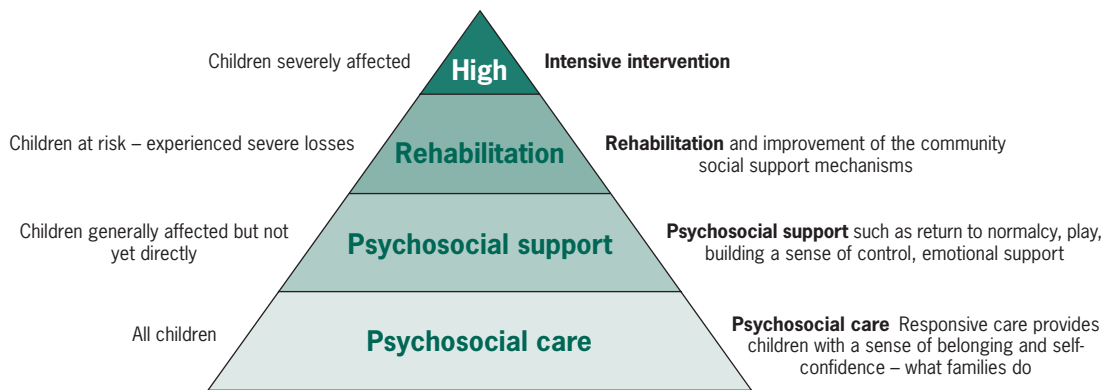
Firstly, children's well-being and their emotional, social, health and educational outcomes are dependent on supportive families and communities, as illustrated by an ecological perspective (see Figure 8). In turn, supportive families and communities are the product

... the available evidence and experience strongly cautions against narrow specialised psychosocial programmes for identifiable groups of children, such as orphans ... Lessons learnt in other fields of intervention to improve the care and protection of children indicate that efforts to promote children's psychosocial well-being in the face of adversity, including among children in communities affected by AIDS, require that care systems around the child be mobilised in an integrated way.

... all interventions should attempt to strengthen family and community support for children.

<sup>1</sup> Mediated learning involves adults and older children describing and explaining the world of objects and events to a young child in ways that enable the toddler to acquire an understanding of a cultural world.

**Figure 9. The hierarchy of children’s needs for psychosocial care, support and intervention**

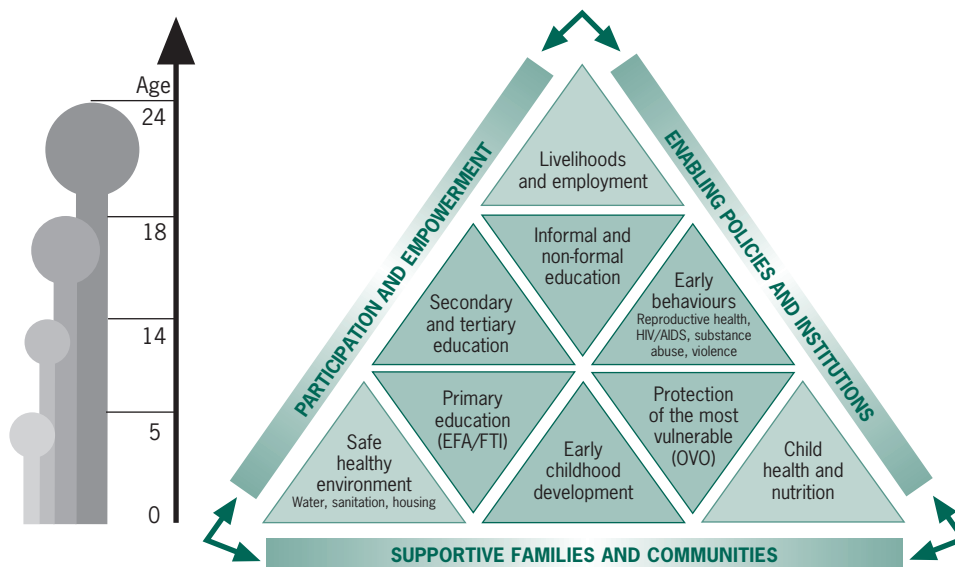


of social and economic participation and empowerment, on the one hand, and enabling policies and institutions, on the other hand. These inter-relationships are illustrated in Figure 10, which depicts the World Bank’s Framework for Action for Children and Youth (2005). For this reason, all interventions should attempt to strengthen family and community support for children.

Secondly, the rates of return on human capital investment, through support for development, nutrition education, improvement of environmental conditions and the like, are greatest when made early in life, as is illustrated by the work of Nobel laureate, James Heckman (see Figure 11).

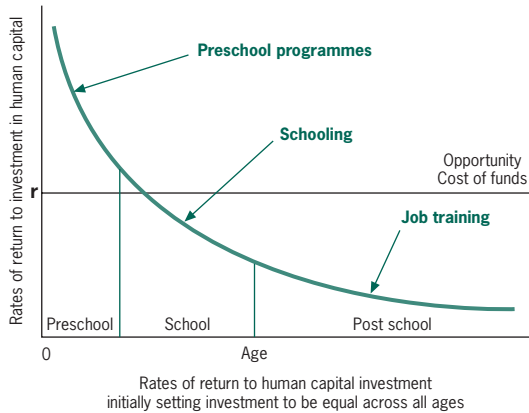
This means that interventions for children living in communities affected by AIDS, as is the case for all children, need to be targeted to the earliest years of life to ensure the greatest gains for children (Lusk et al, 2000; Dunn, 2005a).<sup>1</sup> Specifically this entails supporting children’s nutrition and growth and minimising childhood illnesses (Pelto et al, 1999), promoting strong caregiver-child relationships for children’s nurture and protection (Richter, 2004b), decreasing environmental threats to children’s mortality and morbidity, including through exposure to abuse, toxins and injury (Bradley, 1993), increasing access to early child development programmes for safety,

**Figure 10. Framework for Action for Children and Youth (World Bank, 2005)**



<sup>1</sup> See also: The International HIV/AIDS Alliance; the Working Group on Early Childhood development; the Consultative Group on Early Childhood Care and Development; the World Bank; the Early Childhood Development Network for Africa; the Bernard van Leer Foundation.

**Figure 11. Rates of return to human capital investment**



stimulation and preparation for formal schooling (Barnett & Boocock, 1998; Myers, 2000; Young, 2002), and ensuring access to and retention in education (Ainsworth et al, 2005; UNESCO, 2002; World Bank & UNICEF, 2002).

Early intervention in the context of the AIDS epidemic is an important consideration given that the almost exclusive focus on orphaning is drawing attention away from vulnerable young children.

The time lag between HIV infection and death results in a mean age of orphaning of 6.2 years (Johnson & Dorrington, 2001); Mugabe et al, 2002). This means it is pre-school children who are exposed to the damaging effects of deteriorating care if their mother or other primary caregiver is anxious, withdrawn or beginning to experience bouts of ill-health.

Young children are also subject to inadequate nutrition and health care if households become destitute because of adult illness and death. In addition, there are indications that younger children are more likely to be moved from one household to another during crises of illness and death (Hosegood et al, 2004). This causes instability in caregiving, something that is known to have adverse effects on the adjustment and development of young children.

... it is preschool children who are exposed to the damaging effects of deteriorating care if their mother or other primary caregiver is anxious, withdrawn or beginning to experience bouts of ill-health, as well as subject to inadequate nutrition and health care if households become destitute because of adult illness and death.

### Shortcomings of approaches to date

There have been several substantial reviews by researchers and practitioners of factors affecting children in communities affected by AIDS, as well as of principles and strategies for appropriate programmatic responses (see, for example, Foster & Williamson, 2000; Grainger, Webb & Elliott; 2001; Levine, 1994; Richter et al, 2004; Robinson, 2005; Smart, 2005; Subbarao & Coury, 2003; Williamson, 1995, 2000, among others). Recently, major efforts have been made to pull together research evidence on the needs of children living in communities affected by AIDS (Birdthistle, 2004), including for psychosocial support (Sherr, 2005b), as well as the needs for psychosocial support of HIV infected women (WHO, 2003). Despite what is now a voluminous literature on the topic, policy, programming and practice to meet the needs of children living in communities affected by AIDS remains handicapped by a number of issues that were discernible from the start and still require leadership for their resolution. These include:

#### *The potentially misguided targeting of orphans*

In 2004 WHO and UNICEF cautioned that the meaning of the term orphan varied considerably in different cultural settings. The definition of an orphan as a child under 18 years of age either or both of whose parents have died (WHO/UNICEF, 1994; UNAIDS/UNICEF/USAID, 2004), is well accepted for measurement purposes, especially for the secondary analysis of existing survey data and the collection of new national data. However, the definitional category serves the function of monitoring the stage and impact of the epidemic on a national level better than it does to identify vulnerable children. Children defined as orphans may or may not be vulnerable, depending on their pre-existing child care conditions (such as the overall level of child fosterage, or what has been called child circulation), the health and availability of a surviving parent, the acceptance and affection received from family and kin, the socioeconomic resources of the household that takes in an orphaned child, and the like. In addition, there is growing concern that, because communities are aware of the special assistance given to orphans by external agencies, orphaned children are less likely to be taken in by families and children may be labeled as orphans (World Bank & UNICEF, 2002).

### ***The inappropriate institutionalization of vulnerable children***

Orphanages draw donor interest and have continued to proliferate in sub-Saharan Africa despite the fact that institutional care is an inappropriate response to children living in communities affected by HIV/AIDS (Robinson, 2005; Frank et al, 1996; Tolfree, 1995; 2003; Williamson, 2004). Increased institutionalization of children has occurred in other times and places in response to political, economic, and social upheaval. Wars, epidemics, and political ideology have all been associated with the rise of orphanages in Britain and the United States, Eastern Europe, and South America (McLure, 1981; Ransel, 1988). In addition, child institutions have and continue to be expressions of beneficence during times of crisis (Milanich, 2004). The AIDS epidemic is no exception. Orphanages in many poor countries are a misnomer. Institutional care, when available, is used more often to provide care for children of destitute parents than for children whose parents have died. For this reason, the majority of so-called AIDS orphans in institutions in southern Africa, are not orphans in the strict sense of the word, but have been admitted to care from deeply impoverished families.

Seen from the outside, group or institutional care may appear to be preferable to family destitution, in which children go ill-clad, under-fed and too poor to be in school. This tension is not unique to HIV/AIDS. Jack Goody (1969), in the context of cross-cultural adoption, drew attention to the Western assumption that provision of services to needy children is preferable to traditional modes of support by poor extended families. These sentiments drive donor initiatives to establish child care institutions. Many African societies have rejected institutional care (Beard, 2005; Urassa et al, 1997; Wolff & Fesseha, 1998; World Bank & UNICEF, 2002) and children, when asked, prefer to stay with their families even in dire material circumstances (Kelly, 2002). Institutional care is expensive and detracts resources from much-needed family assistance (Desmond & Gow, 2001; Dunn et al, 2003; World Bank & UNICEF, 2002). Group care is known to be damaging to the development of young children (Frank et al, 1996), and it is difficult to prevent the abuse of older children in institutional environments and for institutionalized children to adjust to conditions in the society at large (Barth, 2005; Kelly, 2002). Lastly, institutional care cannot match the enormity of the needs of poor children in com-

munities affected by age (Kelly, 2002), nor can or should they be sustained over the long time scale of the AIDS epidemic.

### ***Failure to adequately support family and community responses to vulnerable children***

From the earliest writing on the subject, it has been realized that the impact of AIDS on children is felt inside families and households – grandparents nursing their sick adult children, trying to hold the family together and struggling to provide for clusters of grandchildren; kin and neighbourhood families taking in orphaned children; and siblings trying to stay together with the help of aunts, cousins and family friends (Nampanya-Serpell, 2001; WHO/UNICEF 1994). In 2005, Geoff Foster's study, *Bottle necks and drop feeds*, showed that families continue to be the mainstay of the response to care for and protect children, and that they do so from their own meager resources (Deininger, et al, 2003). It is also now known that services to improve child health and mental health are most effectively delivered through the family, through improved family education, support and participation, and that involvement of families maximizes the impact of services for children (Foster, 2000; Hoagwood, 2005). However, families need economic, social, psychological and spiritual support to be able to cope with the additional burden of care caused by increased numbers of vulnerable children (Ansell & Young, 2004; Linsk & Mason, 2004; Oburu, 2005). International and national agencies, as well as governments and national NGOs, need to recognize, and act upon, the importance of getting resources directly to families and communities to sustain, rather than to undermine their efforts to provide care and protection for children affected by HIV/AIDS.

... families need economic, social, psychological and spiritual support to be able to cope with the additional burden of care caused by increased numbers of vulnerable children.

### **Summary**

Among the collective community and programme responses required, activities to protect, support and promote the psychosocial wellbeing of children and families are urgently needed. While

a wide range of psychosocial interventions have been described, it is generally agreed that work in this field should concentrate on promoting the environmental and relationship conditions needed for children to grow well, including emotionally and socially. Most children affected by AIDS will cope well with the support of families, school and friends. Particularly vulnerable families need material, social and spiritual support.

A small number of children need additional assistance. When required, external interventions should be community-based, and build on the strengths and capacities of individuals, families and communities. Stand-alone psychosocial interventions for children often are too narrowly focused to meet the needs of vulnerable children. The quality and stability of caregiving relationships have a strong protective and rehabilitative effect on children, including in the face of adversity. The majority of children cope and thrive if stable and affectionate relationships with caregivers and friends are maintained during difficult and testing times. A key strategy is thus to support children's psychosocial wellbeing by strengthening primary caregiving relationships and promoting normal family and everyday life so

as to reinforce children's natural resilience.

Because interventions to promote development have their greatest effect in early childhood, efforts to help children living in communities affected by AIDS need to be targeted to the youngest age groups. It is largely preschool-aged children who are exposed to the damaging effects of deteriorating care if their mother or other primary caregiver is anxious, withdrawn or beginning to experience bouts of ill-health. They are also most vulnerable to inadequate nutrition and health care if households become destitute because of adult illness and death.

In efforts to support affected children, some harmful practices are beginning to emerge and need to be strongly countered. These include the potentially misguided targeting of orphans to the exclusion of other highly vulnerable children; an increase in institutional care, especially for younger children, without sufficient effort directed to supporting family fostering; and the failure to support family and community care in favour of programmes that give external assistance to children. External resources need to be directed to families, to enable them to care for children, including orphans.

## Chapter 5

# Health sector responses to children affected by the HIV/AIDS epidemic

### Lack of involvement by the health sector in the situation of children affected by HIV/AIDS

In general, the health sector has paid little attention to the situation of children living with and affected by HIV/AIDS in sub-Saharan Africa, especially young children (Dunn, 2005a). This is all the more surprising given the fact that children represent 17% of all new HIV infections and young children younger than 8 years make up 90% of CLHA and one quarter of the population of sub-Saharan African countries affected by HIV/AIDS (UNAIDS, 2004). With respect to programming, most effort has been directed to the psychosocial, educational and sexual and reproductive health needs of older children affected by HIV/AIDS, especially orphans, with a corresponding relative neglect of the needs of young children and children living with and caring for ill and dying parents and other family members. Few studies have examined the needs of very young children living with HIV/AIDS or examined the parenting, health and development needs of children under five living in families affected by HIV/AIDS.

Yet the need to link early childhood with HIV and AIDS is clear. The effects of the epidemic on very young children are profound and have immediate and long-term consequences on children's health and development (Dunn, 2005b; Sherr, 2005b). Despite the importance of preschools and crèches to the development of children, especially those affected by HIV/AIDS, no studies have yet examined the potential of expanding integrated preschool services to support children affected by HIV/AIDS. Considerable publicity and planning is being given to ensure the roll out of anti-retroviral treatment, but without the same level of national or international effort to prevent the premature deaths of young children living with HIV/AIDS by ensuring they receive early diagnosis and the best possible standard of care, nutrition and treatment provided by their guardians and health service providers.

As a result of the general lack of responses, the damaging view that “they’re just going to die anyway” is prevalent and this perception has, to some degree, extended also to children of HIV-positive parents and so-called “AIDS orphans”. To some extent this is due to the mistaken belief that all HIV-positive mothers automatically transmit their infection to their children. The children of HIV-positive parents may be denied health care or treatment in cases where health workers are faced with limited resources and families might decide not to invest in what they see as a terminally ill child (Lusk & O’Gara, 2002).

A study of children affected by HIV/AIDS in several parts of South Africa found malnutrition to be widespread, and health workers reported that diarrhoea, chest infections and child sexual abuse were problems (Giese et al., 2003b).

Early and continued programmes for orphans and vulnerable children have involved civil society organizations and some government departments, with limited engagement by the health ministries of affected countries. The development of *The Framework* was led by representatives from UNAIDS, UNICEF and USAID and endorsed by many other organizations including WHO, but health sector perspectives are noticeably lacking in the final document. In 2003, UNAIDS, the World Bank and UNICEF published *Operational Guidelines for Supporting Early Childhood Development (ECD) in Multi-Sectoral HIV/AIDS Programmes in Africa*, part of a process integrating effective broad-scale interventions to ensure the healthy physical, emotional and cognitive development of young children (Seifman & Surrency, 2002). However, there is little documentation indicating how the health sector has taken this further.

In 2000/2001, WHO convened meetings

... the health sector has paid little attention to the situation of children living with and affected by HIV/AIDS in sub-Saharan Africa, especially young children.

in southern Africa to adapt guidelines for the Integrated Management of Childhood Illness (IMCI) to the context of HIV/AIDS. There were no further major international UN efforts to support infants and children living with HIV/AIDS until global consultations in connection with ART were convened by UNICEF and WHO in 2004. Lack of attention by national health ministries to issues surrounding children living in communities affected by AIDS, including CLHA, have contributed to the failure to ensure that children's issues are adequately addressed in National Strategic HIV/AIDS Plans and in HIV/AIDS-related submissions to the Global Fund. This, in turn, may be a consequence of an excessively medical understanding of the impact of the epidemic on children, leading to the perception that issues related to vulnerable children are the prerogative of social welfare departments rather than health ministries (Matshalaga & Powell, 2002). It may also result from the shortage of child-focused expertise within most hospitals and the lack of child health-oriented medical and nurse practitioners within Ministries of Health and paediatric departments in developing countries (Ebrahim, 1985).

### Anti-retroviral treatment programmes

Recently the health sector has engaged more strongly in specific HIV/AIDS prevention and mitigation programmes in developing countries. Anti-retroviral treatment rollout and prevention of mother-to-child transmission of HIV (PMTCT) programmes have direct benefits to children affected by HIV/AIDS.

An estimated 6.5 million people in low- and middle-income countries will die in the next two years if they do not receive ART. By mid-2005, only an estimated 970,000 people in these regions were receiving this treatment (WHO, 2005b). The WHO "3 by 5" global target aims to assist rollout of ART to enable 3 million people to receive ART by 2005. The adult ART initiative potentially brings large numbers of vulnerable children – those in the care of sick adults living with HIV/AIDS – in contact with health services. To date, few attempts have been made by health service providers to capitalize on this opportunity by extending the focus in such consultations from individual patients to their affected children, through, for example, the offer of HIV testing to family members and referral of children to community-oriented support services.

Children with HIV/AIDS are dying unnecessar-

ily because of a lack of access to ART (Anabwani et al, 2005; Smart, 2005). While a child comprises one in six AIDS deaths, fewer than one in 20 of those individuals now receiving ARV drugs is under 15 years of age (Chase, 2005). The problems arise mainly from a lack of cheap feasible diagnostic tests for infants, lack of trained health personnel and affordable child-friendly ARV drugs. Prices for paediatric ARVs are five times higher than adult regimens. Simplified treatment guidelines coupled with a range of fixed-dose combinations of ARVs that require only one or two pills twice a day make it easier to treat HIV/AIDS in adults. Development of simplified drugs regimens for children lags far behind.

**Children with HIV/AIDS are dying unnecessarily because of a lack of access to ART.**

Current global efforts to scale up access to treatment make a clear commitment to include infants and children. Compared to adults, HIV disease in children is more aggressive and proportionately more children than adults living with HIV/AIDS meet the requirements to commence ART. The '3 by 5' initiative aimed to include children in at least 10–15% of all treatment programmes. Of 12,000 patients who accessed ART by early 2004 in Médecins Sans Frontières projects, only 700 (6%) were children under 15 years of age (WHO, 2004). Most global initiatives and national programmes for HIV care, support and treatment do not have quantitative targets nor clearly defined strategies for including children (UNICEF, 2004). Hardly any health facilities offer integrated adult and paediatric HIV/AIDS services that reduce opportunity costs for affected families and avoid duplication of health services.

In 2004, UNICEF hosted a consultative meeting in Lusaka, Zambia, and a global consultation in New York entitled "Reaching out to Children in the WHO "3 by 5" Initiative: Paediatric HIV Care and Treatment". Conclusions reached at these meetings recognized that the response towards equitable access to care, support and treatment of children living with or exposed to HIV will have to be anchored on strong alliances and partnerships with both international and national actors including non-governmental organizations, faith-based organizations and the private sector. Later that year, WHO and UNICEF held a technical consultation entitled: "Improving Access to Appropriate Paediatric ARV Formulations".

The emphasis on making anti-retroviral treat-

ment available to CLHA in sub-Saharan Africa may have unintended consequences. Rather than increasing access to basic care for all CLHA, ART programs may inadvertently result in a two-tier system with excellent services for a minority of CLHA accepted onto their waiting lists, but little attempt to improve the provision of health care for the majority of CLHA. There are concerns that the most “easy to reach” children living in urban areas and most “easy to treat” such as those with more education and higher incomes will receive treatment. ART programs, if not properly conceived and managed, also have the potential to draw well-trained staff and resources away from primary health care service provision, and thereby increase inequity in access to care and treatment for CLHA. In contrast to the primary health care “bottom-up” approach that sees health care centres as the main implementers of health services, treatment services for CLHA have been established predominantly through tertiary and quaternary level facilities in a “top-down” manner.

While ART is undoubtedly an essential element of a comprehensive package, providing care, support and treatment for children living with HIV/AIDS clearly goes beyond simply providing medication. A recent regional workshop on “How

**Table 2. Comprehensive care for children living with HIV/AIDS**

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**Primarily medical**

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Basic medical care  
 Diagnostic and testing services  
 Prophylaxis against opportunistic infections (OI)  
 Appropriate management of HIV and OI (including ART & complementary traditional treatment)  
 Rehabilitation services  
 Palliative care services when the time comes  
 Counselling, education and information about HIV-related illness

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**Primarily social / community**

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Good nutrition for appropriate growth and development  
 Social support (meeting needs of child – food, clothing, shelter, love)  
 Spiritual & psychosocial support  
 Competent caretakers with best interests of child at heart  
 Home-based care  
 Caring for carers  
 Maintaining schooling

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Communities are Coping with CLHA” brought together implementing partners delivering health facility and community based services for CLHA that defined a comprehensive care package, detailed in Table 2 (Miller et al, 2005).

### Prevention of mother-to-child transmission programmes

One of the successes in HIV/AIDS programming has been the prevention of mother-to-child transmission (PMTCT) in some developed countries. Of the 640,000 HIV-positive children throughout the world newly infected during 2004, only 100 were in Europe or North America whilst 560,000 were in Africa (Médecins Sans Frontières, 2005). Progress in expanding access to preventive ARV regimens into severely affected countries has been slow. In sub-Saharan Africa, Botswana is the only country to have completed pilot PMTCT programmes and entered the scale-up phase. Only 10.5% of pregnant African women can access PMTCT services and only 2.2% of HIV-positive African mothers receive preventive ART (UNAIDS 2004; UNICEF/ESARO/HIV, 2004). In addition to reducing the number of children acquiring HIV through vertical transmission, PMTCT provide opportunities to improve the healthy development of children in communities affected by AIDS. PMTCT-plus programmes provide ART to HIV-positive mothers and fathers, benefiting children by prolonging their parents’ healthy lives; some also provide ART to HIV-positive children for whom attempts to prevent HIV prevention have failed. But PMTCT programmes provide, as yet unrealised, entry points for other interventions, such as support for the nutrition of mothers and children through targeted food assistance and antiretroviral treatment (ART) programmes; groups to provide psychosocial support to HIV+ women (WHO, 2003); and programmes to promote children’s development through caregiver sensitisation and support, and opportunities to identify siblings of index children who may also be HIV-infected.

Children in PMTCT programmes living with, or exposed to, HIV and ART require closer follow-up than is currently being done, for early identification of problems. For CLHA on ART, this involves managing their medication and monitoring the impact of treatment, including drug toxicity. But most CLHA identified through PMTCT programmes do not receive ART, nor are most likely to access treatment in the immediate future. These children are at risk of imminent death and



need to be provided with services supervised by healthworkers. In addition, children exposed to maternal HIV need special health services. These services include, as a minimum:

- Regular follow-up by health workers of children identified to be HIV-infected to monitor and respond to nutritional problems and opportunistic infections.
- Cotrimoxazole prophylaxis to all children exposed to HIV infection until seropositivity has been ruled out and the mother is no longer breastfeeding, and indefinitely to all HIV-positive children not on ART (WHO/UNAIDS/UNICEF, 2004).
- Counseling of caregivers concerning the importance of obtaining early medical assessment for young children exposed to HIV and CLHA for all but minor illnesses.
- Closely supervised basic medical services including health education to mothers and other caregivers on the maintenance of nutrition and the importance of recognizing and promptly treating acute respiratory infections and diarrhoeal disease for both CLHA and infants offered replacement feeding or early weaning.
- Access to HIV testing for HIV exposed children.

Over three-quarters of children in contact with health services through PMTCT programmes are not infected with HIV. These children are nonetheless at risk; firstly, because they are exposed

to HIV and perhaps ART and, secondly, because they are in the care of mothers and other caregivers living with HIV/AIDS. Exposed children need health care in order to reduce their risk of HIV transmission through provision of appropriate advice concerning feeding.

If they are being artificially fed or have discontinued breastfeeding early, they need specific guidance to prevent diarrhoeal disease, respiratory infections and malnutrition.

In addition, these children are at risk because of their mother's predisposition to anxiety,

depression and illness. Some children in PMTCT programmes are orphaned in infancy and are looked after by substitute caregivers. Young children that are maternally orphaned or whose mothers are seriously ill have a higher risk of morbidity and mortality than children whose mothers are well. Children with sick parents are more likely to suffer malnutrition since nutritious foods may become less available for economic reasons and sick mothers are unable to spend time feeding young children (World Bank, 1999). For this reason, children's nutrition and access to education may sometimes improve after the death of parents from AIDS (Gilborn et al, 2001). Increasingly, it is being recognised that young children under these conditions may receive inadequate care, supervision and psychosocial stimulation because their caregivers are preoccupied by stress, depressed, or socially isolated with limited material support (Patel et al, 2004; Rochat et al, 2006; Stein et al, 2005). Few attempts have been made through PMTCT programmes to build services that recognize the need to protect the health and development of young uninfected HIV exposed children who are living with HIV-positive parents.

### Opportunities for health systems through increasing HIV/AIDS resource provision

The lowest child mortality rates in Africa occurred in the 1970s. In the mid 1980s, the rate of decline in child mortality rates slowed significantly, with some countries even experiencing reversals (WHO, 2005a). Overall, there was an alarming deterioration in the effectiveness of health systems. Immunization coverage rates and the proportion of women receiving skilled attendance at birth – two key indicators of effectiveness – declined in many countries in sub-Saharan Africa. Although the impact of HIV/AIDS has been blamed for the reversals in health gains witnessed in many African countries (Adetunji, 2000), the decline predates the emergence of the HIV/AIDS epidemic and relates to the economic crises in the African region and structural adjustments and other reactions that severely undermined social sector spending (Samba, 2004).

Increased financing in response to HIV/AIDS provides an opportunity to expand the coverage of ART and PMTCT programmes that directly benefit children. Scaled up responses also present ministries of health with opportunities to improve the capacity and increase the skills of health

Few attempts have been made through PMTCT programmes to build services that recognize the need to protect the health and development of young uninfected HIV exposed children who are living with HIV-positive parents.

... there is growing recognition that the rapid scale-up of treatment access requires a functional and effective health system ... Vertical ART programmes will undermine the provision of primary health care.

service providers through strengthening infrastructure and health delivery systems. Following the global commitment made to widening treatment access, there has been growing recognition that the rapid scale-up of treatment access requires a functional and effective health system. The heads of state of the Southern African Development Community (SADC) resolved in the 2003 Maseru Declaration to promote responses to HIV and AIDS through strengthened health systems. The Pan African Treatment Access Movement (PATAM) also resolved in 2004 that the 'rollout of anti-retroviral therapy be entwined with rebuilding our health systems'. The EQUINET regional conference in June 2004 asserted that the expansion of ART was an urgent priority that needed to be addressed 'through funding and approaches that strengthen, and do not compromise, our public health services and systems' (McCoy, 2005).

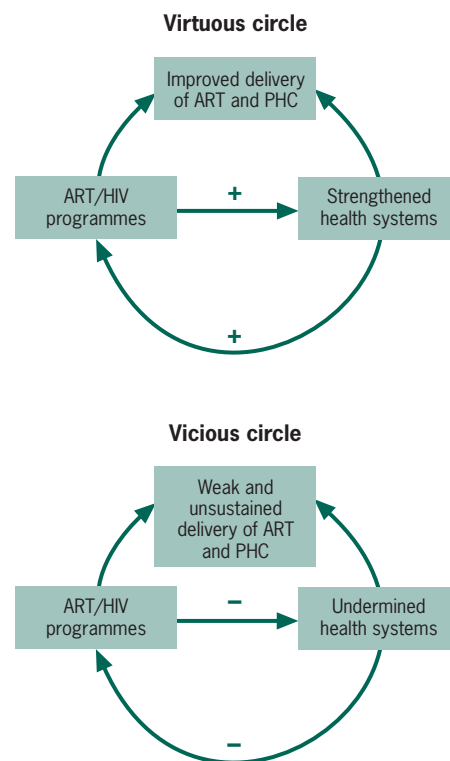
The potential for both negative and positive effects on health care systems (Cornia et al, 2002) can be conceptualised in terms of treatment programmes being caught up within either a 'vicious' or 'virtuous' cycle.

- The 'virtuous cycle' sees an increase in funding for primary health care systems, increasing access and communities empowered to have a variety of choices for comprehensive care at every stage along the continuum of the AIDS epidemic. It also sees ART programmes expanding access to treatment whilst simultaneously strengthening the health care system and reducing health care inequities with positive outcomes both for ART and for primary health care more generally (Figure 12).
- The 'vicious cycle' sees expensive vertical ART programmes focusing only on HIV-positive children and undermining the provision of primary health care to all vulnerable children, as well as negatively affecting the broader health system and the long-term success of treatment programmes.

Initially, AIDS was defined as a health issue, to be handled by health ministries in poor countries and the health departments of aid agencies.

Gradually, AIDS was redefined as a development issue, requiring a multi-sectoral response. However, the ways in which multi-sectoral responses are coordinated remains poorly defined and has been assigned to bodies that lack the necessary capacity, expertise, authority and resources, such as national AIDS committees and vertical programmes. Responsibility has moved away from public health professionals who are trained to appreciate socio-economic dimensions underlying disease and to lead multi-sectoral responses through structures that reach into affected communities. At national level, the advent of effective and simplified interventions and of cheaper ARV drugs has provided governments with the opportunity to spearhead effective national HIV/AIDS responses. Ministries of health have a comparative advantage in implementing systemic approaches to HIV/AIDS responses. Capable people in well-organised institutions are critically needed to lead multisectoral responses and the health sector is particularly well placed to assume this role.

**Figure 12. Vicious and virtuous cycles of ART/HIV programmes and PHC provision (McCoy, 2005)**



## Primary health care and children's healthy development

In 1978, at a joint WHO-UNICEF Conference, the governments of 134 countries and voluntary agencies endorsed the concept of primary health care (PHC) as the way to achieve "Health for All by the Year 2000". PHC was defined as "essential health care made universally accessible to individuals and families in the community by means acceptable to them, through their full participation and at a cost the community and country can afford". In addition to adopting health measures to prevent and treat diseases, this Alma Ata Declaration also affirmed the importance of approaches involving food security, water and sanitation and health promotion. PHC, with its stress on political commitment to equitable socioeconomic development and community participation in its implementation, articulated the founding principles underlying the response of health ministries of developing countries, and of WHO.

There are similarities between the issues leading to the declaration and those surrounding the HIV/AIDS epidemic, nearly thirty years later. At the time of the Alma Ata Declaration, there was an excessive emphasis on hospital-based delivery of curative services and little appreciation by the health sector of the need to influence socioeconomic conditions underlying most ill-health in developing countries. Multisectoral responses to childhood malnutrition were crucial factors reinforcing the PHC approach, since malnutrition was the underlying cause (as it still is) of most deaths, as well as poor development amongst children under five years of age. This highlighted the need for health services to address the social dimensions of disease in order to prevent them, minimise their clinical manifestations, promote recovery, and reduce their reoccurrence.

Throughout the 1980's, UNICEF and WHO targeted selective approaches to child health based on the promotion of GOBI (growth monitoring; oral rehydration, breastfeeding, and immunization) and GOBI-FFF (family spacing, female education, and food supplementation) principles. The approach was effective in dramatically reducing deaths from diarrhoea and deaths that could be prevented by immunization – but had little impact on malnutrition, which is the product of underlying social conditions such as poverty, female illiteracy and disempowerment. The impact of disease-specific approaches, such as the control of diarrhoeal disease (CDD) and the management of acute respiratory infections (ARI) also led to

reductions in specific disease mortality, but these approaches also did little to affect levels of underlying childhood malnutrition, which increased in some sub-Saharan Africa countries in the 1980's and 90's, and thus had limited impacts on overall childhood mortality (WHO, 2005a).

In 1992, WHO and UNICEF initiated a syndromic rather than a disease-oriented approach to child health and development, called the integrated management of childhood illness (IMCI). Unlike GOBI, CDD and ARI programmes, this approach accommodates the holistic needs of children within the context of their families and communities. IMCI initially focused on two main components: improving the case management skills of health workers and improving management systems within the health sector concerned with childhood illness. But the IMCI approach is not limited to service delivery by the health sector. In keeping with the PHC approach and Alma Ata, IMCI also stresses the importance of community participation. In 1997/98, UNICEF was instrumental in developing a "community" component of IMCI – improving family and community health practices – that builds on lessons learned by civil society in relation to child health and development, including the importance of:

- Closer links between health facilities and the communities they serve
- Improved care outside of health facilities
- Integrated promotion of key family practices critical for child health and nutrition
- Multi-sectoral approaches to child health and development.

In 1997, with support from USAID, the CORE (Child Survival Collaboration and Resources) initiative, composed of 37 international NGOs, was established. This initiative sought to advance *Community IMCI* and, in particular, stressed the importance of partnerships between health facilities and the communities they serve. The concept of a multi-sectoral platform for child health, nutrition, and development, an approach similar to what was known as "Comprehensive Primary Health Care", recognized the need for health centres to act as hubs for networking in areas as diverse as income generation, education, agriculture, social and political structures and water and sanitation.

While UNICEF had overall responsibility for Community IMCI, WHO began to explore ways in which to promote children's healthy development

### **Integrated Management of Childhood Illnesses (IMCI) (WHO, 2005c)**

IMCI is an integrated approach to child health that focuses on the well-being of the whole child. IMCI aims to reduce death, illness and disability, and to promote improved growth and development among children under 5 years of age. IMCI includes both preventive and curative elements that are implemented by families and communities as well as by health facilities.

#### ***What does IMCI strive to do?***

In health facilities, the IMCI strategy promotes the accurate identification of childhood illnesses in outpatient settings, ensures appropriate combined treatment of all major illnesses, strengthens the counselling of caretakers, and speeds up the referral of severely ill children. In the home setting, it promotes appropriate careseeking behaviours, improved nutrition and preventative care, and the correct implementation of prescribed care.

#### ***Why is IMCI better than single-condition approaches?***

Children brought for medical treatment in the developing world are often suffering from more than one condition, making a single diagnosis impossible. IMCI is an integrated strategy, which takes into account the variety of factors that put children at serious risk. It ensures the combined treatment of the major childhood illnesses, emphasizing prevention of disease through immunization and improved nutrition.

#### ***How does IMCI accomplish these goals?***

Introducing and implementing the IMCI strategy in a country is a phased process that requires a great deal of coordination among existing health programmes and services.

The main steps involve:

- Adopting an integrated approach to child health and development in the national health policy.
- Adapting the standard IMCI clinical guidelines to the country's needs, available drugs, policies, and to the local foods and language used by the population.
- Upgrading care in local clinics by training health workers in new methods to examine and treat children, and to effectively counsel parents.
- Making upgraded care possible by ensuring that enough of the right low-cost medicines and simple equipment are available.
- Strengthening care in hospitals for those children too sick to be treated in an outpatient clinic.
- Developing support mechanisms within communities for preventing disease, for helping families to care for sick children, and for getting children to clinics or hospitals when needed.

#### ***What are the 3 main components of the strategy?***

The strategy includes three main components:

- Improving case management skills of health-care staff
- Improving overall health systems
- Improving family and community health practices

within IMCI. In 1999 WHO commissioned an extensive review that concluded that combined psychosocial and nutritional interventions to improve children's growth and psychological development have synergistic effects that exceed the separate benefits of psychological interventions to support psychological development and nutrition interventions to support physical growth (Pelto et al, 1999). This was followed by a second comprehensive review that stressed the importance of children's care in the context of childrearing relationships with supportive adults, and the way in which care, including affection, support and stimulation, was affected by social and economic circumstances (Richter, 2004b). Building on the reviews, and knowledge gained from UNICEF's Care Initiative (1997), an additional module, *Care for Development*, was developed for inclusion in the IMCI algorithm.<sup>1</sup> The module targets vulnerable young children and aims to improve the knowledge and skills of caregivers to:

- Strengthen active and responsive feeding to improve nutrition and growth
- Introduce activities to improve interactions with children, to stimulate growth and learning, and to promote responsive care for children's health
- Engage in specific play and communication activities to help children move to the next steps in their development.

In 2003, WHO launched an integrated management approach to chronic HIV care with ARV therapy and prevention, as part of efforts to support the 3by5 scale-up. IMAI (the integrated management of adolescent and adult illness) was developed to complement the IMCI materials. The IMCI was modified to better address case detection and HIV testing of HIV-infected infants and their follow-up care, including co-trimoxazole prophylaxis. The IMAI/IMCI materials support a transition from exclusively acute to good chronic HIV care, based on forming clinical teams and empowering clients in self-management.<sup>2</sup> The paediatric section of the IMAI/IMCI Chronic HIV Care with ART and Prevention guideline module includes simplified, operationalized guidelines for psychosocial support, including age-specific

advise on disclosure of the child's HIV infection and support for development (based on the Care for Development module), advice on linking children and their caregivers with relevant support and guidance in the community and other sectors.

**Example of table from IMAI/IMCI Chronic HIV Care**

**Encourage and help caregiver to:**

- |                |  |
|----------------|--|
| <b>Assess</b>  | <ul style="list-style-type: none"> <li>● Family needs: psychological needs, social with special attention to stigma, financial needs linked to lack of income due to illness and death, practical needs particularly concerning child care, legal assistance</li> <li>● Specific needs of children in the family: quality of care and support; state of health and nutrition; exposure to developmental stimuli such as communication, play, school, learning, recreational activities; psychological conditions linked to fear and understanding of the family member's HIV status; role in caring for parent/siblings and providing for the family; exposure to discrimination, exploitation, abuse, loss of inheritance rights.</li> <li>● Availability of further adult resources in family or community to fill gaps and/or provide continued care and support for the children.</li> <li>● Caregiver's own support and guidance needs, in relation to issues such as disclosure, children's rights, coping with stigma, accessing available services.</li> </ul> |
| <b>Advise</b>  | <ul style="list-style-type: none"> <li>● Disclose HIV status of a family member to children gradually and in an age-appropriate way</li> </ul>   |
| <b>Agree</b>   | <ul style="list-style-type: none"> <li>● Develop a plan addressing assessed needs.</li> <li>● Make sure children are involved in plans for their future.</li> </ul>  |
| <b>Arrange</b> | <ul style="list-style-type: none"> <li>● Link with relevant support and guidance services available in the community, such as social welfare, income generation activities, home care, peer support, spiritual support, organizations of PLWHAs.</li> <li>● Link with relevant services for children, such as schools, day-care, educational, artistic and recreational activities, peer groups for older children, child-counselling, services providing school fees, community volunteer support services, meals for children.</li> </ul>  |

These guidelines are accompanied by a short training course which can be taken by nurses or other clinicians on the clinical team. The course can also be taken by PLHA or other lay providers

<sup>1</sup> [http://www.who.int/child-adolescent-health/New\\_Publications/IMCI/IMCI\\_Care.pdf](http://www.who.int/child-adolescent-health/New_Publications/IMCI/IMCI_Care.pdf). Accessed July 2005.  
<sup>2</sup> To access IMAI/IMCI go to <http://www.who.int/hiv/capacity/en>

who have been trained and paid to join the clinical team to provide counselling services and to link with community activities or by community health workers.

### **Advantages of the health sector in spearheading multi-sectoral child-focused HIV/AIDS responses**

The foregoing discussion builds the case for HIV/AIDS health interventions to move beyond vertical programmes if they are to effect lasting changes for children living in affected communities. Currently, health services are primarily focused on scaling up ART and PMTCT programmes. Lessons learned over the last three decades demonstrate the importance of a public health approach and of engaging with civil society and communities in order to bring sustainable improvements in the healthy development of all groups of vulnerable children living in communities affected by HIV/AIDS. In what follows, we outline the advantages that the health sector, in general, and the World Health Organisation, in particular, have in developing a comprehensive PHC approach to all categories of children living in communities affected by HIV/AIDS.

#### ***A holistic view of health that accommodates multi-sectoral responses***

WHO and its many partners, including in-country ministries of health, is committed to a holistic view of health that goes beyond the treatment of illness. As reiterated in the Alma Ata Declaration (1978), WHO advocates an approach to

health that is holistic and that recognizes the importance of underlying social, economic, religious and cultural factors and institutions. Health ministries bring a considerable amount of experience of strengthening systems to support

children's healthy development in communities affected by HIV/AIDS, and they also have comparative advantages in relation to the responses of governments and intergovernmental organisations. Public health professionals responsible for the design of health systems come from a discipline steeped in the multi-sectoral approach

**Advantages that the health sector has in developing a comprehensive PHC approach to all categories of children living in communities affected by HIV/AIDS.**

to disease prevention and health promotion. Such an approach is highly relevant to children living in communities affected by HIV/AIDS, and includes economics and health, food security and nutrition, literacy and education, psychological factors relating to well-being, rehabilitation and child development, and preventive aspects including health promotion and the importance of water and sanitation to health.

#### ***A strong emphasis on children, including vulnerable and young children***

The health sector embodies a commitment to providing services to difficult-to-reach populations, and does this with considerable success, for example, with respect to immunization. Maternal and child health services comprise more than half of the workload of the health services and, more than any other sector, is in regular contact with children under 5 and their families. Despite this, many children still do not benefit from comprehensive and integrated care. The need to extend the reach of health services is the key theme of the 2005 World Health Report: *Make Every Mother and Child Count*. The report emphasizes that "As child health programmes continue to move towards integration it is necessary to progress towards universal coverage" (WHO, 2005d, p12).

#### ***Considerable infrastructure***

Ministries of health enter communities through health centres and outreach workers. Although the reach of health services is by no means complete, in general, they have more infrastructure and are better organised and coordinated with available referral options, than any other formal system of services in poor communities, including schools. The health sector also has a strong commitment to a systems approach through district, provincial, and national supervisory tiers. Policy in the health sector is implemented in integrated ways through these systems. The central government departments responsible for social services often do not have systems in place to coordinate and integrate services, including those provided by the non-governmental sector. For this reason, they have been unable to control the proliferation of orphanages established to care for children affected by HIV/AIDS, even though institutionalisation has been specifically excluded as an option in international and national policy documents. Ministries of health also have a comparatively stronger commitment and capacity for monitoring

and evaluation which, in turn, is supported by health information systems and research.

***Health is one of the most important ministries within central government***

The health of the population is critical to national socio-economic development and Ministries of Health control substantial budgets, sometimes up to 16 per cent of total government expenditure. The health sector is well-situated to influence agendas to improve children's health and well-being because it deals with a single national government ministry or department. In turn, departments of health have extensive reach into communities and interface directly with families and children.

Policies and strategies that are not followed through with implementation plans and training, indicators, monitoring frameworks, budgets and resource allocations are unlikely to be translated into actions to care for and protect vulnerable children and risk remaining as assertions in statements of intent and guidelines. Having a policy is only one component in developing an enabling environment that supports and protects vulnerable children. The processes by which policies are developed and the ways in which they become translated into effective actions that benefit vulnerable children are equally important. The health sector has considerable experience in these processes and needs to bring this expertise to bear in efforts to support children living in communities affected by HIV/AIDS.

**In order to carry forward the recommendations made in this document, considerable effort and resources will have to go in to extending health services and improving their quality.**

**Summary**

There is an important link between early childhood and HIV/AIDS in view of the profound impacts of the epidemic on young children's survival, health and development. Until recently, the health sector paid little attention to the situation of children living with and affected by HIV/AIDS in sub-Saharan Africa. It also had little involvement in international initiatives to improve the healthy development of children by systematically strengthening responses for children affected by HIV/AIDS.

Recently, the health sector has engaged more strongly in specific HIV/AIDS programmes in developing countries through anti-retroviral treatment (ART) and prevention of mother-to-child transmission programmes with direct benefits to children affected by HIV/AIDS. Increased financing for HIV/AIDS provides an opportunity for both negative and positive effects on health care systems. Ministries of Health could use the additional resources to improve the capacity and increase the skills of health service providers through strengthening infrastructure and health delivery systems. But there is also a danger of increasing vertical ART programmes and reducing equity of health service provision.

The concept of primary health care, endorsed by states in 1978, is timely today. PHC's commitment to equity, cost-effectiveness, multi-sectoral approaches, political commitment and community participation are important counters to vertical approaches to services delivery. It is critical that health interventions for HIV/AIDS move beyond vertical programmes if they are to effect lasting changes for those living in affected communities.

## Systemic approaches to promote children's healthy development

To move forward, it will be necessary to go beyond token, palliative remedies for children infected and affected by HIV/AIDS. To provide comprehensive multisectoral programs, governments and international agencies need to develop national and regional blueprints for dealing with children infected and affected by HIV/AIDS. While recognizing distinct local and national issues, these blueprints should set guidelines and parameters for scaled up remedial efforts including distributing expertise across national boundaries and creating opportunities for communities to share lessons learned.

Agreement is growing that what is needed are holistic, integrated responses to children living in communities affected by HIV/AIDS, rather than narrow HIV/AIDS-specific programmes that target so-called AIDS orphans, or provide for only one aspect of children's needs – broad poverty reduction and empowerment strategies, food security, nutrition, access to health care and education, early child care and development, and

home-visiting and assistance to families who are struggling to cope (Dunn, 2005a). In the same vein, efforts to move closer to achieving the Millennium Development Goals (MDGs) have given new impetus to multi- and inter-sectoral linkages and the importance of combining interventions to maximize

improvements, including with respect to maternal and child health (Fay et al, 2005).

There are precedents for such responses to provide care and protection for children. Primary Health Care (PHC) and Education for All (EFA) are examples of integrated approaches, based on considerations of human rights, equity and

justice, as well as participation and inclusion (UNESCO, 2002). EFA is compelling because it improves both the lives of individual children and the socio-economic well-being of countries. Education gives a child a better chance for a full, healthy and secure life. At the same time, it benefits nations because it improves health, reduces poverty, increases labour productivity, and promotes civic participation (World Bank & UNICEF, 2002).

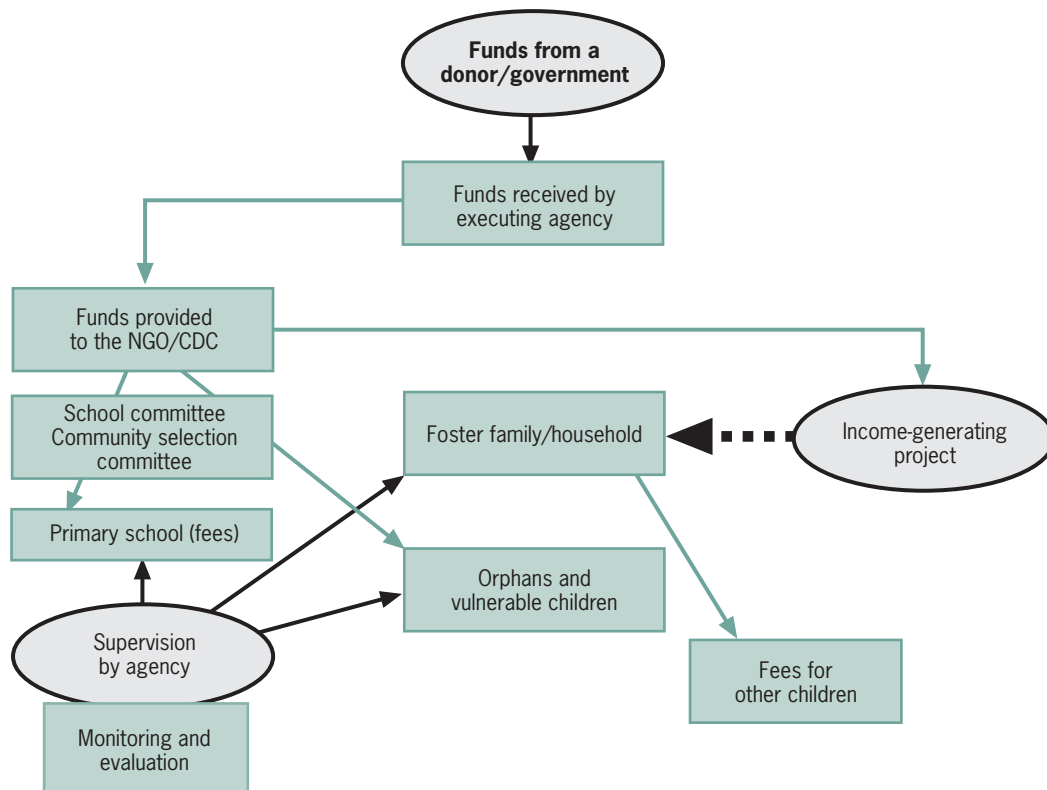
Children living in communities affected by HIV/AIDS are at high risk of not attending school, performing poorly and not completing their education. As a result of this they may be socially and economically marginalized during their childhood and for much of their adult lives. There is consensus in the education sector that the best way of meeting the needs of children affected by AIDS is through mechanisms that achieve Education for All (UNESCO, 2002). Some of the public programmes to achieve EFA include the abolition of school fees, revision of the curriculum, school feeding, increasing the number of teachers, improving the quality of education, and establishing community schools. Non-governmental and community-based initiatives include income-generating activities at the household level, teacher counselling to support vulnerable children, and school fee subsidies for destitute children. Efforts to abolish school fees have been made in Uganda, Kenya, Malawi and Tanzania, with varying degrees of success, depending on financial, planning and organizational resources (Lockheed & Verspoor, 1991). Figure 13 demonstrates the anticipated processes of support needed to enable children in communities affected by HIV/AIDS to receive at least primary education.

It has been proposed that schools should be nodes of care and support for vulnerable children in view of their reach into communities, their enrolment and attendance rates, school feeding schemes and lifeskills programmes, as well as their collaborative relationships with health and social

... what is needed are holistic, integrated responses to children living in communities affected by HIV/AIDS, rather than narrow HIV/AIDS-specific programmes that target so-called AIDS orphans, or provide for only one aspect of children's needs ...



**Figure 13. Flow of funds needed to support the primary education of children living in communities affected by HIV/AIDS (World Bank & UNICEF, 2002)**



development agencies (Giese, 2003; World Bank & UNICEF, 2002; UNAIDS, 2004a). Though this is an appropriate conduit for school-aged children and children enrolled and attending school, for preschool children, children out-of-school, children suffering psychological and mental health impacts of parental illness and death, children living with HIV/AIDS, and disabled children, health facilities and outreach services are better placed as nodes of care. Currently, there is a dearth of health facility-based models in sub-Saharan Africa that map community resources and coordinate with them to create integrated systems that provide for the holistic care and protection of vulnerable children. This is despite the fact that such models are proposed in PHC, and in the later development of comprehensive PHC, community IMCI, and *The Framework* for the care, support and protection of vulnerable children. Such approaches are particularly beneficial to meet the psychosocial needs of children living in communities affected by HIV/AIDS, not just orphans.

Education and health, both essential services to support children’s healthy development, are entry points for government-community-family

linkages. Even at the onset of the AIDS epidemic, a narrow medical effort soon gave way to a massive community response that was largely driven by those most affected by the epidemic, and the same is happening in education.

Health services occupy a unique niche that enables them to lead innovative responses to children living in communities affected by AIDS, in collaboration with a wide range of partners in government, in civil society and with communities and families. Health services have the most far-reaching and frequent contact with children and their families in the countries worst affected by HIV/AIDS – through antenatal visits to prepare women for childbirth and children’s healthy development, through PMTCT programmes, through immunization, growth monitoring and sick child visits to health centres, and through community health worker and home-based care programmes.

**Education and health, both essential services to support children’s healthy development, are entry points for government-community-family linkages.**

Instead of attempting to respond only to orphaned children through narrowly-focused health and psychosocial programmes, the health sector can strengthen the primary health care system, and work through other systems, such as education, to create a broad-based public health approach to improve the health and development of vulnerable children. Many spontaneous programmes to

respond to children affected by war and HIV/AIDS rely on child protection or child welfare committees (Robinson, 2005). While lessons learnt from these structures are not frequently documented, the capacity of health services could help these

... health centres could become nodes of care for children living in communities affected by HIV/AIDS and, together with schools, spearhead "Community Care Coalitions".

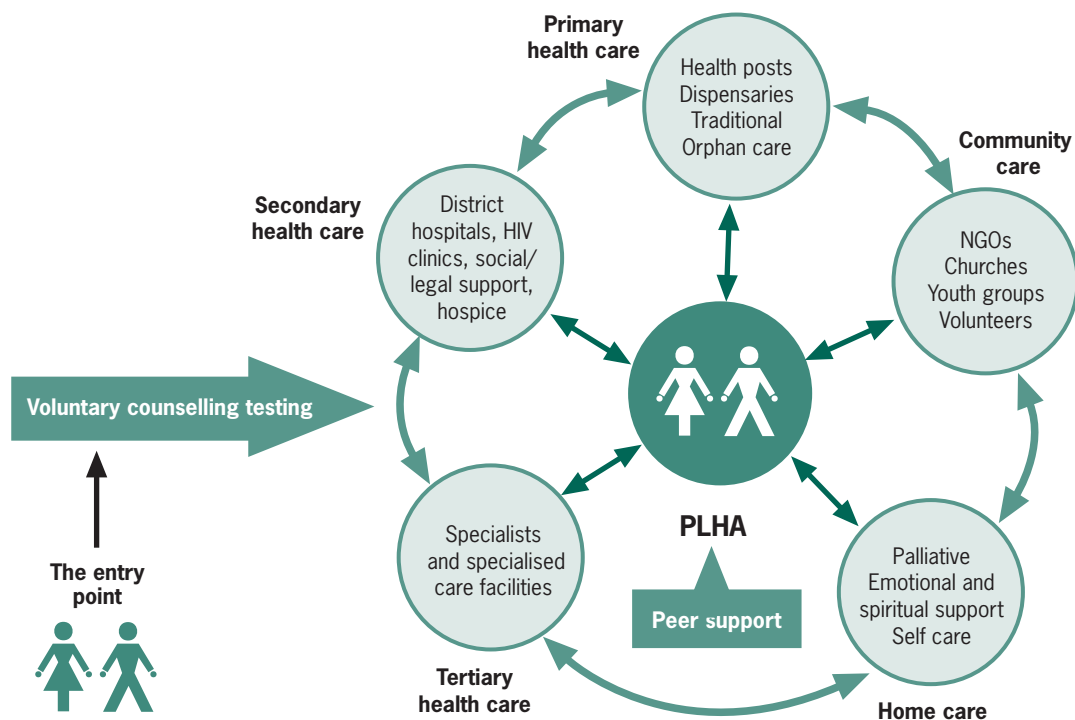
coalitions achieve higher levels of organization, coordination and sustainability. Most importantly, though, health centres could become nodes of care for children living in communities affected by HIV/AIDS and, together with schools, spearhead "Community Care Coalitions".

### HIV/AIDS and the Continuum of Care

In the early 1990's, WHO's Global Programme on AIDS advocated that care and support for people living with HIV/AIDS should be comprehensive – embracing psychological/spiritual, social and medical dimensions – as well as integrated, with various providers offering a "continuum of care" (COC) responding to the clients' many needs (UNAIDS, 2000, p91; Osborne, 1996). The continuum bridges a range of services, including counselling and testing, clinical management, nursing care and community-based support. The provision of care extends from the individual and the home to the hospital, through various levels of care linked with discharge planning and referral networks, and returning back to the individual and the home – in a loop. WHO has promoted this continuum of care concept from a health services perspective with voluntary counselling and testing as the entry point (see Figure 14).

Though it is frequently stated that there should be efficient and effective referral mechanisms between various services and levels of care, the reality is different. It is not at all clear how clients move "across" the continuum. In relation to people living with HIV/AIDS and affected children, the linkage mechanisms for a continuum of care are deficient. Specifically, they need to be improved

Figure 14. The WHO Continuum of Care



within the health delivery system and in the community, between different levels of health services, between the health sector and community-level groups, and between different community groups. Responsibility for establishing and maintaining care networks are in most places poorly defined. (Miller et al, 2005).

**Continuum of care within government health delivery**

In most sub-Saharan African countries, the capacity of health infrastructure does not meet needs. There is inadequate availability of outpatient and inpatient facilities, lack of trained health workers and incomplete drug distribution systems, especially in rural areas. In addition, as described above, the continuum of care within the health sector – the referral and communication mechanisms of the system – functions poorly and targeting of specialized services is poor.

Primary health care clinics are the lowest level treatment facilities and aim to provide management for common and less severe illnesses. The accessibility of primary care clinics is an advantage compared to secondary and tertiary levels, especially for the management of chronic diseases. For example, tuberculosis follow-up rates have been found to be twice as high at health centers compared to hospitals (International Union of Tuberculosis, quoted in Morley & Lovel, 1986).

Health care systems are designed through a continuum that involves referral to secondary (district) or tertiary (provincial) levels for specialized diagnosis or management. Clinic-to-district referrals occur more frequently than district-to-provincial referrals, primarily because of transport costs and staffing differentials, leading to increased dependence on a few central hospitals based in major cities. Referral back to lower levels for management of chronic medical conditions is uncommon, since clinics lack essential drugs and health workers may not be trained in the management of chronic diseases. In practice, throughout most of sub-Saharan Africa, there is little formal communication or referral between the different levels. Public health care systems are urban- and curatively oriented, with over 50% of expenditure in most countries spent in urban hospitals often serving less than 15% of the population. Tertiary level institutions are more expensive because they provide specialized services, though many patients seen at tertiary or district levels could be treated as effectively and

more economically at district or clinic levels. In Zimbabwe, patients with mild illnesses presented directly to tertiary level institutions and different levels of institutions had similar mixes of diseases (Sanders et al, 1998). For example, 69% of visits to a referral hospital in Cape Town by HIV-infected patients were considered suitable for primary care (Metrikin et al, 1995). The main determinant of utilization of the different levels of health facility is the patient’s proximity to the facility rather than the nature of their illness and the need for more specialized management.

**Continuum of care between health centres and other groups and institutions in the community**

Home based care (HBC) programmes have proliferated throughout Africa in the past two decades (Russell & Schneider, 2000). By 1993, there were at least 67 home care projects in Zimbabwe and by 1996, the Ministry of Health of Zambia estimated there were over 100 home care projects (Blinkhoff et al, 1999). Hospital-outreach HBC models were the first to be established but these were costly and unable to provide the types of non-medical services needed by large numbers of clients in the community. Five additional models of community home-based care (CHBC) programmes have been developed. These are:

- NGO-based
- Faith-based
- Community-rooted
- Support groups for PLHAs
- Self-help groups (Ogden et al, 2004).

Despite the proliferation of community HBC programmes, and community responses supporting vulnerable children, there have been few attempts by health services to establish strong linkages with community-based initiatives (O’Hare et al, 2005). In a study of 21 health centres in South Africa, all health workers interviewed acknowledged the importance of health outreach services, but only five were operating such outreach, due largely to lack of transport or staff. There were few examples where health centres were able or willing to

**Despite the proliferation of community HBC programmes, and community responses supporting vulnerable children, there have been few attempts by health services to establish strong linkages with community-based initiatives.**

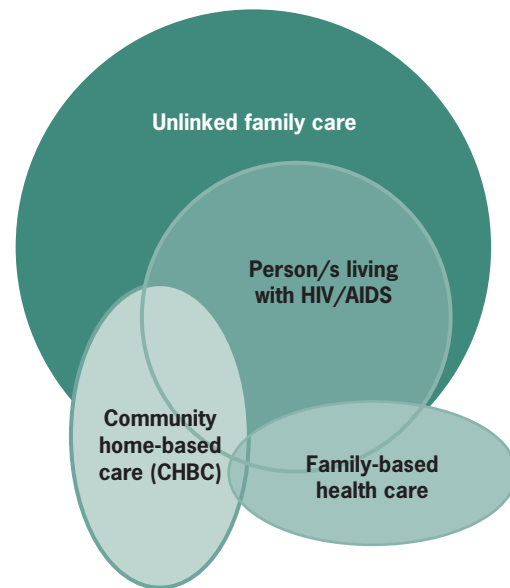
**Faith-based care at home: Integrated health system-community care for people with HIV/AIDS and TB in Zambia**

In 1993, Ndola Catholic Diocese established an AIDS Department in which home care was a priority. The area has 23 townships with a population of some 400,000 people. By 1998, over 5,500 patients were registered with the programme and over 10,000 patients had received assistance in the previous five years. Coverage was estimated to be 78 per cent of chronically ill patients. The Department employs six full-time staff, including one doctor and one clinical officer. A total of 28 nurses work in the 23 compounds where the programme operates, with 10 being seconded by District Health Management Teams (DHMTs). In addition the programme is implemented by over 500 volunteers. The cost of the programme was around \$5 per patient with over half the money being spent on welfare support (food, clothing, blankets and bed sheets) or drugs and equipment. Other contributions by community members to households with chronically ill patients included practical help such as cleaning the house, washing clothes, fetching water, collecting firewood and cooking meals. In addition to the Catholic Diocese and Ministry of Health through its DHMTs and hospitals, the programme also involves local NGOs and community groups, the World Food Programme, local businesses and the Victim Support Unit of the Zambian Police (Blinkhoff et al., 1999).

provide support, food or medical supplies to home-based organizations or volunteers (Giese et al, 2003b).

Studies of care provision for PLHA in Africa suggest that around 90% of HIV-positive people do not access basic health care from health facilities, due to lack of resources, lack of trust in the system or other reasons (UNAIDS, 2002, quoted in SCF, 2004; World Health Organisation, 2001). In addition, only 12% of people living with HIV/AIDS receive support from a community home-based care programme (UNAIDS, 2004b). Figure 15 depicts the limited overlap between community home-based care programmes and health services.

**Figure 15. Care provision for people living with HIV/AIDS in Africa (Ogden et al, 2004)**



There is little communication and referral between facility-based health care and community-based home care systems

**Continuum of care involving community groups and non-health institutions**

The continuum of care for PLHA and children affected by or living with HIV/AIDS is least developed in relation to non-health government institutions (such as schools, agricultural services and justice systems) and community groups (including CHBC and programmes for vulnerable children, faith communities, preschools and crèches, cooperatives, credit associations, and self-help PLHA support groups). In South Africa, where teachers were sensitive to the vulnerabilities of their learners, they often felt frustrated by the inadequacy of options for referral to other services or lacked knowledge about who to refer children to, and what services were provided by the state and the non-governmental sector (Giese et al, 2003b).

The HIV/AIDS epidemic has led to a remarkable proliferation of community home-based care programmes, support groups for people living with HIV/AIDS and initiatives to support vulnerable children. In addition, “community safety nets” made up of existing groups and individuals within communities have modified their approaches in response to needs highlighted by the HIV/AIDS epidemic (Foster, 2005b). A study from Malawi asked members of rural communities to describe care and support structures that existed for their

**Table 3. Perceived efficacy of existing support structures**

Agency	Strength	Weakness
Agricultural	Always around the village	
Extension workers	Provide information to women and children on farming methods Provide loans for fertilizer (especially for tobacco)	
Health surveillance assistants	Get along well with the assistants Providesome useful information	Do not visit the community often
Community development assistants	Encourage the community to build schools and health centres	Do not visit the community often Register orphans but do not return
NGOs (e.g World Vision, Save the Children)	Bring development to the community	Register orphans but don't come back
Traditional healers	Tell you who is bewitching you Understand the community Effective if someone wants luck	Bring enmity among kinsmen Cannot cure AIDS
Traditional birth attendants	Readily available to help deliver children	
Church committees	Help caring for the sick and say prayers	Do not help with orphan care
Grocery and other stores	Sell over the counter drugs	Don't educate people on proper use of drugs
Health facilities (hospitals and clinics)	Care for the chronically ill Doctor examines patient	Situated too far from the community Don't really tell you what is wrong No drugs, or only give "aspirin" or "fansidar" for every illness

children. Table 3 illustrates the strengths and weaknesses of various groups and individuals that play a role in supporting CCA (Cook et al., 1998).

The reality of the continuum of care at community level is that concerned groups and individuals are identifying increasing numbers of vulnerable children, including some who are infected with HIV. Volunteers and staff of child-oriented organizations are placed in the impossible position of having to respond to the overwhelming numbers of sick children and adolescents, in the absence of any clear recognition, resources or structures within which illness and vulnerability, and their consequences (medical, social and emotional) can be managed.

**Continuum of care and children affected by HIV/AIDS – Rethinking the Continuum of Care**

Most community home-based care programmes and support groups for people living with HIV/AIDS focus on adult illness, and seem to fail to recognise that sick adults are surrounded by vulnerable children. Many programmes that do focus on children, limit their response by providing aid and support only to children orphaned

**Quotes from home-based carers (Giese et al, 2003)**

“We don't support children as such. We don't care for the children, we just care for adult patients”

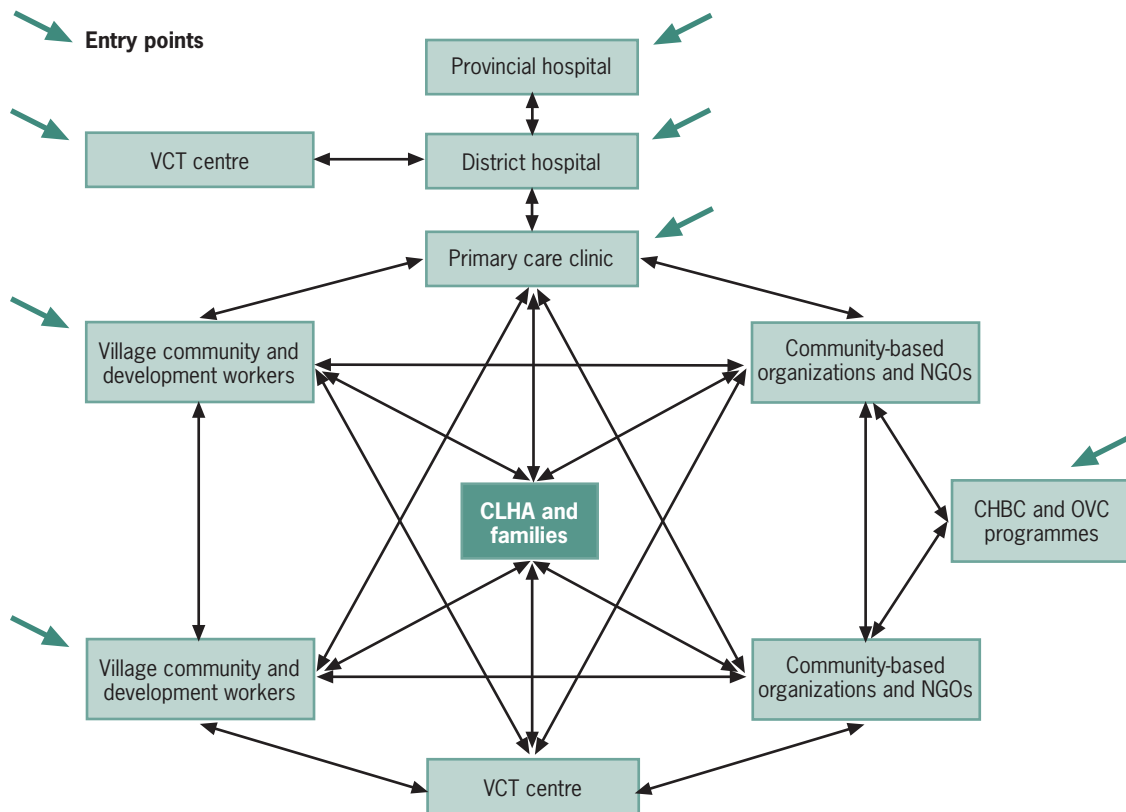
“It is not part of our institution to look for children with TB or HIV/AIDS”

“We never focus on children, we hope that other organisations are focusing on children ... We think like that. We hope, but it doesn't seem to work like that.”

by AIDS. HIV/AIDS service providers, such as home-based carers, health workers and teachers, must be encouraged to view every contact with a child or a caregiver as an opportunity to identify, assist with, or prevent child vulnerability.

An analysis of the continuum of care for CLHA recognised that most vulnerable children affected by or living with HIV/AIDS are being identified and cared for by community groups outside the health sector (see Figure 16). There are few, if any, structures and networks to ensure that vulnerable children are assessed with a view to meeting their

Figure 16. Extending the continuum of care for children living with HIV/AIDS (Miller et al, 2005)



needs in a holistic way through the provision of a seamless system of care and support at institutional and community level. The issue of children affected by HIV/AIDS provides a unique opportunity to advance the recently refined concept of “comprehensive primary health care”. Just as children’s health was a precipitating factor leading to advances in the primary health care movement three decades ago, so also can children affected by HIV/AIDS can serve to advance notions of integrated care activities between health services and community structures with holistic responses combining medical, social, psychological and spiritual support for vulnerable children.

**Summary**

Given the magnitude and duration of the AIDS epidemic, narrow interventions to support children need to give way to holistic approaches that strengthen the systems on which children’s health and development depend. In addition to families and communities, health and education services can be entry points for state-community-family linkages. Primary Health Care and Education for

**Just as children’s health was a precipitating factor leading to advances in the primary health care movement three decades ago, so also can children affected by HIV/AIDS can serve to advance notions of integrated care activities between health services and community structures with holistic responses combining medical, social, psychological and spiritual support for vulnerable children.**

All are examples of systematic efforts to improve children’s outcomes on a large scale.

In developing countries worst affected by the AIDS epidemic, the health sector has the furthest reach and most frequent contact with young children and their caregivers through, for example, antenatal care, immunization and sick baby services. Through outreach activities, such as community health workers and home-based care, health services could become nodes of care for the organization of a continuum of community services for affected children and their families.

## Chapter 7

# The role of the health sector in strengthening support systems for children

The health sector in general, and WHO in particular, has a long history in programmes to strengthen health, school and community efforts to prevent and treat illness, support vulnerable children and promote their growth and development. These programmes include, amongst others, advocacy directed at governments and aid agencies, research, product development,

the application of the programme development cycle to test and evaluate new initiatives, norm-setting for best practice, creating bridges between health centres and communities, and supporting in-country implementation. In these efforts, many valuable lessons are available to enable the health sector to drive and coordinate responses to the needs of children in communities affected by HIV/AIDS.

Experience available to the health sector includes:

### 1. Promoting a holistic view of health and development

WHO has long advocated that health is not merely the absence of disease or infirmity, but the state of complete physical, mental and social well-being (1948). This definition frames a holistic view of children's health and development, a necessity for an adequate response to children in communities affected by HIV/AIDS. Poverty, income and gender inequalities and lack of access and opportunity are major causes of ill-health, and a public health approach takes these into account in addressing causes and solutions to ill-health and poor development.

The health sector has a long history in programmes to strengthen health, school and community systems to prevent and treat illness, support vulnerable children and promote their growth and development.

### 2. Implementing a public health approach

Public health efforts seek to attain health and well-being for the population as a whole, and to develop cost-effective interventions in areas that represent the largest burden of ill-health, disability and impediments to human development, rather than targeting specific sub-groups of children. It does so by applying a systematic model to ensure that programmes are relevant and effective in addressing major health issues. The model moves in a cycle from research to development to implementation to evaluation. This approach to programming, to ensure that actions are based on the best available scientific evidence from a wide range of disciplines, is a specific strength that WHO brings to efforts to assist children living in communities affected by HIV/AIDS.

### 3. Increasing children's access to health services

Like education, health initiatives strive towards universal coverage, thus spearheading the realization of some of the most fundamental human rights as incorporated into the Convention on the Rights of the Child (CRC) and the African Charter on the Rights and Welfare of the Child.

A commitment to universal access to care is the central theme of the 2005 World Health Report *Make Every Mother and Child Count*.

To realize this, it is recognized that a continuum of care

must be established, covering the full age range of children from conception to adulthood, and requiring strong cooperation between health services, on the one hand, and households and communities on the other.

Like education, health initiatives strive towards universal coverage, thus spearheading the realization of some of children's most fundamental human rights ...

**4. Using strong health services as a platform for risk reduction and health promotion**

Health services provide a platform and vehicle for a wide range of related initiatives. For example, antenatal care provides opportunities also for other health programmes, such as HIV/AIDS prevention and treatment, family planning, efforts to reduce violence against women, and preparation for good child care. All of these efforts contribute to improving the health of both women and children. In the same way, maternal and child health services, outreach health programmes, and home-based care, can all be used to initiate, support and coordinate community-based efforts to provide care and protection for vulnerable children.

**5. Working with schools**

The health sector has initiated and collaborated on a range of school programmes including school health services, child-friendly and health-promoting schools, teaching training programmes and, more recently, FRESH (Focusing Resources on Effective School Health: A FRESH Start to Improving the Quality and Equity of Education). These initiatives have been driven by recognition of the inter-relationships between health and education, and the opportunities schools provide to improve the health and well-being of young people. FRESH is built on many of the principles recommended for interventions for children affected by HIV/AIDS – partnerships between sectors and the active engagement of children in addressing the problems that affect them and the solutions devised to assist them.<sup>1</sup>

**6. Working with civil society organizations (CSOs)**

The health sector recognizes the vital role played by CSOs in providing health services for women and children (2005 World Health Report) through mobilizing political will to effective policy development, holding governments accountable for equitable access and service delivery, and social mobilization efforts to improve children's health and development. All of these are critical to expanding care and support for children in communities affected by AIDS, using the five key strategies of the Framework.

**7. Focusing on nutrition and growth to promote children's development**

Undernutrition remains the major cause of ill-health and mortality among young children.

<sup>1</sup> <http://www.freshschools.org/whatisFRESH.htm>

Improved nutrition focusing on breast-feeding, young child feeding practices, management of protein-energy malnutrition, micronutrient supplementation (iodine, iron, Vitamin A, and zinc), emergency nutrition

to support displaced populations, food aid to address widespread hunger, and food and nutrition policy, including the impact of HIV/AIDS on food security, are all areas in which there is long experience. The established leadership the health sector has in improving nutrition to promote children's healthy development needs to be used to benefit children affected by HIV/AIDS.

The established leadership the health sector has in improving nutrition to promote children's healthy development needs to be used to benefit children affected by HIV/AIDS.

**8. Building bridges between health services and households**

The success achieved in reducing child mortality due to diseases such as diarrhoea and acute respiratory infection demonstrated not only the development and availability of effective drugs and the benefits of training health providers, but also the necessity and capacity of health services to establish successful collaborations with caregivers, households and communities. To be effective, caregivers need, amongst other things, to understand and use oral rehydration fluids, continue to feed young children during illness, and recognize symptoms that necessitate visits, and return visits, to a health worker. IMCI and Community IMCI both recognize the important roles that caregivers, families and other sections of the community play in preventing disease and promoting children's healthy development.

**9. Promoting the development of life skills of children and youth**

Life skills programmes for young people have been developed in response to HIV/AIDS, as well as school health initiatives. Skills-based education for better health and development recognizes that knowledge, attitudes, and values are necessary for health promoting decisions and behaviours. These programmes also address attitudes to gender equality, peer pressure and conflict resolution, providing young people with opportunities to adopt values and behaviours conducive to good health across the life span, not only for themselves, but also to protect the health and well-being of peers and partners.



### 10. Addressing mental health as a key aspect of health

Mental health is a critical part of the overall well-being of people in low-income countries because of the effects of chronic stress associated with poverty, conflict, displacement and loss. The PEIMAC programme (see Chapter 4.2) is a broad-based effort to promote the mental health and development of young children. Other efforts by the health sector include adolescent mental health, suicide and substance abuse prevention; stigma reduction, especially in relation to HIV/AIDS; mental health to support adherence to medical regimens; the integration of mental health into general health care; mental health in emergencies; and policy development to improve mental health, especially in poorly resourced countries. Efforts to provide psychosocial assistance to children affected by HIV/AIDS should also be integrated into health services, education, and other programmes to address other difficulties occasioned by the HIV/AIDS epidemic and poverty.

### 11. Adopting a life course approach to child and youth development

A life course approach moves the focus beyond child survival to optimal physical and psychological development from before birth through childhood and adolescence and into adulthood. The promotion of health and well-being in childhood has an impact on health and adjustment in later years, and damage caused in childhood has lifelong repercussions on functioning and productivity. The health and development needs of children change as they move through the age span and public health interventions must respond to a changing agenda. Age-specific interventions for children affected by HIV/AIDS are sorely needed, as is a concentration of effort on the healthy development of young children, also as an investment in their future well-being.

The Framework sets out five key strategies that can be brought into the work of the health sector, Ministries of Health, health services and outreach activities. HIV/AIDS is driving a new set of relationships between health services and the community. New client groups are accessing services previously tailored for women of reproductive age – men, grandmothers, older siblings, unrelated adults, and teachers are amongst those who might accompany a child for immunization or a sick child visit (Foster, 1998). The complexities of, and important of adherence to TB and ARV treatment have led to new coalitions with communities,

through Directly Observed Treatment (DOT) collaborators and Buddy Clubs. This climate is ripe for health services to become part of, and in some cases give leadership to, broad-based community initiatives to support vulnerable children, particularly through Community Care Coalitions.

Community-based Integrated Management of Child Illness (Community-IMCI) is a health-based initiative that fits well with several other approaches discussed in this review – Comprehensive Primary Health Care, strategies outlined in the Framework, and the concept of Community Care Coalitions. The foundations of Community IMCI are not new. Rather C-IMCI aims to reenergize efforts and strategies to reach vulnerable children and their families, as expressed in the Alma Ata Declaration. As described by CORE (Child Survival **C**ollaboration and **R**esources Group, 1996),<sup>1</sup> what is required to improve child health and development is the following:

1. Closer links between health facilities and the communities they serve;
2. Improved care outside of health facilities;
3. Integrated promotion of key family practices critical for child health and nutrition;
4. A multi-sectoral approach to child health and development.

Integrated strategies to improve children's health and well-being recognize that "the care children receive at home, in their families and in their communities is just as important as the treatment available in health facilities" (CORE et al, 2002, p. 3). For this reason, some of the world's leading development agencies have joined forces to target child health and development at the community level. In founding documents for a community arm of IMCI, it is argued that community-based approaches offer a number of advantages, all of which are consistent with the principles outlined in *The Framework*.

Community-IMCI is a health-based initiative that fits well with several other approaches discussed in this review – Comprehensive Primary Health Care, strategies outlined in the Framework, and the concept of Community Care Coalitions.

<sup>1</sup> www.coregroup.org

A community-based approach:

- “Involves people – by acknowledging the vital role of the immediate community in a child’s health growth and development;
- Adapts to community needs – by recognizing that priorities are best set by the people involved;
- Builds on existing resources – by enhancing community structures and expertise, including positive traditional systems of care;
- Strengthens links – between health services and the people they serve, making them a more valuable community resource;
- Avoids duplication – by working in harmony with single focus health programmes, not in competition with them;
- Builds bridges – between community groups, NGOs and the private sector, both within and outside the fields of health, from mother’s support groups to positive living initiatives, education and development;
- Focuses on outcomes – identifying the key practices needed by families to improve their children’s health, while being flexible enough for countries and communities to adapt the practices;
- Is cost-effective – because it maximizes use of existing resources and focuses on low-cost interventions which have the greatest impact on child health and development;
- Is sustainable – because it is cost-effective, builds on existing structures and responds to the needs and priorities of local people” (CORE et al, 2002, p. 4).<sup>1</sup>

Comprehensive Primary Health Care and Community IMCI, adjusted to prioritise the strategies

outlined in *The Framework*, and working through Community Care Coalitions, is the most appropriate contribution that the health sector can make to the care and protection of children living in communities affected by HIV/AIDS. Efforts to improve the psychosocial well-being of children should be integral to these efforts.

### Summary

The health sector has valuable experience in programmes to strengthen health, school and community efforts to prevent and treat illness, support vulnerable children and promote their growth and development. This is derived from, amongst others, a holistic view of children’s health and development; a public health approach; working with other sectors, such as education, civil society, and families; increasing access to services; emphasising health promotion and risk reduction, including mental health; adopting a life course approach and facilitating the acquisition of life skills among children and youth.

In particular, Community-based Integrated Management of Child Illness (Community-IMCI) is a health-based initiative that fits well with Comprehensive Primary Health Care, strategies outlined in the Framework, and the concept of Community Care Coalitions. Through these mechanisms, the health sector can make an invaluable contribution to the care and protection of children living in communities affected by HIV/AIDS, especially by including efforts to improve the psychosocial wellbeing of children.

**... the care children receive at home, in their families and in their communities is just as important as the treatment available in health facilities.**

<sup>1</sup> www.coregroup.org

## Chapter 8

# Conclusions and recommendations

Children have not, to date, received due attention in the global effort to prevent, treat and ameliorate HIV/AIDS. The impact of the HIV/AIDS epidemic is experienced most severely at the household level because it severely exacerbates poverty. The epidemic is having a progressive and cumulative effect on children by depleting their care resources through parental illness, death, destitution and an increased burden of care on families. This is occurring in a context of generally poor access to services and insufficient support from governments and the international community. In desperate attempts to be of assistance, uncoordinated and sometimes inappropriate actions are being taken to support vulnerable children. Much of the current effort is being directed to orphans, despite the fact that a much larger number of children are deeply affected by the epidemic and in very difficult circumstances. Under these conditions, there is widespread consensus that strengthening systems to support children living in communities affected by HIV/AIDS is the best option for achieving population-level improvements in children's health, their psychosocial well-being and their educational development. The health sector is well placed, through its systematic approach and infrastructure that reaches into most affected communities in developing countries, to lead multi-sectoral responses that facilitate the holistic care and protection of children living in communities affected by HIV/AIDS. While it is acknowledged that the health sector is, in many places, deficient, its potential to play a key role is enormous.

The lives of all children living in communities affected by HIV/AIDS are becoming difficult. Amongst these, sub-groups of children are affected in particular ways. These include children infected with HIV, children living with chronically ill parents, orphaned children, and other categories of vulnerable children. Infected children, especially young children, have received little attention to date, and most of them die prematurely from poverty-related diseases as well as

lack of access to appropriate treatment. The greatest proportion of children born to infected parents are, themselves, uninfected. In general, their survival and development is precarious. Nonetheless, most of them will outlive their caregivers, bearing a large portion of the burden of care for a chronically ill parent. However, the greatest part of available resources and intervention efforts are being directed to orphaned children, not all of whom are vulnerable. Many orphans, especially those who are in the care of close and affectionate family need little additional assistance.

Only time heals the terrible experience of losing a parent during childhood. The families that take them in, however, have to stretch their meagre resources among increasing dependents, and are desperately in need of material, social and spiritual support. Many children are doubly disadvantaged by HIV/AIDS, co-occurring as it does with widespread poverty, as well as conflict and instability. There is a danger that programmes that target orphans may inadvertently label children in damaging ways, undermine spontaneous care by extended kin, misdirect resources to children who may not need external assistance, and overlook large numbers of extremely vulnerable children who are not orphans. In the main, what is needed is improved access of all children and families in AIDS-affected countries to health, education, social welfare, and economic strengthening to improve the health and well-being of the child population.

Community initiatives and extended kin were the first to respond to the needs of affected children, and continue to be in the front line. The emergence of community-based care programmes

**The families that take orphans in have to stretch their meagre resources among increasing dependents, and are desperately in need of material, social and spiritual support.**

is one of the outstanding features among responses to the epidemic. These groups play a critical role in easing the impacts of the epidemic, particularly on children. Extended families absorb the largest portion of the economic costs of the epidemic on households, and effective mechanisms need to be developed to get additional resources to families and communities to enable them to continue to support the worst affected children. The fact that families are absorbing the care of affected children does not mean, however, that they are doing so without tremendous difficulty. The involvement of community and faith-based organizations has enormous potential to alleviate suffering and need to be supported and expanded.

International agencies and governments have been slower to generate responses beyond policy, that match the size and time scale of the problems affecting children and families. What stands out is the *Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*. This is a consensual, authoritative statement of strategy that takes into account available knowledge and experience to date. The Framework recommends a comprehensive approach to affected children, including efforts to support children's healthy development. In particular, the Framework draws attention to the importance of sustaining families and extended kin in their key roles of caring for and protecting children. Despite this, few resources are reaching families and communities, especially households that are already on the edge of poverty. One of the major challenges facing efforts by international and local governments, donors and philanthropic organizations is the development of mechanisms for channeling resources to grassroots organizations and to destitute families.

The distress experienced by children is well recognized, as is the negative impact of the AIDS epidemic on children's development, particularly as a result of inadequate food, health care, declining care and neglect, and exclusion from education. While efforts to support the healthy development of children in communities affected by HIV/AIDS are essential, these do not necessarily require separate programmes to address children's psychosocial needs. Support from families and communities, and also from peers, enable children to cope with extremely difficult circumstances. A key strategy to support children's psychosocial well-being is to promote care as part of their everyday life. For this, caregivers and families need assistance and support.

Children have a multiplicity of needs and there

are age differences in the kind of support children require. The affectionate care of families and communities is the only effective and sustainable way of ensuring children's well-being. Stand-alone psychosocial interventions for children can be seen as foreign and experienced as an imposition. They are also frequently too narrowly focused to meet the needs of children identified as vulnerable. For these reasons, there is agreement that measures to support children's healthy growth and psychosocial well-being should be incorporated into other programmatic responses to the HIV/AIDS epidemic. The available evidence and experience strongly cautions against specialized psychosocial programmes for "AIDS orphans". Lessons learnt in other fields of intervention indicate that efforts to promote children's psychosocial well-being in the face of adversity require that care systems around the child be mobilized and strengthened in an integrated way. It is especially important to counter the institutionalization of vulnerable children. Institutional care does not benefit, and can harm children. In addition, it draws large resources away from efforts to support families and communities who take in vulnerable children.

To date, the health sector has paid little attention to the situation of children living with and affected by HIV/AIDS, especially young children. Both anti-retroviral and prevention of mother-to-child programmes must be expanded. These programmes have the potential to strengthen the health care system, in general, and services for children in particular. They especially need to be extended to promote the healthy development of young uninfected children who are living with HIV-positive parents.

In the current climate, there are clear advantages for the health sector to lead a comprehensive primary care approach to children living in communities affected by HIV/AIDS. These advantages include a number of potentialities that must be energized, including a holistic view of health that accommodates a multi-sectoral response; a strong emphasis on children, especially young children; and considerable infrastructure and reach, as well as influence on national agendas.

**A key strategy to support children's psychosocial well-being is to promote care as part of their everyday life. For this, caregivers and families need assistance and support.**

At a local level, health services, together with education, could establish strong linkages with community-based initiatives to form Community Care Coalitions for children made vulnerable by the epidemic. The health sector has a long history in programmes to strengthen health, school and community systems to prevent and treat illness, support vulnerable children and promote their growth and development. In particular, Community-IMCI is a health-based initiative that fits well with several other approaches deemed to be of benefit to vulnerable children, including Comprehensive Primary Health Care, the UNAIDS-led Framework, and the concept of Community Care Coalitions. What is needed is leadership from the health sector for the development of integrated models; tools for assessment, implementation and evaluation; training programmes; and pilot projects, to take this forward.

The recommendations offered are that the health sector plays the following roles in responding to children living in communities affected by HIV/AIDS:

**1. Give strong guidance to Ministries of Health to lead a holistic response to children in communities affected by AIDS that is founded on the Framework.**

- Given the enormity of the threat to children's health and development, and the knock on effects of poor child health and development to human and social well-being productivity, it is imperative that the reach and influence of Ministries of Health are used to champion the care and protection of children.
- Ministries of Health have a comparative advantage to ensure that investments in the health and development of children are made as early as possible.
- Ministries of Health should ensure that children feature prominently in National Strategic HIV/AIDS Plans and Poverty Reduction Strategy Papers.
- Ministries of Health should also strongly engage in the development and implementation of National Programmes of Action for Vulnerable children.
- The Framework should be used to ensure that interventions driven by Ministries of Health to support children are directed to all vulnerable children in communities affected by AIDS and integrated into other programmes to promote children's well-being.

**2. Use the Framework to promote integrated responses to children based on knowledge and experience gained within the organization and by its partners**

- The provision of substantial resources for paediatric HIV/AIDS responses provides an opportunity to strengthen the provision of primary health care for all vulnerable children. However if not conceived within the broad strategies of the Framework, paediatric ART could develop into a vertical programme that draws resources away from the provision of comprehensive care of children.
- The health sector, WHO and partners have accumulated relevant knowledge and experience concerning vulnerable children in fields such as nutrition, mental health, school health and life skills. Much of this knowledge and experience, including careful evaluation where it has been done, needs to be utilized to good effect to guide current responses to children in communities affected by HIV/AIDS.
- Because many stand-alone psychosocial programmes for children in communities affected by HIV/AIDS are not informed by this experience, they are at risk of having to relearn lessons already well documented. These include the importance of peer leadership in life skills programmes, supportive psychosocial environments for children's development, and mental health promotion to reduce the need for psychiatric services. The health sector should ensure that lessons learned are made available to be incorporated into community programmes.

**3. Promote health centres as nodes of support, working together with community initiatives on the common agenda articulated by the Framework to support children and families.**

- HIV/AIDS is reinforcing adaptations by the health sector by recognizing a broad range of health determinants, necessitating delivery of services in communities as well as in health centres, and by reaching a changed age and gender profile of users, including men, the elderly and young people in traditional maternal and child health services.
- No single agency or organization can provide services that encompass the broad range of needs of children. Nonetheless, health centres are well situated to coordinate

local responses for vulnerable children in view of their proximity to communities and frequent contact with young children and their caregivers

- Given that many affected communities have responded to vulnerable children, health centres should expand and extend outreach programmes to identify and strengthen existing community initiatives through establishing collaborative care coalitions.
- Collaborative care coalitions should bring together the respective strengths of health services and community initiatives. Health services can provide structure, training, supplementary nutrition, treatment, and monitoring. Community groups can contribute by identifying vulnerable children, mobilizing voluntary activities, providing flexible and rapid assistance to families in crisis, and ensuring that families and children receive psychosocial, material and spiritual support. In turn, these collaborative initiatives can increase the reach, uptake and impact of health services.
- A review should be undertaken of the programmatic experience and the evidence on health service–community collaborations and develop tools and training materials to expand successful models.

**4. Strengthen the community component of IMCI and ensure that it used to organize and coordinate health sector responses to children in communities affected by HIV/AIDS**

- The community component of IMCI is conceptually and strategically aligned with The Framework. Both community IMCI and the Framework consider families and

communities to be the foundation of an effective scaled up response to children in communities affected by HIV/AIDS.

- WHO, UNICEF and partners are committed the expansion of IMCI at the community level, have already developed tools and training, country level implementation experience and are conducting evaluations of community IMCI.
- This powerful body of programmatic experience can bring considerable benefits to efforts to promote the health and development of children in communities affected by HIV/AIDS, and should therefore be used to provide a powerful vehicle by which to organize and align health sector contributions to efforts to provide assistance and support to children and families affected by the AIDS epidemic.

**Summary**

1. Give strong guidance to Ministries of Health to lead a holistic response to children in communities affected by AIDS that is founded on the Framework
2. Use the Framework to promote integrated responses to children based on knowledge and experience gained within the health sector and its partners
3. Promote health centres as nodes of support, working together with community initiatives on the common agenda articulated by the Framework to support children and families.
4. Strengthen the community component of IMCI and ensure that it used to organize and coordinate health sector responses to children in communities affected by HIV/AIDS.

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