

Programme and Policy Responses to the Impact of HIV and AIDS on Children¹

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Introduction

Every 50 seconds, one child dies of an AIDS-related illness and another becomes infected with HIV. Each day approximately 3,700 children are infected by, or die from, HIV and AIDS (UNAIDS 2004). Today, in sub-Saharan Africa, over 12 million children under the age of 15 are orphaned because of AIDS and by 2010 anywhere from 15 per cent to 25 per cent of children in over a dozen countries will be orphaned (UNAIDS, UNICEF and USAID 2004). These figures represent a shocking failure on the part of the global community. Of the estimated 38 million people living with HIV worldwide, 2.1 million are children. Even if a levelling-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).

Policymakers face strong challenges to mitigate the impact of the growing numbers of children orphaned and affected by AIDS. This chapter outlines these challenges and attempts to offer some solutions, although the complexity and dynamism of the debates make even such snapshot analysis difficult. These challenges relate to (a) reaching consensus on policy-related definitions of orphans and children made vulnerable by HIV and AIDS (OVC); (b) the emergence and realization of rights-based approaches to programming for OVC; (c) the explication and scaling up of 'good' practices in supporting OVC; (d) the effective flow of 'resources to the base'; and finally (e) mobilizing political will. These challenges overlap and interrelate, but constitute the key constraints on widespread and effective responses.

Reaching consensus on policy-related definitions

Defining broader child vulnerability in relation to HIV and AIDS is complex. Communities' own definitions of vulnerability include children who are not classified as

orphans (now agreed to be children aged under 18 who have lost one or both parents), such as disabled or destitute children, who may not necessarily be biological orphans, but may be termed ‘social orphans’. In fact, children start suffering economically, psychologically and in other ways long before they become orphans, i.e. during the period of illness of parents or other adults in the household. This mismatch between a 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 use of the stigmatizing term ‘AIDS orphans’ (sometimes interpreted as ‘orphans with AIDS’) 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 Williamson and Donahue noted in Malawi: ‘...in other communities, however, orphans appeared to be a primary focus because their needs have been emphasized 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).

Variations in the definition of orphans and vulnerable children and how these relate to globally accepted definitions warrants special attention. The variations are sometimes reflected in policy and legislation encompassing the issues surrounding distinctions between those definitions that are for targeting purposes (programme and project level) and those developed for quantitative use (national level/policy/surveillance and macro-resource allocation decisions).

The term ‘children living with HIV/AIDS’ was adopted by the National HIV/AIDS Care and Support Task Team in South Africa to cover all infected children, children in households where one or both parents are infected, children vulnerable to infection and those in households that have no HIV-positive members but who are affected due to societal impacts, reduced access to services; and those who have been abandoned (Smart 2001). The dangers of using such widespread and inclusive definitions in policy are that targeting of the most vulnerable groups becomes difficult and open to localized (mis)interpretation and abuse, and also that the scale of the problem can appear to be overwhelming, so stifling any concerted response. The problem is defined to a point where meaningful action is seen to be no longer feasible. In the United Republic of Tanzania, the concept of ‘most vulnerable children’ has gained currency and this allows a localized response. Reaching consensus on definitions of children about whom to be most concerned is one of the critical challenges facing all of those involved in responses to the needs of children made vulnerable by HIV and AIDS. What is clear is that orphanhood in and of itself is not the sole valid criterion for assistance.

HIV and AIDS and children’s rights

The issue of definitions is pertinent to the emergence of rights-based approaches to supporting children affected by HIV, as questions of vulnerability, categorization

and targeting are under scrutiny. HIV 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 9 and 10). The Convention on the Rights of the Child (CRC) is underpinned by four major principles:

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

However, for many children who have been infected or affected by HIV, these rights are being compromised. Children who are themselves living with HIV, or who have lost one or both parents to the virus, 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 (survey evidence across southern Africa indicates that 1–2 per cent of all households are headed by children). The death 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, 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 and a lack of understanding of how the virus is transmitted. For infected children, and those perceived to be infected, their supposed impending death is at the root of most discrimination they face. This stigmatization 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, children orphaned by AIDS tend to form their own informal groups as a result of this stigma and exclusion by their unaffected peers (Cook 1998). In some extreme cases, teachers often refuse to allow these children into schools. The tragic case of Nkosi Johnson in South Africa was brought to the world's attention in 2000. This young boy living with HIV was denied his rights to education and freedom from discrimination. Similar cases were recently reported in Kenya and NGOs are watching for comparable situations across the continent.

How children's rights to survival and development are affected by the HIV epidemic

HIV also affects the survival and development of children through its impacts on health, family livelihoods, social welfare and protection. The impact of HIV on

the health of children relates not only to the growing number of children being infected with HIV, but also to the effects HIV has on access to health care for children who are HIV-negative. As with access to education, stigmatization 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 will spend a much higher proportion of their income on HIV-related treatments, thereby reducing the income available for general health care, including immunization (see chapters 7 and 8). In Côte d'Ivoire, urban families in which a family member had AIDS were reported to spend four times as much on health care as unaffected families. Also, the parent's level of illness may make it very difficult for them to provide adequate child care and food or to travel to health centres with their children. In Zambia, households in which the head was chronically ill reduced the area of land cultivated by 53 per cent, compared to those without such an ill adult, resulting in lower food availability (SADC reports referenced in UNICEF 2003). Higher rates of stunting and wasting, as well as more elevated rates of severe or moderate malnutrition, have been reported in orphaned children (Human Rights Watch 2001).

The most significant effect of HIV 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. Increasingly, a large proportion of orphans are being taken care of by elderly grandparents who are often old, unable to generate income and may be living in impoverished conditions. Moreover, often these children are orphaned for a second time when their grandparents die.

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 Uganda, surveys reported that 0.25–0.5 per cent of the affected children were not attending school regularly because they had to take care of their sick parents (Gilborn 2000; UNICEF 2003). In Burundi, children in HIV-affected households begin earning earlier than those in unaffected households, becoming involved in petty trading and running errands at the ages of six or seven (Roudy et al. 2001). There is also a growing number of children ending up on city streets. Some children end up working in highly hazardous conditions, such as the informal mining industry, where they risk severe injury. A UNICEF study on HIV and child labour concluded that the epidemic was responsible for pushing a significant percentage of the millions of working children onto the labour market. Rapid assessments in Ethiopia found that more than three quarters of the domestic workers were orphans; in the United Republic of Tanzania, 38 per cent of the children working full-time in

quarrying were orphans; and in Zambia, 47 per cent of the children engaged in prostitution had lost both parents and 24 per cent one parent (UNICEF 2001; 2003).

Child-focused and rights-based programming

Rights-based programming implies a holistic approach, dealing with aspects of prevention, care, protection and impact mitigation. A rights-based response also aims to promote the participation of children and young people in the design and implementation of HIV programmes. This is being achieved through the work of key global institutions working for the rights of children by developing a global strategy and policy framework to guide programming for orphans and other children made vulnerable by HIV and AIDS. Five key strategies have been defined (UNICEF/UNAIDS 2004). These aim to:

1. Strengthen the **capacity of families** to protect and care for orphans and vulnerable children, by prolonging the lives of parents and providing economic, psychosocial and other support.
2. Mobilize and support **community-based responses**.
3. Ensure access for orphans and vulnerable children to **essential services**, including education, health care and birth registration.
4. Ensure that **governments protect** the most vulnerable children through improved policy and legislation and by channelling resources to families and communities.
5. Raise awareness at all levels through advocacy and social mobilization in order to create a **supportive environment** for children and families affected by HIV and AIDS.

These strategies 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.

While conceptually rights remain universal, responses must be grounded in local realities, necessitating a needs assessment and social mobilization process far removed from more traditional welfare responses. This is cost- and time-intensive, creating a crisis of capacity, for when the emphasis becomes prioritizing local conditions, the identification of 'good' and 'best' practices becomes more difficult.

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 up to reach more children. The use of the term 'best

practice' is problematic and remains valid only at a conceptual level (Webb 2001). There is a wide range of approaches being practised by different organizations, governments and communities for the care of orphans and children affected by HIV and AIDS. 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 2001; International HIV/AIDS Alliance 2001).

Scaling up is threatened by, among other things:

- lack of political support or political interference;
- corruption;
- inadequate dissemination of information on government policies and funding;
- reluctance to enact, modify or implement child protection policies and legislation;
- weaknesses and under-resourcing (human, financial and technical) of state service delivery and coordination of child care systems;
- lack of strategic partnerships;
- lack of integration into, or separate, national costed plans.

Difficulties in scaling up are primarily political. Governments have to be convinced of the political, social and economic costs of inaction. They also have to be convinced of the validity of support models, which may complement or intrinsically criticize 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, can and do opt to disengage with the non-state actors, due either to the perceived threat of interaction or just plain disinterest (Webb 2004). This challenge is considerable in parts of south and south-east Asia, where corruption tends to inhibit local government adoption of NGO responses. This is noticeable in Cambodia, China, India and Viet Nam, where local governments are only just starting to consider the impending orphan, and broader children and AIDS, crisis.

Political constraints notwithstanding, at the implementation level there is a basic set of prerequisite questions before scaling up can begin. These include the nature and extent of pre-existing coping strategies, 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 answering key questions:

- if and how the model responds to the physical, material, educational, psychosocial, cultural and spiritual needs of orphans and other vulnerable children;

- number and types/categories of needs addressed;
- numbers of children reached;
- 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’.

Good practices in responding to children affected by HIV and AIDS

We will consider community-based, as well as institution-based, responses here, but some defy simple categorization. Community-based or community-managed responses are centred around ‘informal’ fostering, whereby community members assume responsibility for caring for both biological and ‘social’ orphans. This is the norm in a number of countries in sub-Saharan Africa and Asia and has been observed in rural or semi-urban areas where there is little access to services. Religious faith, compassion, community solidarity, reciprocal altruism, concern for society’s well-being and blood ties are all key factors (Williamson 2000; Phiri et al. 2001).

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 HIV become manifest, there are increasing numbers of institutions such as both registered and unregistered children’s homes and orphanages. In Thailand, the number of HIV-positive children placed in institutions had 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 that is purchased and furnished by an external organization or 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 faith-based 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).

Institutional care

Institutions for children have a long history; early examples were established and maintained by faith-based or missionary groups. For the most part, the growth of institutionalization can be seen as an expedient response to the growing numbers of children in need of care and protection. It may be 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 during their parents' lives or after their deaths.

One factor that makes orphanages attractive 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 offer. 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. 2001a). Yet this can lead to subtle forms of 'abuse' as the *raison d'être* of the institution is compromised. A study in Zimbabwe showed that 75 per cent of the children in institutions had contactable relatives (Powell 1999); this was echoed by a 1991 study in Uganda which found that half the children in institutions had both parents alive and one quarter had one parent alive (Williamson et al. 2001b). In India's Mizoram State, 47 per cent of the children in orphanages were placed there after the divorce of their parents. Another 15 per cent were institutionalized because they had been born out of wedlock (Chakraborty et al. 2000).

While they may provide some '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 as they have lower levels of educational attainment, have problems adjusting to independence after leaving the orphanage, have more difficulties with relationships, lack parental and basic living skills and sometimes have a misplaced sense of entitlement, without a parallel sense of responsibility (Powell 1999; Wright 1999; Verhoef 2001; Rajkumar 2000; Grainger et al. 2001; Williamson et al. 2001b, International Save the Children Alliance 2003). 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 mainspring of people's sense of connectedness, belonging and continuity. They are the basis upon which social, cultural and life skills are attained. Children raised in institutions struggle to be accepted and to 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, after getting used to the trappings of an institution – especially the kind that provides a materially high Western standard of care – children raised in institutions may look down upon their own communities as being inferior (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 a sufficiently significant number to make an impact. The annual cost of keeping a child in a centre in Rwanda, for example, is approximately \$540, plus the cost of donated food (Williamson et al. 2001a). In Eritrea, the cost was estimated at \$1,350 per child per year, while in 1990 in the United Republic of Tanzania it cost \$649 each for a year, and in Burundi the equivalent figure was \$689 (Ainsworth and Rwegalurina 1992; Lusk et al. 2000). In South Africa, statutory residential care was estimated to cost as much as R2,590 (\$180) or R3,525 (\$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 was Z\$1,058 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. Z\$1,000 is about the entire average monthly salary of a typical family in the country.

The costs of setting up institutions also need to be considered. In Zimbabwe, where between a fifth and a third of children are orphans, the capital cost of just one institution was estimated to be Z\$25 million. In contrast, a traditional-type family unit for orphans cost Z\$500,000 to set up, with monthly running costs of Z\$131 per child. It is therefore estimated that institutions are 14 times more expensive than traditional arrangements (Powell 1999). Apart from the costs, the capacity limitations make institutional arrangements illogical for orphans. In Zimbabwe, there are only 41 institutions, accommodating fewer than 3,000 orphans (Powell 1999). Institutions should therefore be the last resort, after family, foster or community care, and in the absence of other models of care being available.

It is sometimes argued that correctly managed institutions can provide emergency temporary care to protect orphans at risk of abuse and that they can help with behavioural 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. During the 1990s, Uganda provided 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.

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 have 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, integrated into communities.

Where children are unable to live with their families, they should be settled in environments that approximate as nearly as possible to the family home. In the family-style units in the China programme, 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 thus participate in the raising of these children, who are therefore not isolated and learn social and cultural skills and self-reliance.

Support can be given to help prevent families breaking down in the first place, and to allow children to get out of institutions. In Ethiopia, the SKIP project and the Jerusalem Association for Children's Homes both worked to de-institutionalize children by enabling them to travel to their birthplaces during school holidays to look for their kin. Older adolescents were helped to become independent by developing their own business plans for which they were given small grants, being placed in apprenticeships where they received skills and mentoring, and being given opportunities to attend higher education. As a result of children being reintegrated into their communities, one home was closed (Gebru and Atnafou [n.d.]). SKIP promoted the concept of family-type units where children lived in the same style of housing as other community children, had the same standards of clothing and nutrition, went to the same schools, worshipped in the same faith-based structures and engaged in the same mode of agriculture as their peers in the communities. After eight years, SKIP had reintegrated 98 per cent of the children back into their communities.

Temple boy systems and community care centres have been suggested as other alternative models of care, especially where there is a strong Buddhist tradition. In Cambodia and Thailand, it is traditional for boys to be placed in a temple where they receive an education. This has been suggested as an option for orphaned boys if the faith community could be encouraged to extend the system to such children and actively destigmatize their links to HIV (Brown and Sittitrai 1996). This may

be a critical model in Cambodia, where the genocide of 1975–1979 (killing 1–3 million people) removed many potential grandparent caregivers for the orphans, estimated to number 60,000 at the end of 2001. Without a concerted and widespread response, rates of child abandonment in Cambodia will be unusually high for AIDS-affected populations. Through their own structures and faith-based organizations (FBOs), other faiths could be encouraged to adapt the system (Foster 2004). Such a system, if developed, would need to recognize 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 realizing that fostering arrangements will be one of the responses that will be promoted in most low- and middle-income 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 3 million children would have had access to the grant. After the first year, however, less than 30,000, or a meagre 1 per cent, had been able to receive the grant. This was because of stringent information requirements. Not everyone in rural and impoverished areas had the birth certificates that the authorities demanded (Loening-Voysey and Wilson 2001). Although the situation has improved, the debate has moved the target processes and the legitimacy of using demographic and health, rather than economic, criteria; i.e. targeting orphans rather than the poorest children (Meintjes et al. 2003).

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 the extended family considers itself to have responsibility for a relative's child. 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 lie with the government social workers and the state. Some fostering schemes were started in countries in political transition in Eastern Europe, intended as alternatives to institutions. They have, however, 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 some instances, 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 panacea.

In most cases, low- and middle-income and transition countries have not ensured that their social policy keeps pace with their economic reform. In those countries where institutions are 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 mind-numbing (Phiri et al. 2001).

Comparing cost-effectiveness and quality of care

Research in South Africa has examined both the quality of care as well as the cost-effectiveness of six models of care for orphans and vulnerable children (Loening-Voysey and Wilson 2001; Desmond and Gow 2001). The six models 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 economic 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 realize 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 were 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. The needs of the orphans being looked after in this manner were therefore not being properly met and their rights were not being recognized.

Table 1. Cost-effectiveness of six models of orphan care in South Africa

Model of care	Cost per child care month (Rands)	Cost per minimum standard child care month (Rands)
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.

Costing exercises are hampered by the fact that there are some aspects of care that are extremely difficult to measure or cost, particularly the affection or love of the carer. It can also be argued that it would be difficult to cost or measure 'community parenting' where significant others in the community contribute to the parenting of orphans. There is also a clear discrepancy between the availability of resources in a given context and the realization 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 costing review are many, and relate to the following:

- variation in intervention types;
- a tendency to cost specific subcomponents of programmes, such as food or education costs;
- varying definitions of target groups and their vulnerability;
- lack 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';
- difficulty in quantifying and measuring quality of support given;
- problems with costing the strengthening of health and social service systems.

Within the COPE Programme in Malawi, by July 2000, the District and Community AIDS Coordinating Committees had raised around \$20,000 of the \$1.6m needed to keep COPE going through to 2001. In other words, only around 1.25 per cent of the total amount needed for the programme was mobilized internally (Williamson and Donahue 2001). This raises the question of the potential for sustainability, as well as the need to better define non-financial resources, since finances are only one component of the social capital generated by the programme structures.

These and other issues are major constraints to reaching universal consensus on costings, and the way forward may be 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. Current costings along these lines are being developed by UNICEF and Futures Group International, and the eventual 'unit costs' of child care will be vital in ascertaining how much interventions, taken to scale, should cost across varying contexts.

Orphan support as community development in eastern and southern Africa

Despite the uncertainties, scaling-up efforts are ongoing. The Uganda Women's Effort to Save Orphans (UWESO) has used the model of children's villages to organize

cluster and community foster care arrangements (chapter 2). The organization gives school and medical costs, assists with food and clothing provision, and organizes training in community-based child care and livelihood support for families with orphans. UWESO uses an approach that enables communities themselves to care for orphans, thus engendering ownership and facilitating sustainability. By the end of 2001, the project had had an impact on over 10,000 orphans, raising income at household level and increasing the nutritional status of the children, as well as improving the quality of shelter in the community.

A further example is provided by the FOCUS project in Zimbabwe. This is a programme of the Family AIDS Caring Trust (FACT). Research on orphan enumeration and community coping mechanisms has been conducted by FACT since 1991. In 1993, the FOCUS programme started by recruiting several volunteers from villages and FBOs throughout the communal farming programme area. The programme emphasized identification and monitoring of vulnerable children through regular household visits; community ownership; keeping children in school; income-generating activities; and volunteer training and motivation.

In the ongoing programme, volunteers are responsible for identifying and visiting orphan households within a two-kilometre radius of their homes. Those considered most vulnerable are allocated priority status on a register and visited at least twice a month. The volunteers identify the unmet basic needs of the households and provide essential material support, including maize seed, fertilizer, food, clothing, blankets and school fees (costing around \$2–4 per year). The visits provide emotional and spiritual support, and the volunteers may also offer to bathe the children, sweep the house, fetch firewood or cook. The visits enable the children's situation to be observed, so that 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 occurs. These visits also enable spiritual activities such as prayer, scripture reading and songs of praise to be shared. Psychosocial support is provided through weekly craft, cultural and sporting activities. Income-generating projects initiated by volunteers include gardening, crocheting, greenhouse horticulture involving mushroom growing, goat keeping, poultry rearing, sewing and knitting. Volunteers who look after orphans in their own homes may receive small amounts of material support (average \$11 per annum). Incentives help to keep volunteer drop-out levels very low. They are also involved in advocacy and awareness-raising on orphan support issues (Phiri et al. 2001). By 2000, 178 volunteers were active in the programme, 97 per cent of whom were female. The lack of male volunteers in the programme is an obvious issue of concern and is part of a wider reluctance on the part of males to take on caring roles.

Total programme costs stayed fairly constant at between \$20,000 and \$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 annual cost per family was approximately \$10, and per vulnerable child \$3. The cost per visit was \$0.11, while the cost per volunteer was \$68. The programme has been replicated within Zimbabwe and in four other countries in Africa.

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 and international visitors. Save the Children US has successfully piloted this concept in Egypt and Viet Nam. 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 being developed during the course of the implementation of the project. At the local level, the living university locales are principally centres of learning, where community-to-community learning through visiting and collaborative review can take place (Phiri et al. 2001). The living university also provides critical technical assistance and quality control and a framework for monitoring and evaluation to local partners (Hunter 2001).

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

The psychosocial needs of children affected by HIV and AIDS, especially orphans, are most often neglected in programme design. Most organizations, 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, the 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. They do not usually verbalize these feelings, making it difficult to assess whether they have reached closure about the terminal illness or death of their parent(s). They may instead become withdrawn, aggressive, play truant, engage in antisocial

behaviour and be 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 of connectedness, a bond, a sense of trust and continuity. Sibling separation also exacerbates feelings of isolation. In a Ugandan 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 and emotional needs. Some commentators and researchers have termed these as 'psycho-economic needs'.²

Often children are also not told about the progression of the parent's disease or the cause of the parent's death. Overtly, this is to protect the child from trauma and pain and to conform to cultural norms regarding discussion of death and loss. 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 and AIDS because of what they hear and 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 sometimes care for 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, and the deep-rooted traditional sensitivities, HIV-positive parents find it very difficult to disclose their status to their children. But children do sense what is going on around them, even if it is not discussed with them or expressly articulated and this can make them more anxious and stressed. Research in the Kagera region of the United Republic of Tanzania concluded that children whose parents had talked to them about dying appreciated the opportunity to share time and listen to their advice about how to do things after the parents' death (UNAIDS 2001). Similarly, in Uganda, 69 per cent of a sample of affected children, whose parents had discussed their HIV status with them, thought that parents' openness about their status was positive (Gilborn 2000; Gilborn et al. 2001).

In the early 1990s, the National Association of Women Living With AIDS in Uganda (NACWOLA) adopted the Barnardo's-initiated idea of a memory book, a journal of facts and memories for children who face imminent loss or separation from a parent. It is an attempt to keep alive the memories and milestones in the child's and family's life. Connecting the past, present and the future, the memory book or box helps the child keep a sense of continuity, belonging and rootedness. It provides an opportunity to talk about HIV and may facilitate disclosure of parental (or even child) serostatus, sometimes with the direct help of counsellors (Alidri 2001).

Planning who will look after the child(ren) after the prospective death of one or both parents is also a crucial element of the programme. Parents or guardians discuss, with the participation of the child(ren), the person who will be their caregiver

or parent after the death of the AIDS-affected parent. In around 40 per cent of cases, the person chosen is an uncle or aunt (Gilborn 2000). Besides surrogate parenting, mothers also discuss other options, identifying someone who would be considered the primary caregiver and others who could play significant roles in the child's life. This mirrors reality, where children are parented not just by the one biological mother and father, but also by relatives, neighbours and other adults. The Memory Project will also initiate projects to address children's and widows' inheritance rights and other legal issues.

The Humuliza project in the United Republic of Tanzania shows that schools and teachers are central to the emotional development of children affected by AIDS (UNAIDS 2001). Teacher training that responds to the psychosocial needs of affected children has become a critical policy and programme response. Teachers were sensitized to identify the needs of children and communicate with them. The teachers in turn advocate response to these needs with politicians and traditional leaders. The teachers have also created a fund for orphaned children in their schools or communities, which helps to buy essential school supplies. They contribute TZ shillings 200 (\$0.26) every month from their own salaries (UNAIDS 2001).

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 help children rebuild a sense of normalcy and continuity. The goals should ideally be to implement programmes that, among other outcomes, enable children to form secure attachments with caregivers, meaningful relationships with their peers, and strong social and cultural ties and connections, while developing their self-esteem and key competencies and being given access to economic opportunities and a sense of hope for the future (Duncan et al. 2001).

Programming should be based on the strengths of the community (Cook 1998), rather than focusing on its negative aspects. Critical to this is identification of protective factors – features of the external and internal environment that facilitate resilience in the children and their community. What are the enduring or transient social supports and characteristics that enable these to emerge? What makes some children thrive despite the poverty and in spite of the death or incapacitation of their parents? How do strong attachments, a sense of trust and security, adaptability, independence and peer relationships help?

In the United States, the importance of a consistent connection to a primary caregiver (in particular the biological father) has been well documented as being one of the main determinants of risk outcomes in adolescents. Children without such a connection are prone to early sexual experience, 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).

Psychosocial support is implicit in support programmes. Microcredit programmes for women, youth skills training, and employment creation are 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 and 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, ritualized routines, recreational activities, traditional games, stories, legends, myths, song, dance, movement, sports all contribute to this end. As parents die from AIDS-related illnesses, these connections are increasingly under threat. The implications of this psychological deficit are not yet manifested, but commentators point to increased levels of violence, deviancy, adult depressive disorders and rather tenuous links to 'terrorism'.

HIV in the context of poverty – the challenge of resource mobilization and flows

It has been suggested that HIV will be the main obstacle to reaching national poverty reduction targets and the UN Millennium Development Goals. Hitherto, internationally, most policy responses have been focused on prevention, control and treatment. There has been little on mitigation, even less specifically on orphans (Loewenson and Whiteside 2001). Yet HIV and its impacts cause and deepen poverty. The epidemic 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; 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 sex work. These outcomes inevitably and unavoidably give rise to perverse household risk management strategies, including the sale of land and assets (Cohen 1999; Hunter 2000a; Loewenson and Whiteside 2001; Adeyi et al. 2001; see also chapter 7).

In response to the challenge, the World Bank's Enhanced Social Protection Programme in Zimbabwe aims to reach vulnerable children. One component of the programme is the Basic Education Assistance Module (BEAM). The programme, which was expected to begin operation in 12 districts, waives school and examination fees in order to reduce the number of needy children dropping out of school because of economic constraints. Broad-based and inclusive school selection committees, comprising members with knowledge of the socioeconomic 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, while the stipend element goes to local post office savings banks. Eligible children can withdraw part of this stipend at the beginning of the school year to cover expenses for uniforms, travel and other school supplies, and are allowed to withdraw the remainder if they satisfy minimum attendance criteria. A system of monitoring and evaluation with periodic participatory assessments has been established. The programme is expected to reach approximately 426,000 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 et al. 2001). It would be ideal if the guidelines in question could be developed with active input from the communities concerned, using their own criteria or index for vulnerability (Phiri et al. 2001).

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

Similarly, the Social Investment Fund in Zimbabwe and the Social Action Fund in Malawi have developed modules and training programmes that are 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.

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, it has been suggested that the heavily indebted poor countries debt initiative (HIPC) provides an opportunity for an unprecedented and significant mobilization of resources. These are the resources to mitigate the impacts of HIV, facilitate multi-partner and multisectoral coordination and collaboration, and allow for scaling up of the 'best' practices in response to the pandemic. Indeed, a critical challenge for country teams working on poverty reduction strategy papers (PRSPs) is to include HIV as a central part of the overall poverty reduction effort. Adeyi et al. (2001) suggest that, as part of the HIPC monitoring conditions, the budgetary savings from debt relief could be earmarked and allocated to the HIV programmes through poverty action funds, national development funds or microprojects in order to reach local public and community institutions. In high-prevalence countries, it is estimated that a minimum of \$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 should be flagged and the analysis should be used as an advocacy tool to make the case for HIV within the strategic plan. Only a few countries to date, however, have seized the opportunity in a thorough manner (Adeyi et al. 2001; Bonnel et al. 2004). This is a missed opportunity, sad but indicative of the gaps in strategic planning, policy formulation, implementation, management and programming.

Resources to base: channelling resources to the frontlines

The frontlines, meaning those affected by, and responding to, the epidemic, are households, community members, families, various grassroots organizations and faith-based initiatives. However, even collectively, they do not have the economic means to manage the needed response adequately, given the pervasive poverty in these communities and the increasing numbers of orphans. It is therefore important that internal and external resources are mobilized to assist. The challenge, however, is to ensure that such external resources do reach the communities. In the past, international organizations' efforts to get resources to the communities have been beset by problems of poor targeting, insignificant impact and the extremely low levels of resources (in proportionate terms) actually reaching the targets (Williamson et al. 2001b). At the same time, we have to be careful that organizations, however well meaning, do not undermine communities' ownership of activities by overwhelming them with resources right at the beginning of the mobilization process, thus creating the impression and expectation that the whole problem will be solved by the external agency providing the money. More often than not, that agency will only be there for two or three years. Large injections of external resources are possibly damaging to ongoing 'development' efforts, and a careful balance needs to be struck. Community action cannot be mobilized and 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).

Mobilizing political will and the creation of frameworks for policy and programme implementation

Most affected countries have been charged with lacking political will and commitment. There have been concerted calls for the mobilization 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 HIV and AIDS. Concerted, active, high-visibility advocacy in all arenas of involvement, including the local, district, national and international, is critical.

The June 2001 UN Declaration of Commitment on HIV/AIDS acknowledges a

strong focus on children infected and affected by HIV, especially those **indirectly** affected. The governments of the world have signed this commitment and are now accountable for its implementation. 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, with waiver of school fees and subsidies for other school costs for orphans and other vulnerable children.
- Recognition of community schools, with provision of financial and technical support for their establishment and development.
- Gender-sensitive policies, including the waiver of school uniforms for girls and the revision of policies expelling pregnant girls from school.
- Elimination of violence against women (inheritance property expropriation has also been defined as violence against women).
- Support for, and endorsement of, community-based care for orphans, rather than institutions.
- Promoting and supporting good governance within decentralization.
- Provision of clean water and sanitation, as well as more water points, to reduce time spent by women collecting water.
- Development of female economic empowerment activities (credit and other microfinance programmes).
- Female literacy programmes.
- Food security programmes.
- Intercropping practices to reduce weeding time and promotion of high-yielding, less labour-intensive, drought-resistant crops.
- Promotion of natural pest management, thus reducing expenses.
- Improvement of access to land, capital and draught power.
- Well-targeted health insurance – e.g. prepayment schemes for health services, such as letting people pay in kind after they harvest.
- Development of efficient stoves to reduce time women spend collecting firewood.
- Preventive health care to reduce morbidity and mortality.

(Hunter 2000; Phiri 2001; Foster 2001; Loewenson and Whiteside 2001).

Decentralization is the dominant political process within which the response to orphans and children affected by HIV and AIDS is evolving. This could facilitate resource flow to the frontline as well as community empowerment, but only if local officials are accountable to the citizenry. Administrative and financial measures need to include political power sharing, accountability, transparency and real participation by the citizenry and civil society. Really autonomous local control will achieve more benefits than merely assigning 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 themselves, and is better placed to work with CBOs and NGOs. Communities also have easier access to the decision- and policy-making processes if they are closer to them.

Strengthened local (district) government departments can coordinate activities of local organizations 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 organizations and that they are transparent and accountable.

The primary constraint remains the disconnect between policies and the laws on the one hand and community participation, awareness and mobilization 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 2001).³

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 on HIV/AIDS 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 documentation experts.

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 and strategies are 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 primarily to resources, and the balance between community-mobilized 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 if young people grow up in environments 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 on 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 we face have never been greater.

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Notes

- 1 Authors' note. The bulk of this chapter was written in 2001. Since then, there has been a great deal of research, which has helped to develop understanding of the situation and responses. A number of key events have also taken place, most notably (a) the development of national plans of action for orphans and children made vulnerable by HIV and AIDS in 16 countries across sub-Saharan Africa, signifying a realization of political will and (b) the increasing funding being allocated to this area of work, especially from the US, UK, Dutch and Scandinavian Governments. While these initiatives are welcome, the policy response challenge remains daunting.
- 2 Geoff Foster, 2001 – Electronic forum on psychosocial programming Think Tank.
- 3 Personal communications with Sian Long and Changu Mannathoko.