Chapter 15

The Impact of HIV/AIDS on Orphans and Programme and Policy Responses*

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Summary. As policy makers assess the growing weight of the orphan and children affected by AIDS burden, there are key policy challenges apparent. These challenges relate to (1) reaching consensus on policy related definitions of orphans and vulnerable children, (2) the emergence and realisation of rights based approaches to programming for orphans and vulnerable children, (3) the explication and scaling up of 'good' practices in supporting orphans and vulnerable children, (4) effective flow of 'resources to the base' and finally (5) mobilising political will. These challenge overlap and interrelate, but constitute the key constraints on widespread and effective responses. The synergy needed between community-rooted responses and international and national political will is slowly emerging but is still fundamentally absent. Policy priorities relate to resources primarily, and the balance between community mobilised resources and external financing and intervention. This balance will vary from place to place and current operational research can provide an understanding of economic realities to be combined with the emerging ethical and principle based ethos of programmers. Addressing the psychosocial welfare elements of orphans and children in affected communities is now a matter of urgency. The cycle of infection will be exacerbated by young people growing up in contexts where mental ill health is rife, combined with feelings of isolation, despair and social disenfranchisement. The responses required are in themselves not complex, but are needed at such an unprecedented scale that we are only starting to comprehend the implications. While constraints remain in the form of chronic and deepening poverty, capacity limitations and political indifference at all levels, the challenges facing themselves have never been greater.

JEL: I12, I31, J12, J13

This study presents the views of its authors and not the official UNICEF position in this field.

UNICEF-IRC (www.unicef-icdc.org) Florence, June 2002

This is chapter 15 of the overall study "AIDS, Public Policy and Child Well-Being" edited by Giovanni Andrea Cornia.

AIDS, PUBLIC POLICY AND CHILD WELL-BEING *

edited by Giovanni Andrea Cornia

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***** This project was started in 2000 at the UNICEF's Innocenti Research Centre under the leadership of the Director of the Centre and of the Regional Director of the Eastern and Southern Africa Region Office (ESARO) of UNICEF. Giovanni Andrea Cornia of the University of Florence took care of the framing, implementation and finalisation of the study, with the assistance of Leonardo Menchini. The project could not have been implemented without the support of many colleagues in many UNICEF offices around the world. The financial support of the Italian Government and UNICEF ESARO is gratefully acknowledged. **The papers included in this study present the views of their authors and not those of UNICEF.**

1. Introduction

Every 50 seconds a child dies of an AIDS related illness and another becomes infected with HIV. Each day approximately 3,500 children are infected by, or die from HIV/AIDS (UNAIDS 2000). These figures represent a shocking failure on the part of the global community. Of the estimated 36.1 million people living with HIV/AIDS world-wide, 1.4 million are children. Even if a leveling off of new infections occurs, due to the long incubation period of the virus, mortality rates will not plateau until at least 2020, and the proportion of orphans will remain strikingly high at least through to 2030 (Levine and Foster 2000).

As policy makers assess the growing weight of the orphan and children affected by AIDS burden, there are key policy challenges apparent. This chapter will outline these challenges and attempt to offer some solutions, although the complexity and dynamism of the debates makes even snapshot analysis such as this difficult. These challenges relate to (1) reaching consensus on policy related definitions of orphans and vulnerable children, (2) the emergence and realisation of rights based approaches to programming for orphans and vulnerable children, (3) the explication and scaling up of 'good' practices in supporting orphans and vulnerable children, (4) effective flow of 'resources to the base' and finally (5) mobilising political will. These challenge overlap and interrelate, but constitute the key constraints on widespread and effective responses.

2. Reaching consensus on policy related definitions

Defining the impacts of AIDS on children can be in demographic or social terms. In terms of its demographic impacts, HIV/AIDS affects children in the following ways:

- higher infant and child morbidity and mortality rates
- lower life expectancy
- higher rates of orphaning.

By December 2000, UNAIDS estimated that some 5.7 million children aged under 15 had become infected with HIV, 4.3 million of whom had died of AIDS. Sadly, HIV/AIDS will have the greatest impact in countries that have achieved the most impressive reductions in under five child mortality (see also chapter 13 of this compilation): by 2005-2010, for example, 61 out of every 1,000 infants born in South Africa are expected to die before they are twelve months old. Were it not for AIDS, it is thought that infant mortality would have been as low as 38 deaths per 1,000 children by this time.[1] One study has estimated that, where the prevalence of adult HIV is three per

[1] From 'The children left behind: UNICEF and UNAIDS issue new report on AIDS orphans', press release 1999, UNAIDS.

cent, child mortality will increase by three to six per cent, and where the adult HIV prevalence is ten per cent, mortality will increase by nine to 26 per cent (Nicoll et al. 1994).

Most young children born HIV-positive begin to show symptoms of HIV infection in their first year of life and many show retarded growth and development due to frequent bouts of opportunistic infections (Alidri 2001). A study in Uganda found that roughly a third of HIV-positive children died in their first year, half had died by 21 months and three quarters after five years (Marum et al. 1996). Similarly in Malawi, an estimated 90 per cent of HIV-infected children do not survive beyond their third birthday.[2]

The trend in most developing countries is towards older people outnumbering younger people, but the decrease in life expectancy caused by the AIDS epidemic means that the reverse will remain true in sub-Saharan Africa. By 2020, nearly 90 per cent of the world's children aged under 15 will be living in developing countries. In sub-Saharan Africa, there will be twelve times as many children under 15 as adults over 64. This is likely to lead to increased dependency ratios within households[3] (Hunter and Williamson 1998a).

The figure of 13 milllion AIDS orphans at the end of 2000 underestimates the true scale of the problem. UNAIDS defines an orphan as a child under 15 years of age who has lost their mother (maternal orphan) or both parents (double orphan) to AIDS. Based on this definition, the figure of 13 million is projected to rise to 24.3 million in 2010 and to reach 40 million by 2020. The definitions used by UNAIDS, however, excludes the following categories of orphans and other children affected by AIDS;

- paternal orphans;
- orphans aged 15 to 18;
- non-AIDS and 'social' orphans – i.e. children orphaned or abandoned as a result of other causes.

Recent research into the orphan situation in one district in Uganda (Monk 2000a; 2000b) found that the children in these three categories are often as severely affected, according to basic welfare criteria, as orphans that fitted the UNAIDS definition. Indeed, paternal orphans were often more severely affected than maternal orphans. Moreover, the experience of orphanhood often increases the age at which adolescents become independent, due to factors such as disrupted school attendance. Hence, it is argued that 18 years is a more appropriate upper age limit, and is consistent with the UN Convention on the Rights of the Child (CRC). The research also showed that children who are not themselves orphans but who shared households with fostered orphans, experienced increased poverty as a result. Differentiation about how a child becomes an orphan can

[2] 'Malawi: most untreated African HIV Children will die by age 3' Reuters news release, 26-12-00. Original paper in *Paediatrics*, December 2000.

[3] Defined as the sum of children under 15 and persons 60 years or older divided by the number of persons aged 15 to 59 years. There is as yet little evidence of an increase in this ratio as a result of HIV/AIDS, as households have adjusted to cope with the growing number of orphans.

lead to stigmatisation and discrimination even amongst this already 'under privileged group' group of children.

A broad definition of AIDS-affected children including all the categories described above, i.e., maternal, paternal and double orphans from all causes under the age of 18, plus co-residents, when applied to the study district in Uganda yielded a total that was *nine times higher* than the one based on the UNAIDS definition of AIDS orphans. If other research yielded similar findings this would give rise to even more alarming estimates and projections than those produced by UNAIDS, i.e. 218.7 million by 2010 and 360 million by 2020.

2.1 Estimates of the global orphan situation

Since the UNAIDS definition is limited, the following tables of orphan estimates give estimates for other definitions as well as those provided by UNAIDS. The definitions used are as follows:

i) UNAIDS estimated number of orphans (under 15): Estimated number of children who have lost their mother (maternal orphans) or both parents (double orphans) to AIDS and were alive and under 15 at the end of 1999. [4]

ii) USAID estimated number of orphans (under 15): Estimated number of children who have lost their mother (maternal orphans), their father (paternal orphans), or both parents (double orphans) due to all causes (i.e., not only due to AIDS), alive and under 15 in 2000 (Hunter and Williamson 2000).

iii). Estimated number of orphans under 18 – all causes: Estimated number of children who have lost their mother (maternal orphans), their father (paternal orphans), or both parents (double orphans) due to all causes, alive and under 18 at the end of 1999 (Monk, N. 2000).

These estimates were derived using the ratio between the total yielded by the UNAIDS definition of orphans in the study area in Uganda (Monk 2000), and the total after three additional categories were added – i.e., paternal orphans, children between 15 and 17, and children whose parents were recorded as having died of causes other than AIDS. The figures for the Uganda study derived from adding the three additional categories were 4.7 times higher than the UNAIDS definition. The UNAIDS estimates for the different countries were then multiplied by 4.7 to arrive at the new estimates incorporating the additional categories. These estimates are shown to give an idea of the potential scale of the current orphan situation, although it is acknowledged that similar research would be needed in other countries to verify their accuracy.

[4] UNAIDS website: www.unaids.org

Table 1. Orphan estimates in Africa

	1.a UNAIDS estimated number of orphans (under 15)	**1.b UNAIDS estimated orphans as a percentage of population under 15**[5]	**2.a USAID estimated number of orphans (under 15)**	**2.b USAID estimated orphans as a percentage of population under 15**[6]	**3. Estimated number of orphans under 18 (all causes)**	**4. Population of children under 15**
East and Central Africa						
Kenya	546,965	4.2	1,216,711	9.4	2,570,736	12,985,458
Burundi	150,086	5.3	515,971	18.1	705,404	2,854,493
Rwanda	172,398	5.5	936,691	30.1	810,271	3,106,905
Ethiopia	903,372	3.0	5,149,467	17.1	4,245,848	30,144,741
Uganda	997,426	8.4	2,354,064	19.7	4,687,902	11,923,399
Tanzania	666,697	4.2	1,533,084	9.7	3,133,476	15,853,895
DRC	464,322	1.9	2,245,571	9.0	2,182,313	25,087,723
Southern Africa						
Swaziland	7,200	1.5	74,991	15.2	33,840	493,451
Zimbabwe	623,883	13.9	1,066,702	23.7	2,932,250	4,496,405
Lesotho	29,469	3.5	75,811	8.9	138,504	848,119
South Africa	370,952	2.6	1,283,211	9.1	1,743,474	14,093,765
Malawi	275,539	5.9	947,602	20.3	1,295,033	4,659,452
Mozambique	248,177	3.0	1,511,718	18.4	1,166,432	8,201,818
West Africa						
Côte d'Ivoire	287,269	3.8	1,246,669	16.6	1,350,164	7,500,047
Burkina Faso	211,503	3.7	724,933	12.7	994,064	5,689,351
Ghana	119,410	1.5	601,013	7.3	561,227	8,184,200
Sierra Leone	36,456		n/a		171,343	n/a
Liberia	20,337		n/a		95,584	n/a

[5] Column 1.b figures were calculated by taking column 1.a as a percentage of column 4 figures, derived from Hunter and Williamson (2000).

[6] Column 2.b was calculated using figures from Hunter and Williamson (2000).

Table 2. Orphan estimates for Asia and the Pacific

	1.a UNAIDS estimated number of orphans (under 15)	**1.b UNAIDS estimated orphans as a percentage of population under 15**	**2.a USAID estimated number of orphans (under 15)**	**2.b USAID estimated orphans as a percentage of population under 15**	**3. Estimated number of orphans under 18 (all causes)**	**4. Population of children under 15**
South East Asia and the Pacific						
Cambodia	11,649	0.2	373,082	7.3	54,750	5,115,941
Myanmar	35,458	0.3	1,195,422	9.6	166,653	12,428,196
Thailand	n/a	n/a	494,924	3.4		14,493,241
Vietnam	2,772		n/a		13,028	n/a
China	3,901		n/a		18,335	n/a
Philippines	1,313		n/a		6,171	n/a
Indonesia	1,735		n/a		8,155	n/a
Laos	236		n/a		1,109	n/a
South and Central Asia						
India	557,570		n/a		2,620,579	n/a
Nepal	2,157		n/a		10,138	n/a

Table 3. Orphan estimates for Latin America and the Caribbean

	1.a UNAIDS estimated number of orphans (under 15)	**1.b UNAIDS estimated orphans as a percentage of population under 15**	**2.a USAID estimated number of orphans (under 15)**	**2.b USAID estimated orphans as a percentage of population under 15**	**3. Estimated number of orphans under 18 (all causes)**	**4. Population of children under 15**
Latin America						
Honduras	13,599	0.5	65,553	2.5	63,915	2,664,300
Guatemala	4,654		n/a		21,874	n/a
El Salvador	1,885		n/a		8,860	n/a
Brazil	30,828		n/a		144,892	n/a
Peru	6,261		n/a		29,427	n/a
Colombia	2,301		n/a		10,815	n/a
Nicaragua	427		n/a		2,007	n/a
Caribbean						
Haiti	49,134	1.7	350,924	12.4	230,930	2,823,683

Frequently, the community's own definition of vulnerability also includes children who are not defined as orphans in the western sense, such as disabled or destitute children who may not necessary be biological orphans but may be termed as social orphans. In fact, children start suffering economically, psychologically and in other ways long before they become orphans. This mismatch between community's notions of vulnerability and the imposition of external definitions tends to result in a top-down approach that is unlikely to encourage community 'ownership' of programme

activities. In addition, the focus on the stigmatising term 'AIDS Orphans' creates a situation where other vulnerable children may be left out of assistance activities. Communities know the children about whom they are most concerned, as in Malawi;

> '…in other communities, however, orphans appeared to be a primary focus because their needs have been emphasised by external bodies. Some communities were coming to see orphans as a privileged group and resented this displacement because it undermined extended family mechanisms.' (Williamson and Donahue, 2001)

This definitional problem is sometimes reflected in policy and legislation. As an example, the term 'children living with HIV/AIDS' was adopted by the National HIV/AIDS Care and Support Task Team in South Africa to encompass all infected children as well as those from uninfected households but who are affected due to societal impacts including reduced access to and quality of services; those children who had been abandoned; children from households where one or both parents are infected, and children vulnerable to infection (Smart 2001). The dangers of using such widespread and inclusive definitions in policy is that targeting practice is more complex (and potentially open to abuse) and that the scale of the problem can appear to be overwhelming, so stifling any concerted response. Reaching consensus on definitions of children about whom we are most concerned is one of the critical challenges facing all of us involved in responses to the needs of children made vulnerable by AIDS. What is clear is that orphanhood in and of itself is not a sole and valid criterion for assistance.

3. HIV/AIDS and children's rights

The issue of definitions is pertinent regarding the emergence of rights based approaches to supporting children affected by AIDS, as questions of vulnerability, categorisation and targeting are under scrutiny. HIV/AIDS has many direct and indirect impacts on children's rights, ranging from the consequences of the psychological impact of losing one or both parents, to reduced access to quality education and health services(see chapters 12 and 13 of this study). The CRC is underpinned by four major principles;

- the right to survival, development and protection from abuse and neglect;
- the right to have a voice and be listened to;
- that the best interests of the child should be of primary consideration;
- the right to freedom from discrimination.

However, for many children who have been infected or affected by HIV/AIDS, these rights are being compromised. Children who are themselves living with HIV/AIDS, or have lost one or both parents to HIV/AIDS, often experience discrimination and exclusion from the community as a result of stigma. The growing number of child-headed households also affects the rights of children to education, to rest and leisure, to survival and development, to protection from sexual and economic exploitation, and to protection from abuse and neglect. The deaths of parents and worsening poverty are contributing to the growing number of children working in hazardous and exploitative conditions.

For many children infected or affected by HIV/AIDS, the fundamental principles of the CRC, especially the rights to non-discrimination, survival and development, are most often compromised. This results from fear of HIV/AIDS and a lack of understanding of how HIV is transmitted. For infected children their supposed impending death is at the root of most discrimination they face. Misconceptions regarding HIV/AIDS result in many children, whose parents are living with HIV, being stigmatised, whether or not they themselves are infected. This stigmatisation is made worse by the fact that it comes from every section of the community including other children, guardians, teachers and even parents themselves (especially widows and stepmothers: Alidri 2001). In Malawi orphans of AIDS tend to form their own informal peer groups as a result of this stigma and process of peer exclusion (Cook 1998). Teachers often refuse to allow these children into schools. The tragic case of Nkosi Johnson in South Africa was recently brought to the world's attention. This young boy living with HIV was denied his rights to education and freedom from discrimination.

Other, equally significant, reasons for reduced access to education for children, especially girls, affected by HIV/AIDS include loss of earnings or the need to re-direct household spending towards medical treatment denying the funds to send children to school. In addition, children whose parents become ill often have to leave school to care for them. In Uganda in one study around half of affected children reported that attendance and grades had been adversely affected by parental illness (Gilborn 2000).

3.1 How Children's rights to survival and development are affected by the HIV/AIDS epidemic

HIV/AIDS also affects the survival and development of children through its impacts on health, family livelihoods, social welfare and protection. The impact of HIV/AIDS on the health of children relates not only to the growing number of children being infected with HIV, but also to the effects HIV/AIDS has on access to health care for children who are HIV-negative. As with access to education, stigmatisation and discrimination also threaten access to health services. The reduction and reorientation of the family's income to cover the costs of HIV-related treatments has significant impacts on the health of children. For example, families with one or more members living with HIV/AIDS will spend a much higher proportion of their income on HIV-related treatments, thereby reducing the income available for general health care, including immunisation (see chapters 10, and 11 of this compilation of studies). Also, the parent's level of illness may make it very difficult for them to provide adequate childcare and food or to travel to health centres with their children. Higher rates of stunting and wasting have been reported in orphaned children as well as higher rates of severe or moderate malnutrition (Human Rights Watch 2001).

The most significant effect of HIV/AIDS on the social welfare and protection of children is the disintegration of traditional support structures and 'social safety nets'. As the number of affected children increases, the capacity of the community to support these children is being stretched significantly. There is a growing number of child-headed

households, especially in sub-Saharan African countries. As parents' livelihoods are increasingly threatened, children are forced to take on a premature adult role.

The death of one or both parents and the resulting increased household expenditure on health, place more economic responsibilities on children. Many are forced to drop out of school and take up work to contribute to family incomes. In Burundi, children in AIDS affected households begin work for income at younger ages compared to unaffected households, becoming involved in petty trading and running errands at the ages of six or seven (Roudy et al. 2001). Some children end up working in highly hazardous conditions, for example, in the informal mining industry where they risk severe injury. A UNICEF study on HIV/AIDS and child labour concluded that AIDS was responsible for pushing a significant percentage of the millions of working children onto the labour market. (UNICEF – ESARO 2001).

Growing household poverty and the increase in 'demand' for uninfected younger sexual partners has also increased the numbers of children who are sexually abused and paid as sex workers. This inevitably puts children, especially girls, at extreme risk of contracting HIV. Once out of school, these young people may find it very difficult to gain access to HIV prevention messages and sexual health services as they become 'out of reach'. In South and south-east Asia, children who are orphaned may be at greater risk of being trafficked and sexually exploited. In seriously affected communities the whole nature of childhood is changing fundamentally.

3.2 Child-focused and rights based programming

Rights based programming implies holism in approach; dealing with aspects of prevention, care, protection and the impact mitigation. These responses must involve not only young adolescents, but also, where appropriate, children under the age of 15. A rights based response also aims to promote the participation of children and young people in HIV/AIDS programmes. This is being achieved through the work of key global institutions working for the rights of children through developing a set of principles to guide programming for orphans and other vulnerable children. These principles aim to provide a framework for a much broader response to children and young people affected by HIV/AIDS.

The main aspects of these principles are;

- to foster links between HIV/AIDS prevention activities, home-based care, and efforts to support orphans and other vulnerable children;
- to target the most vulnerable children and communities;
- to give particular attention to the gender-specific needs of boys and girls;
- to involve children and adolescents as part of the solution;
- to strengthen the role of schools and education systems;
- to reduce stigma and discrimination;
- to strengthen the caring capacities of families through community-based mechanisms;
- to strengthen the economic coping capacities of families and communities;

- to enhance the capacity of families and communities to respond to the; psychosocial needs of orphans and vulnerable children, and their caregivers;
- to find sustainable ways to remove children from hazardous and exploitative work;
- to accelerate learning and information exchange;
- to strengthen partnerships at all levels and build coalitions among key stakeholders;
- to ensure that external support does not undermine community initiative and motivation.

These programming principles are fundamental to effective care and support and to the development of the coping capacities of affected households and communities, with child participation at the centre of the response. How can we be more child focused and not just child centered? Looking at the entire array of the child's needs and the situation from the child's perspective, but without including the child's participation is being 'child centered'. On the other hand looking at all their needs and including their participation in the decisions being made about their lives is being 'child focused.' Most programmes aimed at children fail as far as ensuring full child participation in their design, implementation and evaluation. Children's participation is critical and it is one of the enduring challenges facing all stakeholders.

As these principles enjoy increasing rhetorical dominance, there remains the issue of translation of principles into activities. Such programming implies the move away from pre-determined categories of vulnerability towards local and context specific definitions. While rights conceptually remain universal, responses must be grounded in local realities, necessitating a needs assessment and social mobilisation process far removed from more traditional welfare responses. This itself is cost and time intensive, creating a crisis of capacity, for when the emphasis becomes prioritising local conditions, the identification of 'good' and 'best' practices becomes itself more difficult.

4. Defining and scaling up of good practices – doing more of 'what works'

A critical challenge is the identification of what constitutes or defines 'good practices' and how these can be scaled out to impact upon more children. The use of the term 'best practice' is problematic and remains valid at a conceptual level only (Webb 2001). There is a wide range of approaches being practiced by different organisations, governments and communities in the care of orphans and children affected by AIDS. Given the rising number of orphans in Africa for example, responses are far smaller than the scale commensurate with the nature and extent of the problem. Approaches that could go to scale have to be simple, owned and managed in the community, cost efficient and easy to replicate (Phiri et al. 2001, Foster 2001a; International HIV/AIDS Alliance 2001).

Scaling up is threatened by:

- lack of political support or political interference
- corruption

- inadequate information dissemination about government policies and funding
- Reluctance to modify child protection legislation
- Under funding of state service delivery and coordination of child care systems

Difficulties in scaling up are primarily grounded in the political economy of the response. Governments have to be convinced of the validity of support models, which may complement or intrinsically criticise government responses by addressing key support gaps. NGOs and CBOs will have differing agendas and governments, acting through the mediation of district and provincial officialdom, opt to disengage with the non state actors due to the perceived threat of interaction of plain disinterest. This challenge is considerable in parts of south and south-east Asia where rigid corruption structures tend to scupper local government adoption of NGO responses, pushed often by bilateral funding. This factor is considerable in India, China, Cambodia and Vietnam where local governments are only starting to consider the impending orphan crisis.

Political constraints not withstanding, at the implementation level there is a basic set of prerequisite questions before scaling up can begin. These include what the existing coping strategies are, what structures frame these responses, what could be described or agreed upon as the basic minimum package for an effective response and how it can be delivered or helped to emerge without eroding community capacity.

Assessing models of care involves key questions:

- if and how the model responds to the needs of orphans – physical, material, educational, psychosocial, cultural and spiritual;
- the number and types/categories of needs addressed,
- numbers of children reached,
- the degree of 'child focus';
- transparency in targeting;
- nature of community ownership;
- sustainability;
- influence on policy at local and national level.

Underpinning these assessment criteria is the search for 'good practices'.

4.1 Good practices in responding to children affected by HIV/AIDS

We will consider community as well as institution based responses here, but some responses discussed defy simple categorisation. Community based or community managed responses are centered around 'informal' fostering where community members assume responsibility for caring for orphans. This is the norm in a number of countries in sub Saharan Africa and Asian developing nations and has been observed in rural or semi urban areas where there is little access to services. Religiosity, compassion, community solidarity, reciprocal altruism, concern for society's well being and blood ties are all key factors (Williamson 2001; Phiri et al. 2001).

4.2 Community based care versus institutional care

While the discussions surrounding scaling up are usually related to community based responses, externally imposed 'solutions' take on a more welfare character. As the impacts of AIDS become manifest, there are increasing numbers of institutions such as both unregistered and registered children's homes and orphanages. In Thailand, numbers of HIV positive children placed in institutions has increased tenfold between 1992 and 1997 (Hennessy 2001). Statutory foster care processes vary, according to whether there is a court or officially appointed figure given the authority to identify, monitor and supervise the foster placement of a child. Guidelines and standards of care act as criteria to determine where to place a child and the failure or success of placement, but their use is inconsistent.

Alternative care options differ from country to country. Typical of South Africa are community family models where up to six children are placed with a foster mother in a home which is purchased and furnished by an external organisation/individual (Loening-Voysey and Wilson 2001). The foster mother is paid an allowance and receives foster grants for the children, with periodical assistance from a 'relief mother'. Siblings are kept together where possible. Community leadership structures are involved in the process of monitoring, and cluster foster homes are typically run by volunteer women or couples who keep up to six children each and receive foster care grants, material and child care support as well as health services and income generation activities. Less common is collective foster care, where religious groups of women or couples collectively agree to act as surrogate mothers for children who remain in their own deceased parents' houses (McKerrow 1996; Loening-Voysey and Wilson 2001).

4.3 Institutional care

Institutions for children have a long history; early examples being established and maintained by religious or missionary groups. For the most part, the growth of institutionalisation can be seen as an expedient social policy response to the growing numbers of children in need of care and protection. It is seen as an easy option for social or child care workers to place children in these institutions, and a growing number of families also 'place ' their children in orphanages. In many countries there is no principle of the State as parent and no legal requirements governing whom a child can be placed with by the parents during their life or on death.

One factor that make orphanages an attraction is the perception among some members of impoverished communities that they will provide the food, education, health and other services that the caregivers are unable to provide to the children. A survey by the International Rescue Committee in Rwanda has shown that economic pressure was one of the prime reasons that children were living in institutions (Williamson 2000; Williamson et al. 2001). Yet this can lead to subtle forms of 'abuse' as the raison d'etre of the institution is compromised. For example a study in Zimbabwe showed that 75 per cent of the children in institutions had contactable relatives (Powell 1999); similar to an earlier study in Uganda in 1991 where it was found that half of the children in institutions had

both parents alive and one quarter had one parent alive (Dunn 1992; Williamson et al. 2001). In India's Mizoram State 47 per cent of the children were placed in orphanages after the divorce of their parents. Another 15 per cent were placed there because they had been born out of wedlock (Chakraborty et al. 2000). It is clear that these types of arrangements would significantly contribute to the undermining of more 'traditional' community coping processes.

While they may provide some of the 'nurture', typical institutions do not provide the holistic care that children are entitled to for all round development. Research has shown that children in institutions lack basic and traditionally accepted social and cultural skills to function in their societies; they have lower levels of educational attainment; have problems adjusting to independence after leaving the orphanage, lack basic living skills; have more difficulties with relationships, lack parental skills and some of them often have a misplaced sense of entitlement without a parallel sense of responsibility (Powell 1999; Wright 1999; Verhoef 2000; Rajkumar 2000; Grainger et al. 2001; Williamson et al. 2001). Children in institutions have tenuous cultural, spiritual and kinship ties with families, clans and communities. These ties are especially critical in Africa and Asia as they are the basis for people's sense of connectedness, belonging and continuity. They are the basis upon which life skills as well as social and cultural skills are attained. Children raised in institutions struggle to be accepted or fit into traditional rituals and ceremonies as well as contracts and alliance arrangements. The feelings of ostracism these situations engender further adversely affect psychological and emotional well being. It may also be the case that children raised in institutions may likely look down upon their own communities as being inferior after getting used to the trappings of an institution – especially the kind that provides a materially high,western standard of care (Powell 1999).

A separate critical issue with institutions is cost. In most countries with mature epidemics and an unprecedented growth in the numbers of orphans, it is impossible to accommodate any significant number to make an impact. The cost of keeping a child in a centre in Rwanda, for example, is approximately $540, plus the cost of donated food, per child, per year (Williamson et al. 2001). In Eritrea the cost per orphan in an institution was estimated at $1,350 per year, while in Tanzania it cost $649 per child per year in 1990 and $689 per child per year in Burundi (Ainsworth and Rwegalurina 1992; Lusk et al. 2000). In South Africa statutory residential care was estimated to cost as high as R2590 rands ($180) or R3525 ($245) per child per month with palliative care costs. A 1995 survey in Zimbabwe revealed that the average monthly cost of maintaining a child in an institution in the country was Z$1,058 at that time in the most expensive facility and Z$341 in the least expensive. Rapid inflation would have pushed these figures to Z$3,000 and Z$1,000 respectively. The latter figure approximates to the average monthly salary of a typical family in the country.

The capital costs of setting up institutions also need to be considered. In Zimbabwe, where between a fifth and one third of children are orphans, one institution was estimated to cost Z$25 million. In contrast, a traditional type family unit for orphans cost Z$500,000 and the running costs for the family type unit was Z$131 per child per month.

It is therefore estimated that the institutions are 14 times more expensive than the traditional arrangements (Powell 1999). Just based on capacity, it is evident that this option is illogical. In Zimbabwe there are only 41 institutions accommodating less than 3,000 orphans (Powell 1999).

Institutions should be the last resort after family, foster or community care in the absence of other models of care being available. It has been recognised, however, that for a small number of children, residential care will be necessary and that other alternatives may not be feasible. For example, the abused, children abandoned soon after birth, those whose families refuse to take them in for various reasons, including the fear of evil spirits, street children who need night shelters, those that might be in need of temporary care who later return to their communities, some of the unaccompanied minors in war times, even those that have been sold as labour or slaves across borders (Brown and Sittitrai 1996; Wright 1999; Subbarao et al. 2001; Grainger et al. 2001; Williamson et al. 2001).

Correctly managed institutions can provide emergency temporary care particularly to protect orphans at risk of abuse. They can help with behaviour and emotional difficulties. However they are an expensive resource, with an inherent danger of institutionalization, and placements for children should only be used when it is in the child's best interest and subject to the CRC article of periodic review.

Uganda, during the 1990s provides a model for inspecting and monitoring the use of residential care facilities. The process involved collecting information on institutions and the children in them, followed by legal regulation and policy guidelines, staff training through open distance learning materials, an implemented policy of reunifying children able to return to families plus inspection and monitoring by the government.

4.4 Evolving models of community based care

Precisely to respond to these problems with institutions, a number of countries have developed alternative models of care. The Civil Affairs Departments of Anhui Province and Guangde County in China, for example, has been working in partnership with Save the Children (UK) embarking on a programme to shift from large scale institutions to smaller groups of family type homes. Many of these homes are integrated into communities and they have begun promoting more foster care. The changes from large institutions to smaller units will take sometime, in an initial model the smaller units were on the same campus and the care units were subject to overall rules of the total establishment. Another problem encountered was how to avoid staffing the units on a permanent basis with young single women, inexperienced as mothers, and how to integrate children with disabilities.

Where children are unable to live with their families, they should be afforded as near as possible environments that approximate to those of families. Thus family style units have been established; children attend nurseries and schools in the community just like other children; girls and boys live in the same unit as siblings and disabled children are not

segregated. Communities are thus participating in the raising of these children who are not isolated and learn social, cultural skills and self-reliance.

Some lessons of this programme highlighted what needed to be changed in policies regarding children in need of special protection in China. Subsequently, there was a change in the guidelines and standards for admission, placement and care. The new guidelines for foster care influenced policy and legislation. For instance, in 1998 the law changed in that the minimum age at which a person would be allowed to foster went down to 30 years. It is important for institutions to have well developed, stringent admission criteria so that they do not become dumping grounds for unwanted children, or that they do not act as magnets for families that feel children will be better off in the institutions. Criteria and guidelines will ensure that the children that absolutely need this service have access and opportunities to receive them while at the same time ensure that community coping mechanisms are not undermined.

Aggressively working to prevent families breaking down in the first place through supportive interventions obviates the need for alternative care (Wright 1999), and equally interventions can focus on getting children out of institutions. In Ethiopia, the SKIP project and the Jerusalem Association for Children's Homes both worked to de-institutionalise children by first enabling them to travel to their birthplaces during school holidays to look for their kin. Older adolescents were helped to become independent through their own development of business plans for which they were given small grants, having apprenticeships organised where they received skills and mentoring, and were given opportunities to attend higher education. As a result of children being reintegrated into their communities one home was closed (Gebru and Atnafou 2000). SKIP promoted the concept of family type units where children lived in the same style of housing as other community children, had same standards of clothing and nutrition, went to the same schools, worshipped in the same religious structures and engaged in the same mode of agriculture as their peers in the communities. SKIP reintegrated 98 per cent of all the children back into their communities after eight years.

Temple boy systems and community care centers have been suggested as other alternative models of care especially where there is a strong Buddhist tradition. In Thailand and Cambodia, for example, it is traditional for boys to be placed in a temple where they receive an education. This has been suggested as an option for male children orphaned by AIDS if the religious community would be encouraged to extend the system to target orphans and actively destigmatise AIDS related orphanhood (Brown and Sittitrai 1996). This may be a critical model in Cambodia, where the genocide of 1975-1979 (killing between one and three million people) has removed many potential grandparent caregivers for the estimated 60,000 orphans at the end of 2001 (NAA 2001). In Cambodia, without a concerted a widespread response, rates of child abandonment will be unusually for AIDS affected populations. In addition, other faiths through their own structures and through faith based organisations (FBOs) could be encouraged in the uptake or adaptation of the system to fit their faiths. This system if developed would need to recognise the situation of girl orphans and monitor the children's welfare in the long term.

Given the scale of the current and impending orphan crisis and realising that fostering arrangements will be one of the responses that will be promoted in most developing countries, it is important to note that most of these countries still retain legislation, criteria, guidelines and administrative procedures based on western models. For example, in South Africa in 1998, the government introduced child support grants for under sevens living in impoverished households with the intent that within five years up to three million children would have had access to the grant. After the first year, however, less than 30,000 or a meager one per cent had been able to receive the grant. This was because of stringent information requirements. For example, not everyone in rural and impoverished areas had birth certificates that the department was demanding (Loening-Voysey and Wilson 2001).

Models of fostering and adoption services developed in the west are by no means universally useful. Adoption requires rigorous legal oversight and assessment procedures and may not be applicable in societies where extended family consider themselves to have responsibilities for a relative's child. (and of course this is being reinforced in high prevalence areas) Fostering also provides definitional problems as it is necessary to be clear as to exactly which parental responsibilities are being transferred to the foster parent and in the case of formal fostering what responsibilities are being held by government social workers and the state. Fostering schemes started in countries in transition , intended as alternatives to institutions have rarely reduced numbers of children in residential care but have emerged as a parallel system requiring both fostering allowances and supervision on a long-term basis . In FYR relatives have refused to care for children when allowances were not forthcoming. Formal fostering on a long-term basis raises many rights issues and may not be the panecea.

In most cases, developing and transition countries have not ensured that their social policy keeps pace with their economic reform. In those countries where the context facilitates the choice of institutions as the first policy choice for care, state revenues have dwindled to levels where institutions can no longer be supported adequately. The impending huge numbers of orphans will make the situation even more unmanageable if no alternative models of care are developed. In addition, the minimum standards set for formal foster care and adoption are often too high for the many poor but willing community members. The concept of 'good enough' standards appropriate to the local context, norms and traditions of the community in which the child will grow up should be seriously considered in these countries where the numbers of orphans are numbing (Phiri et al. 2001).

4.5 Comparing Cost Effectiveness and Quality of Care

Research in South Africa has examined both the quality of care as well as cost effectiveness of six models of care for orphans and vulnerable children (Loening-Voysey and Wilson 2001; Desmond and Gow 2001). 'Cost effectiveness' was defined as the cost of care per month per child and the cost of providing a minimum standard of care per month in each of the six models which included: statutory residential care; statutory

adoption and foster care; unregistered residential care, home based care and support types; community based support structures and informal fostering or non-statutory foster care. The authors argued that it was imperative to develop a framework for evaluating the quality of service as well as assessing the feasibility of each approach. 'Quality of care' was defined as 'care which meets the needs of children in a culturally relevant and acceptable manner and at the same time, enables them to realise their rights' (Loening-Voysey and Wilson 2001). The analysis concluded that institutional care was the most expensive and least cost effective of the models and that community based care and informal fostering was cheaper and more cost effective. However, the study also pointed out that the quality of care in family or informal fostering was increasingly being compromised by a distinct lack of, as well as access to, resources. As such the needs of orphans in this care were not being responded and children's rights were not being recognised.

Table 4. Cost Effectiveness of Six Models of Orphan Care in South Africa

Model of care	**Cost per childcare month (Rands)**	**Cost per minimum standard child care month**
Statutory residential care	2938 (3873*)	2590 (3525*)
Statutory adoption and foster care	609	410
Unregistered residential care	996	957
Home-based care and support	506	306
Community-based support structures	**	276
Informal fostering/ Non-statutory foster care	**	325

Notes: *including medical costs associated with the child's HIV positive status
**fail to meet material minimum .
Source: Desmond and Gow 2001

Costings exercises are hampered by the fact that there are some aspects of care that are extremely difficult to measure or cost – for example affection or love of the carer. It can also be argued that it would be difficult to cost or measure local advocacy or even 'community parenting' where significant others in the community contribute to the parenting of orphans. There is also the clear discrepancy between the availability of resources in a given context and the realisation of children's rights. As discussed above, a lack of awareness of the rights of children as enshrined in the CRC, as well as difficulties involved in the application of rights based approaches to policy and programming, remain a serious challenge. The difficulties involved in such a costings review are many and relate to the following:

- The variation in intervention types
- The tendency to cost specific sub components of programmes such as food or education costs
- Varying definitions of target groups and vulnerabilities
- The absence of capacity inventories for different community contexts
- Varying values of resources in different contexts: of land, population density, leadership strength, human resource availability.

- Subjective nature of costing human resources and other aspects of 'social capital'
- How to quantify and measure quality of support given
- How to conceptualise, and cost the strengthening of health and social service systems.

The aim of defining an equation of external resources mobilising internal capacity and 'social capital' in order to supporting OVC to an agreed standard is simplistic but presents the nature of the challenge. Where internal resources have been mobilised these have been measured when connected to micro-credit programmes, material outputs such as foodstuffs and sometimes money itself. Within the COPE Programme in Malawi by July 2000 the DACCs and CACs had raised around $20,000, compared to the $1.6m needed to keep COPE going through to 2001. Although the time frames may be different, in this case we are looking at internal financial mobilisation of around 1.25 per cent of the total amount needed for the programme (Williamson and Donahue 2001). This raises the question of the potential for sustainability when considering financial stability, as well as the need to better define non financial resources, as finances are only one component of social capital generated by the programme structures.

These and other issues are major constraints on reaching universal consensus on costings, and the way forward may be to firstly to define support packages per capita/family, and have estimates according to each, using methods employed in health systems management models, or those developed to cost home care structures.

4.6 Orphan support as community development in Eastern and southern Africa

Despite the uncertainties, scaling up efforts are ongoing. The Uganda Women's Efforts to Save Orphans (UWESO) has used the model of children's villages to organise cluster and community foster care arrangements (see chapter 2). The organisation gives school and medical costs, assists with food and clothing provision and organises training in community-based childcare and livelihood support families with orphans. UWESO uses an approach that enables communities themselves to care for orphans, where orphans live in their own communities and are assisted using traditional structures, thus engendering ownership and facilitating sustainability. Communities are responsible for identifying the most needy, prioritising using their own index of vulnerability. Thus far the project has had an impact on over 10,000 orphans, raising income at households levels, increasing the nutritional status of orphans as well as improving the quality of shelter in the community. Costs for primary schooling have been reported as being $35 per child per year and $75 per year for secondary school students (Subbarao 2001).

A further example is provided by the FOCUS project in Zimbabwe. This is a programme of Family AIDS Caring Trust (FACT), an AIDS service organisation established in 1987. Research on orphan enumeration and community coping mechanisms has been conducted by FACT since 1991. In 1993, the FOCUS programme started by recruiting 25 women from 18 villages and several churches throughout the communal farming programme area, approximately 200 square kilometers with a population of 10,611 people in 2,089 households. Traditional leaders in adjoining areas asked for the programme to expand to

cover their villages so more volunteers were recruited. In addition, more volunteers were recruited as more vulnerable children were identified. This enabled the visiting caseload of volunteers to be reduced to around 10 families per volunteer. By 2000, the FOCUS program in this area had expanded to involve 40 volunteers and covered 22 villages.

The programme emphasised identification and monitoring of vulnerable children through regular household visits; community ownership; keeping children in school; income generating activities; and volunteer training and motivation. The programme was established and maintained in close liaison with community leaders. The community and church leaders nominated volunteers as respected and credible people of good standing. Most volunteers were widows or women already caring for orphans themselves with experience in caring for vulnerable children. Volunteers were initially trained by FACT staff; ongoing training, supervision and monitoring was provided by the Programme Coordinator during monthly volunteer meetings in the community.

Volunteers were responsible for identifying and visiting orphan households within a two-kilometer radius of their homes. Those considered more vulnerable are allocated priority status on a register and are visited at least twice per month. Volunteers identify unmet basic needs of the households and provide essential material support including maize seed, fertilizer, food, clothing, blankets, school fees ($2-4 p.a.) etc. Visits provide emotional and spiritual support; in addition volunteers may offer to bathe children, sweep the house, fetch firewood or cook. Visits enable the children's situation to be observed; children who are out-of-school, in emotional distress or being abused are identified and appropriate action can then be taken. The likelihood of abuse, exploitation and maltreatment of orphans lessens in communities where frequent visiting is occurring. Visits also enable spiritual activities such as prayer, scripture reading and praise songs to be shared. Psychosocial support is provided through weekly craft, cultural and sporting activities. Volunteers are also involved in advocacy and awareness raising on orphan issues (Phiri et al. 2001).

Small volunteer incentives were provided, in the form of uniforms, shoes and training and meeting expenses, as well as an annual Christmas bonus of $10. Some volunteers visit other programmes through an exchange visit scheme. Volunteers who look after orphans in their own homes may receive small amounts of material support (average US$11 per annum). Incentives help to keep volunteer drop out levels very low.

By 2000 programme replication meant that there were nine sites, which had 2,764 orphan households on their priority registers; 178 volunteers were active in the programmes, 97 per cent of whom were female. This lack of male voluntarism in the programme is an obvious issue of concern and is part of a wider reluctance of males to take on caring roles. Indeed, of the five active males, four were site supervisors, mostly pastors paid small monthly allowances by FACT. During 1999, 142 volunteers at seven FOCUS sites reported making 93,000 visits to 2,170 households containing some 6,500 orphans and vulnerable children; 992 children had their school levies paid and as a result were attending primary school. Income generating projects initiated by volunteers included

gardening, crocheting, greenhouse horticulture involving mushroom growing, goat keeping, poultry rearing, sewing and knitting.

During the period 1996-99, the number of households visited increased from 798 to 2,170 and volunteers from 81 to 142; total programme costs stayed fairly constant at between $20-30,000 per annum, and approximately 50 per cent of programme expenditure was at community level in the form of material support, volunteer incentives and meeting costs. The cost per family was approximately $10 and per vulnerable child $3 per year. The cost per visit was $0.11 while the cost per volunteer was $68.

Now the programme is expanding and strengthening its approach. The visits include activities and routines to include interaction with the orphans themselves not just the adult caregivers. This is meant to ensure that the orphan point of view is included in planning responses, and more psychosocial activities have been introduced. The further development of nutrition gardens is assisted by the fact that some of the gardens have been set aside by chiefs – through the tradition of Zunde raMambo – the 'chief's garden'. This is what the government has been advocating as community resource mobilisation and advocacy to respond to the needs of orphans (Phiri et al. 2001).

4.7 Multi sectoral responses: The COPE Programme of Malawi

The Community-based Options for Protection and Empowerment of Save the Children (US) in Malawi has developed multi-pronged strategies of assisting communities to respond to the needs of children, families and communities affected by HIV/AIDS. It works through existing structures or organisations at district, community and village level. The structures or organisations can include community based religious organisations or local CBOs. For the most part COPE revitalised a structure set up by the National AIDS Control Programme with the help of UNICEF and other donors in 1992. The structure through which the programme works comprises the District AIDS Coordinating Committee (DACCs) (a multi-sectoral, multi stakeholder structure at the district level), the Community AIDS Committee- CACs (usually defined by a health catchment area or traditional authority, comprising as many as 100 villages) and the Village AIDS Committees (VACs). COPE resuscitates the DACCs, which in turn work to establish or strengthen existing CACs. The CACs are then responsible for catalysing the communities. After defining broad based community based and community managed care coalitions, the programme also develops their leadership and organisational capacities to undertake activities intended to respond to the diverse needs of affected children and families. At the CAC and VAC level, coalitions typically include traditional leaders, religious leaders, teachers, community based government workers including social workers, community development workers, agricultural extension workers, health surveillance assistants, nurses, etc. They also include businesspersons, widows, married and unmarried women, single and married men, and youth.

There are four technical subcommittees that are tasked with the different areas of response: orphans, youth, home based care, and prevention. The coalitions also are trained to raise resources internally and externally. Each community decides on what

activities it will implement. All communities include in their activities identification, monitoring, assistance and protection of orphans. Other activities include home based care activities for the terminally and chronically ill, youth and anti-AIDS club formation (both for prevention, peer education activities as well as support and care activities for other orphans and other vulnerable families), community gardens, structured recreational activities to respond to the psychosocial needs of the children, community managed child care centres to provide community care, stimulation and psychosocial activities for under sixes – both orphans and others; vocational skills and life skills training. Teachers and other workers that interact with children are also trained on the psychosocial needs of children. The programme also links communities with other economic activities, opportunities and programmes in the district or beyond. In this respect activities have included links with micro-finance institutions, and the World Bank Funded Social Action Fund which has assisted with the establishment of community child care centres, school fees assistance and other activities defined by the communities themselves. The programme planned to link closely its plans and partner with the National Safety Net Program and the poverty reduction activities at national level which proposes support through nutrition programmes and direct transfers to transient poor as well as the core poor (including orphans, vulnerable children, the elderly). The district assemblies of which the DACCs and CACs are a part are expected to play a key role in targeting, coordination and resource mobilisation (Hunter 2001).

A 2001 review (Hunter 2001) concluded that COPE mobilisation has created a demand in other communities, some actually starting their own activities or requesting assistance to initiate a response. It also created an increase in the demand for basic services in health, education, and access to water, sanitation and agricultural services. The potential for sustainability is enhanced through the fostering of ownership and the flexibility of services, the deliberate involvement and empowerment of the youth, and that the training and capacity development which has added subsidiary value, so often unrecognised in traditional cost analysis. COPE has and continues to have major influence on the national policies and programmes affecting orphans.

The COPE programme has scaled up from one district in 1995 to four districts and currently serves upwards of 12 per cent of the population in Malawi. In its third phase COPE plans to scale up to cover the whole country through three principle strategies. One is through strategic partnership with other INGOs, local NGOs, the government and FBOs who would then replicate the programme in other areas to reach at least 75 per cent of the country and 100 per cent of all districts by 2006. This is the first proposed partnership programme in sub-Saharan Africa to take up the challenge of going to national scale to meet the various needs of children affected by HIV/AIDS. Evidently the partnership will itself have a powerful influence on national policy and practice. The second strategy is through coordination of capacity building at the local and national level.

4.8 Good practice learning and dissemination

Capacity building also provides for international learning. The basic concept is that of the 'living university'. This is an ongoing resource and technical assistance centre for local, national as well as international visitors. Save the Children (US) has successfully piloted this concept in Vietnam and Egypt. FACT has also successfully developed and implemented the concept in Zimbabwe where it has resulted in replication of its model orphan visiting and assistance programme within Zimbabwe as well as four other countries in Africa. The living university is an ongoing social laboratory where an implemented project can be observed and discussed at various stages of implementation. Its 'campus' is the key locales of the programme and the 'faculty' comprises the key staff members who have been trained as trainers as well as the community members who are implementing the activities. The curriculum is largely the training manuals, constantly evolving and adaptive developed and being developed during the course of the implementation of the project. The living university also provides critical technical assistance and quality control and framework for monitoring and evaluation to local partners (Hunter 2001). It is a critical element in influencing policy and practice as well as scaling up responses.

At the local level the living university locales are principally centres of learning where community to community learning through visiting and collaborative review can also take place (Phiri et al. 2001). Save the Children (US) will also continue implementing through mobilisation in some districts without or with partners. At the regional level there are plans to use the principles, guidelines and lessons learned to start up COPE like programmes in Mozambique and Ethiopia and later to other countries in the region and beyond.

4.9 Addressing the non-material needs of orphans: succession planning and psychosocial support

Psychosocial needs of children affected by AIDS, especially orphans, are most often neglected in programme design. Most organisations, governments, donors and indeed even CBOs have felt that the material, economic, nutritional and other physical needs are the most critical, requiring immediate response. However intangible, psychosocial needs of children are critical – as they have a direct bearing on all the development aspects of a child growing in any context. Psychological wounds might be manifest in different guises including, but not limited to, depression, isolation, aggression, listlessness, attention deficits, nightmares, unresolved guilt and eating disorders.

As parents become sick, children worry about them and about their own future. Children usually do not verbalise these feelings, making it difficult to assess whether the child has reached closure about the terminal illness or death of their parent. Children may instead become withdrawn, aggressive, play truant, engage in antisocial behavior and are prone to depressive disorders in adult life (Poulter 1997). The children do not just lose parents, they also suffer a loss of parenting – which entails a loss connectedness, a bond, a sense of trust and continuity. Sibling separation also exacerbates feelings of isolation. In a

Uganda study two thirds of older children in affected households are separated from at least some of their siblings (Gilborn 2000). Children's needs for security from all aspects of economic want (based on their families' capacities and context) cannot be separated from their psychosocial needs. Some commentators and researchers have termed these as 'psycho-economic needs'.[7]

Children begin to be affected well before the parents die. Denial of education and involvement in informal sector labour can lead to reduced play opportunities and socialisation is adversely affected, impeding self-esteem development. Orphans often are deprived of education as foster parents (often mistakenly) assume the child is HIV positive and consider the opportunity costs of education as too high. Infected children are sometimes denied school-fees from caregivers due to impending funeral costs (Alidri 2001). For those remaining in school, performance deteriorates due to worry, depression and other physiological manifestations of anxiety. Often children are also not told about the progression of the parent's disease or the cause of the parent's death, overtly to protect the child from the trauma, pain and to conform to cultural norms regarding discussion of death.

Some experts feel that it is important to disclose the status of the parent's illness to children aged seven and over as they are mature enough to understand the finality of death and are aware of HIV/AIDS because of what they hear, learn at school and in the community. It is argued that having this information may help to protect children from contracting the disease since they are sometimes caring from the parents. Others argue that disclosing the information only makes life harder for children. Yet the decision should rest with the parents. Because of the strong and deep emotions involved, the deep-rooted traditional sensitivities, HIV positive parents find it very difficult to disclose their status to their children. Children do sense what is going on around them even if it is not discussed with them or expressly articulated. Others have argued that this makes the children more anxious and stressed. Research in the Kagera region in Tanzania concluded that children whose parents had talked to them about dying appreciated the opportunity to share time and listen to parental advice about how to do things when their parents die (UNAIDS 2001). Similarly in Uganda, where 69 per cent of a sample of affected children whose parents had discussed their HIV status with them thought that parent's openness about their status was positive (Gilborn 2000; Gilborn et al. 2001).

The National Association of Women Living With AIDS in Uganda (NACWOLA) is a project addressing these needs. The project had adapted the Memory Book approach, originally developed in the UK by Barnados. The book is a journal of facts and memories for children who face imminent loss or separation from a parent. It is an attempt to keep the memories, milestones in the child's and family's life alive and create a sense of enduring belonging and connection. It connects the past, the present and the future of the child helping them keep a sense of continuity and belonging and rootedness. It may include descriptions of the favorite memories of the mother or father, family traditions, special events, health and education and a family tree. The parents can complete it and then take the child through the steps or the child can be part of the process of completing

[7] Geoff Foster, 2001 – Electronic forum on psychosocial programming Think Tank.

it. The Memory Book provides opportunity to talk about HIV and may facilitate disclosure of parental (or even child) serostatus. Future challenges relate to helping caregivers disclose the HIV status of children and their parents, sometimes with the direct help of counsellors (Alidri 2001).

The issue of succession planning is integrated in the activities. Parents or guardians discuss with the participation of the child the person who will be their caregiver or parent after the death of the parent. This is most often an uncle or aunt of the children (in around 40 per cent of cases; Gilborn 2000). Mothers are now discussing not just surrogate parenting but also other options, by identifying one who is considered primary care giver and at the same time identifying others who might play certain other significant roles in the child's life. This mirrors reality, where the child is parented not just by the one biological mother and father but by other relatives, neighbours and other significant adults.

A cadre of facilitators continue to undergo training sessions to enable them to train mothers in communication skills with children, child and community counseling, the writing of memory books, home visits, facilitating psychosocial activities for children, basic will preparation, literacy for mothers and identification of supportive future care takers. One of the critical lessons learned is that in order for infected and affected children living in rural areas to receive quality care and support, external agents should integrate programmes for these children into existing community based structures and services. A child focused home care handbook is also being prepared for community health workers by Save the Children UK, in consultation with NACWOLA. The Memory Project will also initiate children and mothers' legal projects to address children and widows' inheritance rights and other legal issues.

The experience of the Humuliza project in Tanzania show that schools and teachers are critical to the development of children affected by AIDS, especially in the wake of the loss of parents and parenting (UNAIDS 2001). Teacher training that responds to the psychosocial needs of affected children has become a critical policy and programme response. Teachers are expected to become sensitive to children playing truant, being disruptive and withdrawn in class. For example, as part of the Humuliza project in Tanzania teachers were sensitised to identifying the needs of children and communicating with them. The teachers in turn are sensitising and advocating with politicians and traditional leaders to respond to the needs of thee children. Most importantly the teachers themselves have created a fund for orphaned children in their schools or communities, which helps to buy essential school supplies. The teachers contribute 200 TZ shillings ($0.26) every month from their own salaries (UNAIDS 2001). The critical first step in building a school based response is acknowledging that teachers are also in need of counselling, as a significant proportion of them are living with HIV, are battling with terminal and debilitating illnesses, and themselves losing loved ones.

In Uganda, schools are spontaneously responding to needs of affected children (Alidri 2001), although teachers are in need of further sensitisation and counselling training. Affected children are reported by teachers to be late for school more often, have irregular

attendance, have poor concentration due to hunger and sickness and suffer stigma from fellow students (such as deliberate avoidance or sitting apart from them). When parents take the initiative to disclose to the school the serostatus of their child, the schools do consider action such as exemption from strenuous activity, preferential seating at the front of class, fewer disciplinary measures and exemption from some school related costs. At a broader level it is clear that schools are critical in responding to the needs of children orphaned by AIDS. Governments affected by the epidemic must be assisted in the development of country-level strategic and implementation plans for HIV/AIDS prevention and impact management in education systems which aim to;

- assess, manage and mitigate the impacts of HIV/AIDS on education systems;
- improve the capacity of the education system to reduce vulnerability to HIV/AIDS and promote factors and environments that are inclusive, healthy and protective for individuals, communities and societies;
- strengthen capacities of education systems, especially schools, to implement well-resourced, full-scale HIV/AIDS prevention (and care) programmes that specifically address risk behaviours and situations.[8]

A working definition of psychosocial programming should be embedded in the psychological and social dimensions of a specific culture. Generally the main aim of psychosocial programming is to protect children from the accumulation of stressful events; to enhance the capacities of families and communities to respond to the psychosocial needs of children as well as to enable children's participation in their own rebuilding of a sense of normalcy and continuity. The goals should be to ideally implement programmes that support outcomes that include the enabling of secure attachments with caregivers, the establishment of meaningful peer relationships, social and cultural ties and connections, the development of self esteem, trust and key competencies; access to economic opportunities and a sense of hope for the future (Duncan et al. 2001).

To help programming there is a need to start from strengths of the community (Cook 1998) not to focus so much on the negative aspects. Critical to this is the identification of protective factors; features of the external and internal environment that facilitates resiliency in the children and their community. What are the enduring or transient social supports and characteristics that enable this to emerge? What makes some children thrive despite the poverty, in spite of the death or incapacitation of their parents? How do strong attachment, sense of trust and security, adaptability, independence and peer relationships help?

The importance of a consistent connection to a primary care giver (in particular the biological father), has been well documented in the United States as being a prime determinant of risk outcomes in adolescents. Children without such a connection are prone to early sexual debut, violence, greater involvement in risk activities and a negative social outlook (Kirby 1999; Resnick et al 1997; Blum and Reinhart 2000; Jessor et al. 1998). As parent die due to AIDS this connection is increasingly under threat, as well

[8] HIV/AIDS, Schools and Education: Global Strategy Framework, Inter Agency Working Group on HIV/AIDS, Schools and Education, May 2001.

connections to other members of ones own cultural group or routines, community resources and educational opportunities. The implications of this psychological deficit are not yet manifested but commentators point to increased levels of violence, deviancy and adult depressive disorders.

Psychosocial support is implicit in support programmes. Micro-credit programmes for women, youth skills training and employment creation is critical to economic needs but also fundamental to psychosocial health. These programmes may help to reduce stress related to worry about the future economic status, and in the case of adolescents the programmes increase their self esteem, provide opportunities for peer relationships and social skills (Duncan et al. 2001). Structure, predictability, and stimulation contribute to a strong sense of connection for children, and rites of passage, ritualised routines, recreational activities, traditional games, stories, legends, myths, song, dance, movement, sports, all contribute to this end.

5. AIDS in the context of poverty – the challenge of resource mobilisation and flows

It has been suggested that HIV/AIDS will be the main obstacle to reaching national poverty reduction targets and the UN Millenium Development Goals. Hitherto most policy responses internationally has been focused on prevention, control and treatment. There has been little on mitigation, even less specifically on orphans (Loewenson and Whiteside 2001). Yet AIDS and impacts cause and deepen poverty. HIV/AIDS is directly and indirectly linked to a host of negative outcomes that include reduced social sector spending, giving rise to a lack of access to affordable health care and prevention services; and lower education status; falling household per capita income, increased spending on medicines and funerals; lost productivity, disrupted farming cycles and systems; increased dependency ratios, worse gender inequalities, increased number of orphans, street children, crime, and commercial sex work. These outcomes inevitably and unavoidably give rise to perverse household risk management strategies including sell of land and assets (Cohen 1998; Hunter 2000; Loewenson and Whiteside 2001; Adeyi et al. 2001, see also chapter 11 of this compilation of studies)

In response to the challenge, in Zimbabwe, in 2001 the World Bank's Enhanced Social Protection Program aims to reach vulnerable children. One component of the programme is the Basic Education Assistance Module (BEAM). The programme, which is expected to begin operations in twelve districts, is a targeted school fees, examination fees and levy waiver aimed at reducing the number of needy children dropping out of school due to economic constraints. Broad based and inclusive School Selection Committees comprising members with knowledge of the socio-economic situations of the communities in which they live are responsible for identifying the children most in need of assistance. The funds for fees and levies go directly to the accounts of the schools each semester whereas the stipend element flow to the local post office savings banks where eligible children are permitted to withdraw one part of the stipend at the beginning of the school year to cover expenses for uniforms, travel and other school supplies. They are allowed to withdraw the remainder if they satisfy some minimum attendance criteria. A

system of monitoring and evaluation with periodic participatory assessments has been established. The programme is expected to reach approximately 426,00 children at both primary and secondary schools throughout the country and will cost $6.8 million or an annual cost of $16 per child (Subbarao 2001). It would be ideal if the guidelines in question are developed with active input from the communities using their own criteria or index for vulnerability (Phiri et al. 2001).

Another component of the programme is the Children in Extremely Difficult Circumstances (CEDC) whose objective is to intensify various forms of assistance to CEDCs through strengthening the communities' capacities to respond to their needs. Child Welfare fora have been established in the country to assist communities with training and grants to CBOs and NGOs working with CEDCs and their families. Two other components are the public works, which will supplement incomes of poor households through temporary employment and the social protection strategy for capacity building for planning, implementation and monitoring of the institutions (World Bank 2000).

Similarly in Zambia, the Social Investment Fund has developed a Children In Difficult Circumstances module that is offered to each community as part of the outreach process. Grants are now being made available in tandem with technical assistance, monitoring and evaluation support. These are grants for communities to respond to the needs of orphans and other vulnerable children. Malawi too has a similar initiative underway. There is a need, however, for these programmes to demonstrate credibility. The programmes need to ensure effective targeting of the vulnerable, have adequate implementation capacity, and allow genuine participation by communities and children. Questions of sustainability are also paramount.

Given the interrelationship of poverty and HIV/AIDS, it has been suggested that the Highly Indebted Poor Countries Debt Initiative provides an opportunity for an unprecedented and significant mobilisation of resources. These are the resources to mitigate the impacts of HIV/AIDS; provide an opportunity for a multi-partner and multi sector coordination and collaboration as well as an opportunity to scale out and scale up the best practices in the response to the pandemic. Indeed a critical challenge for country teams working on Poverty Reduction Strategy Papers (PRSPs) is to include HIV/AIDS as a central part of the overall poverty reduction effort. Adeyi et al. (2001) suggest that as part of the HIPC monitorable conditions, the budgetary savings from the debt relief could be earmarked and allocated to the AIDS programmes through Poverty Action Funds, national development funds or micro projects to reach local public and community institutions. In high prevalence countries it is estimated that a minimum of US$1.50-2.00 per capita is needed for a solid programme. The savings would constitute an important financial and political investment by the government and thus also prove its political commitment and will. It is imperative that the relationship between poverty and HIV/AIDS should be flagged and the analysis should be used as an advocacy tool to make the case for HIV/AIDS within the strategic plan. Only a few countries to date, however, have seized the opportunity in a thorough manner (Adeyi et al. 2001). This is a

missed opportunity, sad but indicative of the gaps in strategic planning, policy formulation, implementation, management and programming.

The establishment of a Global Fund for AIDS, TB and Malaria in late 2001, of a requested US$7–10 billion a year, could be a crucial access point for governments seeking resources to tackle the impacts of AIDS. One of the key objectives of the Fund is the protection of those made most vulnerable by the epidemic, especially orphans. Underfunding of this initiative ($1.5 billion by December 2001) hints that commitment to fighting the impacts of AIDS is still woefully lacking.

5.1 Resources to base: channeling resources to the frontline of the response

It is evident that households, community members and families are the ones that are caring for orphans, visiting and supporting them in various ways, raising whatever they need to pay the various educational and health costs. Various grassroots organisations and faith-based initiatives are also helping in the effort. However given the fact that most of the communities, carers and grassroots organisations do not have the economic means to manage adequately, given the pervasive poverty in these communities and the increasing numbers of orphans it is important that internal and external resources are mobilised to assist. The challenge however is to ensure those external resources trickle right down to the communities. In the past international organisations efforts to get resources to the communities have been beset by problems of poor targeting, insignificant impact and extremely low levels of resources in proportionate terms actually reaching the targets (Williamson et al. 2001). At the same time we have to be careful that organisations, as well meaning as they may be, do not undermine communities' ownership of responses by overwhelming them with resources right at the beginning of the mobilisation process, thus creating the impression and expectation that this is a problem that will be solved by the external agency providing the money. More often than not that agency, at any rate, will only be there for two or three years. Community action cannot be mobilised as well as sustained by providing resources as a carrot for motivation. Funding should come in tandem with capacity building geared to the establishment of structures to strengthen absorption, accountability and democratic principles (Phiri et al. 2001).

Williamson et al. (2001) suggest a number of mechanisms than can be utilised, adapted singly, or in parallel. They caution that these are not the only options and they are not mutually exclusive and they all may have advantages as well as limitations in given contexts.

Networks or Umbrella Organisations Working with Children. The membership of these organisations may include NGOs, government departments and FBOs. They may assist with writing proposals, monitoring and accountability. Examples are Children in Need Network (CHIN) in Zambia, UCOBAC in Uganda, and Network for OVC in Ethiopia.

Multilayer Committee Structures. Examples are the AIDS Committee structures in Malawi, the AIDS committees in Kenya, the Orphans and Vulnerable Children

Committees in Zambia and the Child Welfare Forums in Zimbabwe. These structures reach the grassroots, incorporate various stakeholders including government departments and personnel, thus enhancing accountability and promoting multi-partner coordination. Some of them may not have legal status or operational capacity to absorb funds and may rely on one of the members to do this.

Capacity building NGOs. Most of these have strong management, fiscal accountability systems and training capacity. They focus on building the capacity of local organisations and provide technical assistance, which enables local organisations to in turn mobilise communities to respond to the needs of orphans and other children affected by HIV/AIDS. For example, the International HIV/AIDS Alliance provides capacity building to local organisations in Africa, Asia and elsewhere. So too does Private Agencies Cooperating Together (PACT) in Ethiopia and Zimbabwe. Family AIDS Caring Trust (FACT) in Zimbabwe is now providing technical assistance and capacity building to over 200 organisations with a vision to scale up and scale out. The limitations may include the fact most of these organisations are grant funded and will only be there for a while. The other is that they may focus on capacity building to deliver services rather than to the catalytic role of mobilising action in comminutes.

National Funds. This category may include Social Action Funds, independent foundations, trusts or such legal entities. These can receive external funds and sub grant to local organisations, play advocacy roles, monitor as well as build capacities. Examples include the Nelson Mandela Children's Foundation in South Africa, The Kenneth Kaunda Foundation in Zambia, the Tanzania Social Action Trust Fund, the Malawi Social Action Fund and the Zimbabwe Enhanced Social Protection Fund. All are assisting orphans and other vulnerable children through various programmes and mechanisms. Sometimes these funds are wholly donor funded while others are supported by the private sector. A case in the latter category is the Tanzania Social Action Trust Fund. It uses interest earned from loans and investments in the private sector to make grants to local CBOs and NGOs to assist orphans. 50 per cent of its earnings are ploughed back into investments and loans to ensure sustainability of the program of assistance. SATF has expanded grants from 100 million Tanzania shillings ($112,000) covering eight regions in 1999 to 195 million shillings ($218,000) covering NGOs in twelve regions.

Other mechanisms include international funding structures whose advantage is that they can raise more money faster and effectively. Examples are the Global Initiative on AIDS in Africa, Communities Organized to Respond to HIV/AIDS Epidemic (CORE) and the Hope for African Children Initiative which all provide grants and technical assistance to local NGOs. They have strong management capacity but on the other hand are too far to make consistently right decisions or to be able to include other stakeholder in the process of identifying the recipients.

The role of faith based organizations (FBOs) needs to be highlighted also. FBOs are significantly involved in the education, health, agriculture and basic community development sectors. Religious women's guilds in the Christian churches and the Dawa sisters in some of the Muslim faithful communities in Malawi are both examples of

women groups that help, support the needs of widows and orphans by visits, with spiritual, moral and other resource support. (Phiri et al. 2001). It has been suggested that the facilitation of local family and neighborhood spiritual connectedness is one of the key foundations for an effective response (Campbell and Rader 2000), and it is known that religiosity is a significant protective factor for young people regarding risk behaviours (Ref).

How FBOs are to be brought in to wider coalition based, programme responses is still a relatively unexplored area. To date there is no documented organisation of sets of partners with an explicit strategy to work or partner with FBOs to mitigate the impacts of AIDS on orphans. Indeed structured dialogue between donors, INGOs and FBOs is limited.

6. Mobilising political will and the creation of frameworks for policy and programme implementation

Most affected countries have been charged with a lack of political will and commitment. There have been concerted calls for the mobilisation of high level leadership as one of the critical elements in an expanded and effective response to the needs of orphans and children affected by AIDS. Concerted, active, high visibility advocacy in all arenas of involvement including the local, district, national and international is critical. Yet this commitment is sorely lacking. For example in Malawi the AIDS Coordinating Committee Structure has been neglected by central government, even though the model is held up as a regional standard (Williamson and Donahue 2001). At the International Conference on AIDS and STDs in Africa held in Lusaka in 1999, not one head of state attended.

The UN's Declaration of Commitment on HIV/AIDS of June 2001 acknowledges that while prevention of HIV infection must be central to responses to the epidemic, for these to be effective they must also address the care and support of people living with HIV. These responses also need to have a strong focus on children infected and affected by HIV/AIDS, especially those *indirectly* affected – as all too often the needs of these children are forgotten. The governments of the world have signed this commitment and are now accountable to its implementation.

And we know what to do. There are a number of specific laws, policies and practices that are likely to contribute significantly to improving the lives of affected children. These include:

- Policies and Laws to uphold the property rights of orphans and widows in case of the death of their husband and father.
- Free primary school education including the waiver of school fees for orphans and other vulnerable children. This should include subsidising other school costs
- Recognition of community schools and related financial and technical support provision for their establishment and development

- Gender sensitive policies including the waiver of school uniforms for girls and the revision of policies that expel pregnant girls from school
- Elimination of violence against women (inheritance property grabbing has also been defined as violence against women)
- Support and endorsement to community based care for orphans rather than institutions
- Promoting and supporting good governance within decentralisation
- Provision of clean water, sanitation as well as more water points availability to reduce time spent by women collecting water
- Development of female economic empowerment programmes (credit and other micro-finance programmes)
- Female literacy programmes
- Food security programmes
- Inter-cropping practices to reduce weeding time and the promotion of high yielding drought resistant crops that are less labour intensive,
- The promoting of natural pest management thus reducing expenses.
- The improvement of access to land, capital, draught power,
- Well targeted health insurance – e.g. prepayment schemes for health services – e.g. letting people pay in-kind after they harvest,
- The development of efficient stoves to reduce time women spend collecting firewood,
- Preventive health care to reduce morbidity and mortality

(Mutagandura et al. 1998; 2000; Hunter and Williamson 2000; Phiri 2001; WLSA, Malawi 2001; Foster 2001a; Loewenson and Whiteside 2001).

Decentralisation is the dominant political process within which the response to orphans and children affected by AIDS is evolving. This could facilitate resource flow to the frontline as well as community empowerment. Full and prolonged 'engagement' is a necessary step. "(Engagement) blends good governance, participation, consensus building and indeed, stewardship" (Van Sant 2000). Decentralisation is not enough when local officials are not accountable to the citizenry. Decentralisation should go beyond administrative and financial measures to include political power sharing, accountability, transparency and full-fledged participation by the citizenry and civil society. At the same time, autonomous local control will achieve more benefits than the mere assignment of figurative responsibility to local government while substantive programme and resource control remains with central government (Van Sant 2000). Local government is closer to the communities and will be better placed to work there, along with CBOs and NGOs. Communities will also have easier access to the decision and policy-making processes if they come closer to them.

Strengthened local (district) government departments can coordinate activities of local organisations by monitoring and evaluating responses to support orphans. There is also the role of providing technical assistance, engaging in advocacy, implementing targeted income transfers, facilitating local economic growth, and leading poverty reduction programmes. Local government must involve the local citizenry in the design, implementation and evaluation of the responses to AIDS, ensuring that these are implemented by local organisations and that they are transparent and accountable.

The primary constraint remains the disconnection between policies and the laws on the one hand and community participation, awareness and mobilisation on the other. There is also disconnection between policies and legal instruments and the perceptions, practices, knowledge, capacities, capabilities and resources of the population. This is one area that external change agents need to address urgently (Smart 2000).[9]

7. Conclusions

The programme and policy challenges highlighted here are only some of the difficulties facing those tasked with designing or facilitating responses to the epidemic. The synergy needed between community-rooted responses and international and national political will is slowly emerging but is still fundamentally absent. The rhetoric of the UN Declaration of Commitment is not matched by efforts to make such proclamations a reality. Meanwhile on the ground responses to the epidemic continue to evolve, mostly hidden from the eyes and ears of researchers and documentalists.

There is no one size fits all. Different communities depending on their specific needs and prevailing national and local contexts may require or call for a set of specific responses. There is no widely accepted model of response, but principles of responses are being agreed upon. These must evolve further to better define the vulnerabilities of affected children within communities and the meanings of rights based approaches through their application in different contexts. Policy priorities relate to resources primarily, and the balance between community mobilised resources and external financing and intervention. This balance will vary from place to place and current operational research can provide an understanding of economic realities to be combined with the emerging ethical and principle based ethos of programmers.

Addressing the psychosocial welfare elements of orphans and children in affected communities is now a matter of urgency. The cycle of infection will be exacerbated by young people growing up in contexts where mental ill health is rife, combined with feelings of isolation, despair and social disenfranchisement. The responses required are in themselves not complex, but are needed at such an unprecedented scale that we are only starting to comprehend the implications. While constraints remain in the form of chronic and deepening poverty, capacity limitations and political indifference at all levels, the challenges facing themselves have never been greater.

[9] Personal communications with Sian Long and Changu Mannathoko.

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