



**CHILDREN IN COMMUNITIES
AFFECTED BY HIV AND AIDS
EMERGING ISSUES**

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1. Background

Calls for action to alleviate the impacts of HIV and AIDS on children are growing. As efforts to respond to children gain momentum, a number of long-standing debates in the fields of children, families, social services and development aid come into focus and new issues emerge.

Calls for action to alleviate the impact of HIV and AIDS on children are growing.

This think-piece is based on a project commissioned by the Bernard van Leer Foundation, aimed at understanding in-country variables affecting opportunities and barriers for advocacy to achieve better support for children affected by HIV/AIDS. The project consisted of a case study of South Africa, and was situated in prior and continuing work in the Child Youth Family and Social Development (CYFSD) programme at the Human Sciences Research Council in South Africa. A summary *Situation Analysis: Evidence for Advocacy* and five detailed papers were produced:

- *The Impact of HIV/AIDS on Children: Indicators of Large-Scale Vulnerability Due to Poverty and Social Exclusion* - Chris Desmond & Linda Richter
- *Civil Society Programme Intervention for Children and Families Living in Communities Affected by HIV and AIDS in South Africa* - Andrew Dellis
- *People who Matter: What Do They Think about Issues Relating to Children Affected by HIV and AIDS?* - Vuyiswa Mathambo
- *Discerning the Mind of the Public: Representing Children Living in Conditions Affected by HIV/AIDS in South African Newspapers* - Kunda lengwe John-eudes
- *Not a Penny More, Always a Penny Less: Barriers to the Distribution of Funds to Orphans and Vulnerable Children through Existing Funding Channels* - Sharmila Rama, Gerard Boyce and Marisha Ramdeen,
- *Making Social Policy Count* - Tamsen Rochat and Linda Richter.

CYFSD analyses of international trends and issues in efforts to ameliorate the impact of HIV/AIDS on children and families have been published in four widely distributed publications, including one supported by the Bernard van Leer Foundation¹. *Where the*

¹ Richter, L., Manegold, J. & Pather, R. (2004). *Family and community interventions for children affected by AIDS*. Cape Town: Human Sciences Research Council; Richter, L., Foster, G. & Sherr, L. (2006). *Where the heart is: Meeting the psychosocial needs of young children in the context of HIV/AIDS*. The Hague:

Heart is, together with a set of postcards communicating key messages (*Call to Action*), was released in Toronto in August 2006 at a specially convened satellite session at the XVI the International AIDS Conference.

These publications, each conveying similar messages about the importance of large-scale systemic approaches, have significantly influenced a number of funders and international organizations, prompting them to reconsider their approaches. The publications have also contributed to efforts to bring support for children affected by HIV/AIDS closer to global initiatives, such as *Education for All*, universal access and the push for social protection in developing countries.

In our work to date, we have challenged, amongst other things, the practice of targeting services and programmes specifically at so-called AIDS orphans, child-headed households and skip generation households. Our argument has been that these categories of children are not necessarily the most in need, that narrow targeting excludes other groups of children in difficulty, and that a public health and rights-based approach – raising the level of support and services for all children – is what is required in high HIV prevalence communities simultaneously affected by poverty.

The messages we have conveyed include the following:

1. HIV and AIDS cause children great suffering, not least because of the fear, bereavement, uncertainty, instability and increasing hardship associated with the illness and death of adults on whom children depend for their security, basic needs and sense of future.
2. Very large numbers of children in countries hardest hit by HIV and AIDS are susceptible to poor growth, ill-health and are at risk of not reaching their human potential, predominantly as a result of widespread destitution – in some cases, also because of conflict, war, corruption and despotism.
3. These conditions make life exceptionally difficult for children and families already vulnerable as a result of parental death, disability, minority status, and the like.
4. Mitigation efforts that target only AIDS-affected children are inefficient, likely to result in unintended negative consequences (such as the stigmatization and exploitation of affected children), and can undermine services by sidetracking resources into vertical programmes.

Bernard van Leer Foundation; Richter, L. & Foster, G. (2006). *The role of the health sector in strengthening systems to support children's healthy development in communities affected by HIV/AIDS*. Geneva: World Health Organization; Richter, L. & Rama, S. (2006). *Building resilience: A rights-based approach to children and HIV/AIDS in Africa*. Save the Children Sweden.

5. Especially vulnerable children are best helped by efforts to strengthen the formal and informal systems of services and supports necessary for all children – access to education, health, social protection, as well as community programmes and facilities for families in whose care children thrive.
6. The more widespread and stronger these systems, the smaller the number of children requiring special or targeted forms of assistance, referred to in public health terminology as “shifting the curve” (a concept dealt with in greater detail in a following section of the paper)
7. To date, the predominant response to affected children and families has come from extended kin, neighbours, community groups and civil society organisations (CSOs).
8. The next big step forward in protecting children affected by AIDS must come from governments, with the assistance of local CSO’s and the international community. States have to strengthen health, education, social protection for children to create general conditions within which families, community groups and CSOs can provide assistance to extremely vulnerable children, including those also affected by HIV and AIDS.

The world is beginning to heed the call for ‘more’ to be done for children. We now have to be specific about what ‘more’ involves. There are a number of central issues to be grasped if we are to respond to children in the context of HIV and AIDS in a coherent, efficient and sustainable manner, consistent with the goals of hard-hit states to keep poverty and under-development as their core priorities.

The world is beginning to heed the call for ‘more’ to be done for children. We now have to be specific about what ‘more’ involves.

This paper identifies some of these issues and lays out the arguments for prioritising, at this juncture, strengthening families, the role of the state, social protection and coherence in the roles of the variety of actors needed to achieve measurable gains. The paper begins with an overview of issues about which there is now some consensus, especially the neglect of children in the overall HIV/AIDS response. The paper then contextualises HIV and AIDS and poverty. In the following section we identify emerging issues in this field, concentrating on targeting, new forms of vulnerability, the importance of a human rights approach, income transfers, the role of government, and the need to join up efforts across government and between governments and civil society organizations. We end with conclusions, highlighting the most important points made in the paper.

2. Children: The forgotten face of HIV and AIDS

The sad faces of children who look lonely and neglected are marketed as part of the appeal for resources for many good causes, including for HIV and AIDS. But, on the occasion of the launch of the *Unite for Children, Unite against AIDS* campaign in October 2005, Ann Veneman, then UNICEF's Executive Director, stated that "Children have really been the forgotten face of AIDS" (UNICEF, 2005). This is demonstrable in achievements to date in prevention, treatment, and care and support.

In this section, we briefly review evidence of the neglect of children in prevention and treatment, and well-intentioned, but largely ineffectual, efforts to provide care and support to families and children affected by HIV and AIDS on a scale commensurate with the impact of the epidemic. It is evident that in all areas renewed, more effective, strategies are needed to respond to children and families

Children have really been the forgotten face of AIDS.

(i) Low levels of prevention

Prevention of infection among infants born to women living with HIV (PMTCT) only began in the United States in the late 1990s, many years after the first case of vertical transmission was identified by the Centers for Disease Control in 1983.

Dual therapy, and well-supported formula feeding, has led to reductions in vertical transmission in developed country contexts to below 4 percent². A single dose of Nevirapine – the regimen in place in much of southern Africa – reduces transmission to 15-25%. Arguments given for the use of a single dose drug – a tablet for the mother before birth, and syrup for the infant within 72 hours of delivery – are that health system deficiencies inhibit a more intensive regimen. There is consensus that monotherapy is second best. But, lack of access to health facilities, failures of drug supply, cost of drugs, late and inconsistent antenatal service use, and poor follow-up during the postnatal period have been cited as reasons for the lack of progress in implementing multi-drug prevention of mother-to-child transmission.

In addition to poor coverage by less effective drugs with more potential for resistance, the benefits of breastfeeding, the costs and operational difficulties in ensuring a steady and sufficient supply of formula, as well as high transmission rates associated with mixed feeding (breast- and bottle-feeding), have led to inconsistent and often confusing advice to policy makers, health providers, and parents. Children, parents, families and countries in southern Africa and other hard-hit parts of the world are ill-served by the lack of effort to date to eliminate vertical transmission.

² Kaiser Network (2007). Botswana reduces mother-to-child HIV transmission rate to less than 4%, Boston Globe reports. http://www.kaisernetwork.org/daily_reports/rep_index.cfm?hint=1&DR_ID=47112 [Online].

PMTCT coverage remains low.

PMTCT coverage remains low. In 2005, only 11 percent of pregnant women living with HIV/AIDS received drugs to prevent transmission. Coverage in selected southern African countries in 2005 is shown in Table 1, together with antiretroviral (ARV) coverage for 2005 and 2006, and HIV prevalence³. With advocacy and assistance, most countries have improved ARV coverage. However, except for South Africa and Zambia, PMTCT is very much less than ARV coverage, indicating the lag in prevention of HIV infection in children. This is despite the fact that PMTCT programmes generally began earlier than adult ARV and are simpler to implement.

Table 1: PMTCT Coverage

Country	PMTCT Coverage 2005 %	ARV Coverage 2006 (2005) %	HIV Prevalence %
Angola	1	10 (6)	3.7
Botswana	54	95 (85)	24.1
D Republic Congo	2	11 (4)	3.2
Lesotho	12	31 (14)	23.2
Malawi	6	43 (20)	14.1
Mozambique	6	14 (9)	16.1
Namibia	29	71 (71)	19.6
South Africa	30	33 (21)	18.8
Swaziland	34	42 (31)	33.4
Zambia	15	35 (26)	21.1
Zimbabwe	9	15 (8)	20.1

Source: WHO, UNAIDS, UNICEF, 2007

(ii) High rates of infection among children

In the first national household study on HIV/AIDS conducted in sub-Saharan Africa in 2002, the Human Sciences Research Council reported that between 5 and 6 percent of South African children between 2 and 14 years of age were HIV+ (Shisana & Simbayi, 2002; Brookes et al, 2004). A repeat household study conducted in 2005 found childhood HIV prevalence to be lower, at 3.3 percent (Shisana et al, 2005). Both surveys found comparable prevalence rates in boys and girls and similar HIV rates across most age groups. The prevalence rates in children in all age groups were considerably higher than those expected, and suggested infections due to causes other than vertical transmission. Using BED assays, it was estimated that HIV incidence among 2-14 year-old children was 0.5 percent per year, comprising some 11 percent of all new HIV infections in South Africa.

³ PMTCT data for 2006 has not yet been released.

... infections due to causes other than vertical transmission.

Together with data indicating that mothers of some children who test HIV+ are themselves negative, it appears that the rate and mechanisms of infection among children have largely been ignored. Child infections are hypothesized to occur through, amongst others, sexual abuse, scarification, care of infected people in the home, and nosocomial infections, or infections which result from treatment in a health facility.

According to Geoff Foster, “Were the South African data extrapolated to other countries in southern Africa, it would imply that 225,000 young children were HIV-infected annually ... The disregard of the HIV/AIDS community concerning ongoing HIV transmission to substantial numbers of children through as-yet unclear mechanisms is an indictment that HIV/AIDS priorities are not being determined on the basis of public health concerns. If proof be needed that children are the missing face of AIDS, one need no look no further than the way that policymakers have ignored or dismissed these findings, without giving thought to the likelihood that large numbers of children are being silently infected with HIV”⁴

(iii) Poor treatment coverage

Treatment for HIV-infected children has lagged behind treatment of adults, despite the fact that instances of HIV infection in children were detected early in the course of the epidemic. The case of Ryan White, a child with haemophilia in the USA, who was diagnosed HIV+ in 1982, brought to the fore the discrimination and social exclusion experienced by so-called *innocent* children. These early cases also set the scene for attitudes towards what were considered to be *culpable adults*. Children are perceived to be the victims of transmission by tainted fluids of adults, even from those responsible for their care. Blame towards adults for failing their responsibilities towards children has coloured efforts to mitigate HIV/AIDS impacts on children, as is described in a later section of the paper.

Treatment of HIV-infected children has lagged behind adults ...

In 2006 it was estimated that there were 2.3 million children (0-14 years of age) who were living with HIV and that, in the southern African region, 380 000 children died from causes attributable to HIV/AIDS (WHO, 2007). Despite the need for treatment and recent expansions in coverage, levels remain low and lag behind rates achieved for adults. The percentage of children on treatment has increased recently by 50 percent. This increase, though, only takes to 15 percent of children in need of ARV estimated to

⁴ Personal communication

be receiving the treatment, compared to almost double that coverage level among adults (WHO, 2007).

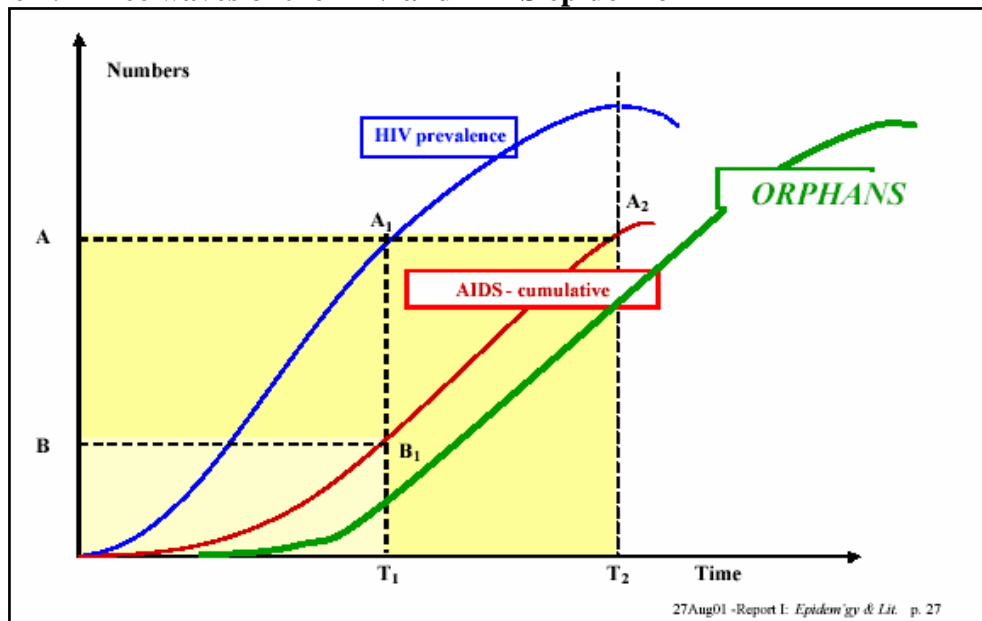
There is substantial evidence that ARV therapy is highly effective in the treatment of children, including those in resource-poor settings. Rapid initiation of ARV treatment restores and preserves immune functions, promotes normal growth and development, and prolongs life. Generally, some 80 percent of children with HIV die by age five years if they do not receive ARV therapy. In high-income countries, where most children with vertically acquired HIV infection are treated early, therapy has been shown to reduce mortality by five-fold or more, resulting in survival rates of 80 percent and higher (Wilfert, 2005). In addition, low-cost antibiotics (co-trimoxazole) can provide protection against opportunistic and other childhood infections which are potentially life threatening. It is estimated that only 4 percent of the 4 million children younger than age 15 years worldwide, which could benefit from such combined treatment, receive it.

Specific barriers to the roll out of ARV treatment for children include human resource constraints and inefficient health care systems, limited screening for HIV-positive children because tests are unavailable and/or unaffordable, misconceptions about the effectiveness of ARV treatment for children, and expensive and challenging paediatric formulations (Van Damme et al., 2006). All of these need to be addressed to ensure that children receive treatment.

(iv) Inappropriate targeting and ineffectual efforts to mitigate impacts on children

There are several overlapping waves in HIV/AIDS epidemics. The first wave consists of rising infection rates; the second wave rising rates of severe illness and death; and a third wave the rising rates of children whose parent or parents have died. This is illustrated in Figure 1. Other waves relate to the impact on social services, industry, and the economy.

Figure 1: Three waves of the HIV and AIDS epidemic



Source: Whiteside and Barnett, 2006.

Given the increase in adult mortality and the age profile of those who are being lost, much of the response to impacts on children have been targeted to orphans. The UNAIDS definition of an orphan is a child under 18 who has lost one or both parents.

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This has prompted debates on what constitutes an orphan. Susan Hunter who first wrote on the issue in 1990, defined an orphan as a child with one or both parents *missing* (dead or displaced) due to any cause (war, dislocation or AIDS) (p. 684). Her intention was to draw attention to the widespread vulnerability of children in communities under stress, including as a result of HIV and AIDS. She cited the 1989 study of Elizabeth Preble, published in 1990, which indicated that the orphan problem was “just the tip of the iceberg’ (p. 686) of social and economic disruption. Hunter also posed a question that is only now beginning to be heeded “Does world wide resource maldistribution and artificial scarcity create the conditions under which the ‘orphan problem’ and AIDS itself become unmanageable”?

Under normal circumstances, the loss of one parent doesn’t make a child an orphan, indicating that the definition is intended to measure epidemiological rather than individual impact. UNICEF (2007) has recently reiterated the point that the provision of assistance to children in highly impacted communities should not be restricted to orphans.

It is widely agreed that “orphan targeting” is having adverse effects.

Despite this, both government and civil society programmes continue to profile assistance to so-called *AIDS orphans*, largely because of earmarked funding driven by advocacy in donor countries. It is widely agreed that “orphan targeting” is having adverse effects. It is leading to children being labelled orphans by families who would not previously have used the term, and more children are being called orphans in order for families to access desperately needed assistance. At the same time, destitute children and families, and other needy groups, are being bypassed in the provision of help. Most important though, the focus on orphans has framed mitigation for children as an individual, rather than a national social problem, and separated assistance to children from assistance to families and communities. As a result of individualising the challenge of care and support, efforts to mitigate the effects of HIV and AIDS among the very large numbers of children who need assistance over a long period, have largely been ineffectual.

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(v) Moving forward

Shortfalls in prevention, understanding of causes of infection, treatment, and the failure to grasp the extent of mitigation needed are now being acknowledged. There is still much to be done. However, as we proceed, our perspective on old issues change and new issues emerge. This paper is not intended to be comprehensive, but it attempts to identify emerging issues in care and support for children affected by HIV and AIDS. In the remaining sections of the paper, we do not deal with prevention and treatment specifically, except when either or both is relevant to care and support.

A number of issues have received attention in recent years and not all of them are resolved. These include the vulnerability of so-called single orphans, the relative deprivation of orphans compared to non-orphans, institutionalisation of children and expansion of orphanage facilities, the scalability of psychosocial support (Richter, Foster & Sherr 2006), and how child rights have been interpreted by agencies providing support to children and families (Richter & Rama, 2006). These topics are not specifically covered in the document unless they are included with what is called an emerging issue.

3. The context of HIV/AIDS in Southern Africa

The southern African region is experiencing the most intense HIV and AIDS epidemic in the world. Prevalence rates in the region are far higher than elsewhere. As a result, adult mortality has increased substantially and this has kept life expectancy low. While the high point in incidence in most countries is thought to have passed, prevalence will continue to increase for a number of years to come, and deaths will continue to increase for a number of years after that. Although treatment rates are increasing, with Botswana leading the way with close to universal coverage of adult programmes, mortality in the region remains high.

Life in southern Africa has long been shaped by high rates of migrant labour, concentrations of wealth and poverty, and gender inequality. The HIV/ AIDS epidemic has exposed these cracks in society and exploited them. It is not the epidemic alone which has generated the scale of social problems we now see, but it is the interaction between the epidemic and the complex historical and socioeconomic characteristics of the region.

The HIV/ AIDS epidemic has exposed these cracks in society and exploited them.

The intense and long-range HIV/AIDS epidemic has the potential to impact on children in a number of ways. For example, increasing adult illness or severity of illness can place a great deal of strain on families and compromise their ability to provide care for children. The concentration of HIV among the productive and reproductive age range means that many of those infected are parents, caregivers and providers – key people in the lives of children. Adult infections can lead to infection of the child, reduced human capital to provide care, and reduced income to provide resources required for the care of children.

The situation is worst in the context of poverty. Poverty itself compromises the ability of families to provide care and adult illness aggravates an often already difficult situation (McLoyd & Flanagan, 1990; Richter, 1994). Illness reduces the ability of an adult to generate income and to contribute to home tasks. At the same time, adults own needs for care and income increase, particularly as illness progresses and they access an extended range of health providers and treatments. In the context of poverty, households face tight human and income resource constraints typically with little or no savings.

Unless support is forthcoming, the increased need for resources and the reduced productivity of household members means that there are fewer resources available, both human and income, for the care of children. Similarly if children are moved following the death of a parent or caregiver, then the household to which they are moved incurs increased expenditure and requires additional human effort to care for them. Again, if outside support is not forthcoming then resources available per head in the household are reduced. If the household absorbing additional children was already poor, the situation is

exacerbated; and if the absorbing household is already facing human resource constraints as a result of migration and dislocation, these will also be put under strain by the addition of more children (Deininger et al, 2003).

Poverty itself compromises the ability of families to provide care ...

Many of the impacts on children that are associated with HIV/AIDS, such as reduced adult support and care, reduced consumption, reduced access to education, increased labour demands on children and so forth, occur as a result of the interaction of the epidemic with the context of poverty. If households had excess or even basic human and income resources sufficient to cushion the impact of HIV and AIDS, many of these impacts, mainly due to resource constraints, would not occur. Similarly, if outside support was available to help families and households meet the shortfalls, many of the impacts could be avoided.

When families themselves do not have sufficient resources and do not receive support, they may be forced into meeting the short fall via the sale of assets. Assets are often held as a form of savings and may be kept for such situations. It is however a more serious problem when productive assets are sold as this affects the long term livelihood productivity and associated economic well-being of the family (Donahue, 2005). The sale of productive assets and other means of meeting short-term needs, such as migrant labour, may well compromise the ability of families to provide care for children over the longer-term.

There are other impacts on children that are not directly linked to resources, such as the emotional impact of long parental illness followed by death and/or the stigma associated with AIDS-related illnesses. The availability of human resources within the household can, however, help to minimise the long-term implications of these impacts by providing support to the child. The situation is again likely to be worse in poor contexts as human resources might be low as a consequence of high dependency ratios, and families are often overstretched in efforts to meet material needs and weakened by migration and family dislocation.

The scale of both poverty and HIV/AIDS must be at the forefront ... of the formulation of responses.

In high HIV prevalence settings poverty rates are also typically high, particularly for children. It is not uncommon in southern Africa to find over 60 percent of children living in poverty. The interaction between HIV and poverty in determining the level of impact on children is important for understanding the formulation of responses. The scale of both poverty and HIV/AIDS must be at the forefront. In such a situation, considerations of impacts concern not a few children but millions.

As indicated before, many of the impacts of HIV and AIDS on children are also the impacts of poverty, and when both are present in the same family the impact of each is amplified by the other. Both poverty and HIV/AIDS have a range of effects on children and appropriate responses require a range of services. Some services may be more important than others at particular stages in the lifecycle of the epidemic, the lifecycle of the family, and the lifecycle of the child - but no one response will address all impacts.

In addition to the need to provide support to the family in these contexts, poverty and HIV/AIDS also increase the importance of supporting other service providers. Education and health services are very important for any child. In the context of HIV and poverty, the need for health services increases. Education is essential for the child's development and continued social inclusion. Schools can also play a role in facilitating the delivery of services to meet other needs of children and families – such as food support and bursary programmes (Richter, 2004)..

The HIV/AIDS epidemic increases mainly adult illness, and the quality of prevention, treatment and care provided to adults has impacts on children. If services for adults are poor and their health deteriorates, children cared for or supported by these adults will suffer along with them, and children may also be called upon to assist with care or earning. Keeping children in school, where they receive care and support from friends and other adults, is especially important when a child faces difficult times at home.

The family is the point of interaction between adult illness and child care.

The family is the point of interaction between adult illness and child care. It is within the family that care is provided and where care is compromised when the family is under strain. The context of socioeconomic conditions, services and support in which families find themselves, the resources which they have at their disposal, and the safety nets they can access determine the nature and extent of impacts of the epidemic on children

4. Emerging issues

In this section we identify a number of related emerging issues – better understanding of vulnerability among children, the importance of human rights as a compass pointing to social protection, the need to focus on families and systems, the role of government in social protection, and how responses to children affected by HIV/AIDS can be better coordinated across sectors and players.

(i) Better understanding of vulnerability among children

Two aspects of vulnerability seem to us to require further study. Firstly, to better understand why orphaning may put children at risk over the long term and secondly, what social risks are created when an ‘excess’ of children either exists or are perceived to exist, as is claimed in narratives about children and HIV/AIDS (Meintjes & Giese, 2006).

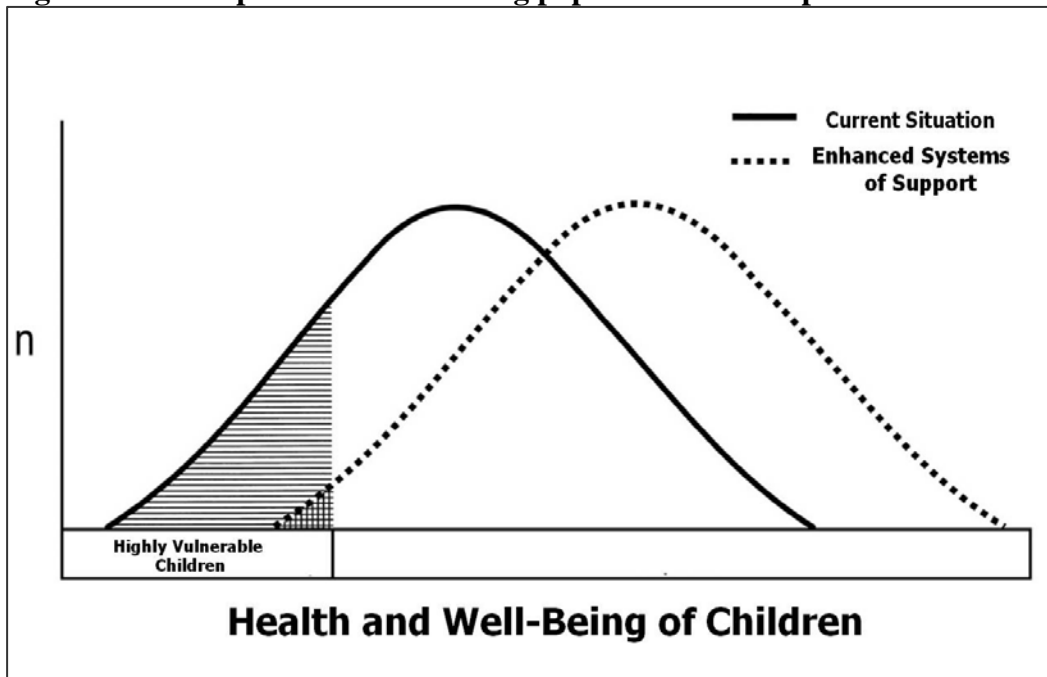
As indicated earlier, the focus on orphaning has individualised understanding of child vulnerability in the face of the HIV/AIDS epidemic – for good and ill. We have outlined in several documents the problems of targeting orphans, principally on the basis that this limits the response to individual children when what are needed are large-scale efforts to ‘shift the curve’ (Richter & Foster, 2006).

... the focus on orphaning has individualised understanding of child vulnerability in the face of the HIV/AIDS epidemic.

The solid line in Figure 2 demonstrates a simplified, unskewed distribution of the health and well-being of children within a population. The large shaded area illustrates the effects of increased conditions of stress, as are precipitated, for example, by high rates of HIV and AIDS. Large numbers of children become vulnerable. In the context of the co-occurrence of HIV/AIDS and poverty in high prevalence countries, there are insufficient resources and services to respond to individual children. Efforts to support individual children may be of considerable benefit to the children who receives support. But, no matter how intensive or widespread individual support is, it is unlikely to reduce the numbers of children made vulnerable under the co-occurring conditions of HIV/AIDS and poverty

In contrast, a ‘public health’, or systemic approach is one in which attempts are made to shift the entire curve to the right, and to reduce the total number of children needing assistance. This can be done by, amongst others, increased provision of social protection, education and health care, and removing barriers to access. By this means, the number of children needing individualised services becomes manageable.

Figure 2: The importance of achieving population-level impact



Source: Richter & Foster (2006).

Providing assistance chiefly to orphans is a prime example of a necessary but individualistic response to children affected by HIV/AIDS. Later in the document, we suggest how different actors might respond to problems on the continuum from the micro (individual) to the macro (socio-economic).

Understanding why orphaning might have long-term adverse effects on children?

Bereavement among children is associated with withdrawal and depression but, in the absence of other predisposing factors, is unlikely to fully account for long-term adverse effects of orphaning (Currier et al, 2007). The context of bereavement, including personal and familial historical factors are important as are – like in the field of trauma associated with disasters and forced migration – factors pertaining after the bereavement.

With respect to family context, a substantial number of children in southern Africa live apart from their parents, for shorter and longer periods even when their parents are alive. This occurs as a result of family inter-dependencies between households in which children's presence helps to cement relational bonds, children can receive opportunities for education and care, and they can help out when needed. Family fostering of this kind predates the impact of HIV/AIDS by several decades (Madhavan, 2004).

Nonetheless, parents and, in particular mothers, are often the primary caregiver to their children. The loss of a parent increases the chances of a child being without a dedicated carer and of the child becoming a social as well as biological orphan. A social orphan is a child without affectionate and stable family care. There are children whose parents are alive but who are uninvolved, and the child has so few other supports that they live the

life of a social orphan even if, biologically, they are not. On the other hand there are biological orphans who are loved and accepted within extended families and have not become social orphans.

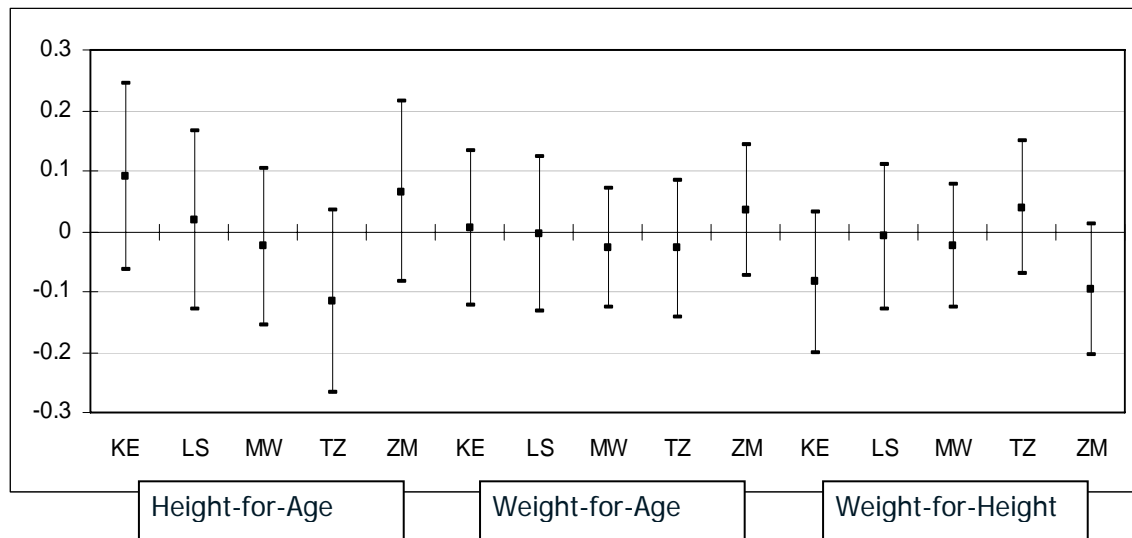
There are, however, children whose parents are alive but who are uninvolved, and the child has so few other supports that they live the life of a social orphan ...

Orphaning associated with HIV/AIDS in southern Africa also occurs in the context of extreme poverty. Because of this, it is difficult to separate out effects that are specific to single, double or non-orphaning. A number of studies have suggested that orphans (often unspecified as to whether they are single or double orphans, or whether they have lost their mother, father or both) are at a disadvantage as a result of increased poverty, discrimination, emotional strain and stigma (Makame et al, 2002). Others, however, have noted that children in households which take in orphans are affected in similar ways to orphans because they share the same environmental disadvantages (Deininger et al, 2003). Yet other studies indicate there are no, or statistically insignificant, differences between orphans and non-orphans, suggesting that orphans are no worse off than other similarly poor children.

Figure 3 shows the means of three anthropometric measures among orphans in five southern African countries – Kenya (KE), Lesotho (LS), Malawi (MW), Tanzania (TZ) and Zimbabwe (ZM). Height-for-age is an indicator of longer-term under-nutrition which causes stunting of linear growth; weight-for-height is a measure of proportion and indicates wasting in the short term, usually caused by illness or acute food shortage; and weight-for-age is a composite index of the previous two measures. A child can be underweight for his age because he is stunted, wasted, or both stunted and wasted.

As can be seen, the groups of children – which, it should be noted, are not representative of orphans in the country or district from which they were drawn – differ significantly by country. For example, orphans in Kenya and Zimbabwe are wasted in comparison to their peers, while in Tanzania, Malawi and Lesotho orphans aren't worse off than other children. There are also wide variations among orphans in each country on all three measures.

Figure 3: Mean anthropometric measures among orphans in 5 southern African countries



Source: Doug Webb (personal communication 2007)

Without better understanding of the circumstances of orphans, we are unlikely to be able to know how best to support affected children. These indicators illustrate that the difficulties of orphans are not limited to bereavement, no matter how devastating it is to lose a parent. As most children are orphaned in late childhood and their early teens, stunting of linear growth, which occurs in the first two years of life, suggests disadvantage long before orphaning – and probably for long after, if deprivation is not addressed.

... the difficulties of orphans are not limited to bereavement no matter how devastating it is to lose a parent.

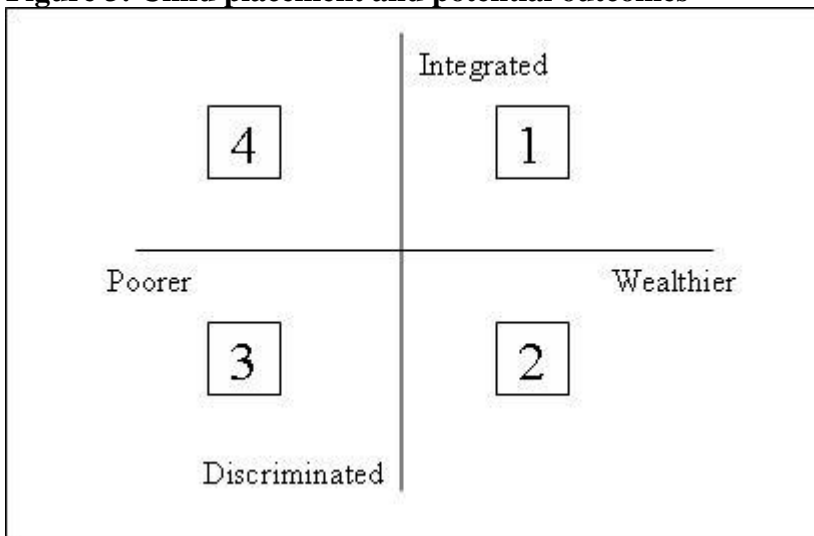
Part of the problem of measuring the impact of orphaning is that it interacts so much with the social and economic context. In some situations it has been argued that orphans are placed in relatively wealthier households as these families are more able to provide additional care for children. Because of widespread poverty, orphans may also be sent to live with already poor families whose situation is worsened by additional dependency (Abebe & Aase, 2007).

There is also the question of the extent to which absorbed orphan/s will be integrated or discriminated against in the household into which they move. Figure 4 depicts how socioeconomic status and socio-emotional integration, putting aside other factors such as age and gender, may interact to shape the situation of orphaned children in recipient households. The figure illustrates the different situations in which children who are moved to another household may find themselves. The horizontal line indicates the relative poverty and wealth of the household and the vertical the level to which the child

is integrated into the household. For example, the relationship between the child's parent/s and the recipient household might have been close, the child may have lived for some period in the household before parental illness, and subsequently, the child may be treated no differently from other children.

If children are placed in relatively wealthier households and are well integrated into them, Quadrant 1, they are not likely to suffer significant disadvantage. If, however, they find themselves in Quadrant 3, in poorer households and discriminated against in comparison to other children in the household, they may well be living in much worse conditions than the average child in the community. The outcome of children in Quadrants 2 and 4 is less clear – and indicates how much more needs to be known. However, the futility of trying to understand impact, and respond to it, only on the basis of the biological status of a child's parents is clear.

Figure 3: Child placement and potential outcomes



While there is still a great deal to be learned about its impacts, orphaning is gradually becoming less central to programme targeting. Understanding the pathways through which HIV affects children is important for the design and delivery of assistance to individual children. However, even if orphaning increases the risks faced by children, at the point of service delivery what is most important is actual need. If targeting is necessary, it should be based on need itself not on a marker that a child is, on average, more at risk of being in need. For example at the point of implementation of a feeding scheme, it is important to provide food for children who are going hungry, rather than children whose characteristics suggest that, on average, they are more likely to be hungry.

... at the point of service delivery what is most important is actual need ...

Large scale vulnerability associated with a perceived ‘excess’ of children

In addition to the impact of HIV/AIDS on individual children – such as orphans and other children in difficult circumstances - large numbers of children can become vulnerable as a result of the weakening of traditional systems of social protection. This weakening might be associated with HIV/AIDS, war and/or poverty, and the opportunities created by gaps for exploitation and abuse. Three examples will be discussed briefly:

- The increase in orphanages and other out-of-home care environments, some of which are intended as income-earning activities for those who run them;
- Orphan tourism, and
- Trafficking and international adoption.

The increase in institutional care

All over the world there are increases in institutional care, currently associated with HIV/AIDS. At the same time, there are strenuous efforts to de-institutionalise children previously placed in orphanages in Eastern European countries because of the deprivation suffered by children in residential group care.

Discrimination, abuse and neglect thrive in orphanages ...

Efforts to protect children from stigma and abuse, and provide for their material and emotional needs through institutionalisation are misguided. Discrimination, abuse and neglect thrive in orphanages, and other closed environments⁵, even when they are run by informed and sensitive managers, with trained and stable staff, sufficient sustainable funding, and strong links with the community from which the children come. Recent reviews of the literature, including from studies with randomised designs, show conclusively that children reared in institutions do significantly worse on a range of indicators than children who live with their families (Nelson, 2007).

In South Africa, for example, the numbers of un-registered children’s homes has increased dramatically. Moreover, foster care grants are being misused by seemingly benevolent civil society organizations which make application for the grant on behalf of a parent or caregiver. The child is declared a ward of the state as a condition of the grant, and the caregiver is employed in the organization, usually as a menial worker. The organization takes the bulk of the grant, apparently for the care of the child, and pays a small amount to the caregiver as an intermediary (Meintjes et al, 2007).

⁵ Consider the current highly-publicized case of sexual and physical abuse of children at Oprah Winfrey’s elite leadership boarding school for girls near Johannesburg.

Orphan tourism

Several intermediary international commercial agencies have been established to provide volunteer tourism experiences for young people.⁶ I-to-I Meaningful Travel, a large company operating online, placed this advert:

Working at a residential home for orphaned, neglected and abused children in Cape Town's Athlone suburb, this is a great chance to improve the lives of youngsters who haven't had the best start in life. You'll need to have a genuine love of children and a willingness to get involved in all aspects of their daily life, from playing games and organising activities, to feeding and changing nappies.

The following advertisement by the same organization highlights the attraction of working with very vulnerable young children.

The home provides full residential for care for children between the ages of 0-5. The home aims to provide a healthy and nurturing environment for orphaned, neglected and abused children. The children have often had to deal with the stress of loss, abuse or neglect and so need lots of love and attention.

In the following combination of volunteering and game watching, a South African celebrity finds a perfect way to escape – to work at a children's orphanage in Mombasa (see Figure 4).

⁶ Time Magazine, August 13, 2007 – Vacationing like Brangelina, p39.

Figure 4: An example of orphan tourism

‘My great escape’

Donna Gibson has itchy feet. But being a wife and mom of two, she always thought a faraway adventure was out of the question. Until, that is, she found the perfect way to escape...

‘It was amazing to escape my reality, if only for a little while’

Donna is planning another trip this year

‘I knew I’d have to find an adventure that wouldn’t make me feel torn in two’

GREAT WEBSITES
<http://volunteer-travel.africa.co.za>
www.voluntours.co.za
www.wisya.co.za

46 May 2007 essentials

Source: Essentials, May 2007, p46-47.

What is not considered in these opportunities to ‘grow up’, ‘help others’, ‘find oneself’ and ‘escape’ is the potential damage caused to children who are already vulnerable. The combination of adversity, institutional care, and unstable attachments for young children is a lethal combination and demonstrates a high-level of unconscious and quite extreme exploitation of children.

Trafficking and international adoption

Madonna set a tone with the adoption of David Banda. Why David was in an orphanage is not clear; but at least one reason was that his family was too poor to care for him and probably volunteered him into an available residential facility. If the funds spent on residential care were directed to supporting families, there would be fewer fathers like David Banda’s - in the impossible situation of choosing to be separated from your child in the hope and conviction that it is for the child’s good. Whether Madonna helped baby David, and whether he will grow up to have a happier life than he would at home in Malawi, is not the point. Rather, as a result of HIV/AIDS impacts, and its associated

advocacy – often portraying children as alone and abandoned –children in southern Africa are becoming vulnerable to international adoption and trafficking.

Some 27 000 children were adopted into the United States in 2006, most of them from China and India. Africa is becoming a new source of children, for whom very high prices are paid by parents desperate to provide love and care to a needy child. Too little attention is being paid to systems and procedures to protect children and families from exploitation and unscrupulous intermediaries (Rochat & Richter, 2007).

This has been brought to light very forcibly by a recent incident in which a group of 16 or 17 European volunteers, many of them young, were arrested while trying to take 103 children out of Chad. Operating under a pseudonym name – *Children's Rescue* – the group claimed to transporting orphans from the Darfur region to safety in Europe. It subsequently came to light that the group worked for *Zoe's Ark (L'Arche de Zoe)* – a group of about 50 four-wheel drive enthusiasts who set up temporary camps to help children in Indonesia in the wake of the 2004 tsunami. Some newspapers dubbed the organization “a controversial charity involved in adoption”⁷

An email recently received indicates that entrepreneurs are exploiting both vulnerable children and young people with big hearts from well-off families in the West.

Dear ladies and gentlemen,

I am A, 19 years old and from germany. Actually i am in durbanville in a children''s home, but there is no need for all of us because we are about 25 volunteers. Thats why i am looking for a new project as soon as possible. Do you have some projects in which help is needed in kwa-zulu-natal? here i workedae speacially with the disabled children togheter but unluckily this section has been closed 3 weeks ago.

PLease let me know if you need me somewhere.

Regards A

While there is enormous appeal and need to respond to vulnerable children who are orphaned as a result of HIV/AIDS, vulnerability of children is being created and exacerbated by both heartfelt and exploitative attempts to help. There is an urgent need for international guidelines, regulations and advocacy to protect large numbers of children in southern Africa.

⁷ NGO hid truth of operations, Mail & Guardian November 2-8, 2007.

(ii) Broader and deeper applications of rights-based approaches

The importance of adopting a rights-orientation to HIV/AIDS is critical, as demonstrated by Jonathan Mann in the early stages of the epidemic (Marks, 2000). Mann outlined a two-way relationship between health and rights such that human rights violations adversely affected health and poor health prevented individuals from realising their human rights. The relationship between HIV/AIDS and human rights demonstrates very specifically the principles Mann described. At different stages of the epidemic HIV/AIDS has brought human rights issues into the spotlight and, approaching HIV/AIDS from a rights perspective has enabled people living with HIV/AIDS to increasingly fulfil their human rights.

At different stages of the epidemic HIV/AIDS has brought human rights issues into the spotlight ...

Three examples of the way in which HIV/AIDS has brought rights-issues under the spotlight for the benefit of people affected by HIV and AIDS are stigma and discrimination, gender and access to treatment. With respect to each of these examples, HIV/AIDS has served as a platform to challenge aspects of the social order and abuse and disregard of human rights. In a similar way, the impacts of HIV and AIDS on children are bringing to the fore the right of poor families in southern Africa to social protection.

All countries in southern Africa are signatories to the United Nations Convention on the Rights of the Child (UNCRC), but a child rights approach is differently understood and implemented in current attempts to mitigate the impact of HIV/AIDS on children and families. There is, in particular, a tension between ensuring all or most of the rights of some children (those in the catchment area of CSO activity, for example) and ensuring some rights of all children (Richter & Rama, 2006).

It is recognised that some socioeconomic rights of children will be realised progressively, reflecting a realistic acceptance that lack of resources - financial and other resources - can hamper the full implementation of economic, social and cultural rights in some countries. However, the CRC must be used to mobilise for the fulfilment of children's rights including, for example, Article 27.

Adequate Standard of Living

States Parties recognize the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development. Parents have the primary responsibility to ensure that the child has an adequate standard of living. The state's duty is to ensure that this responsibility can be fulfilled. State responsibility can include material assistance to parents and their children.

Rights-based approaches strengthen the case for social protection (SP) in particular and offer normative standards and principles, analytical tools and operational guidance, which are relevant in both justifying social protection measures and informing their design, implementation and evaluation. According to Piron (2004, p. 3), the key contributions of a rights-based approach to social protection are that it:

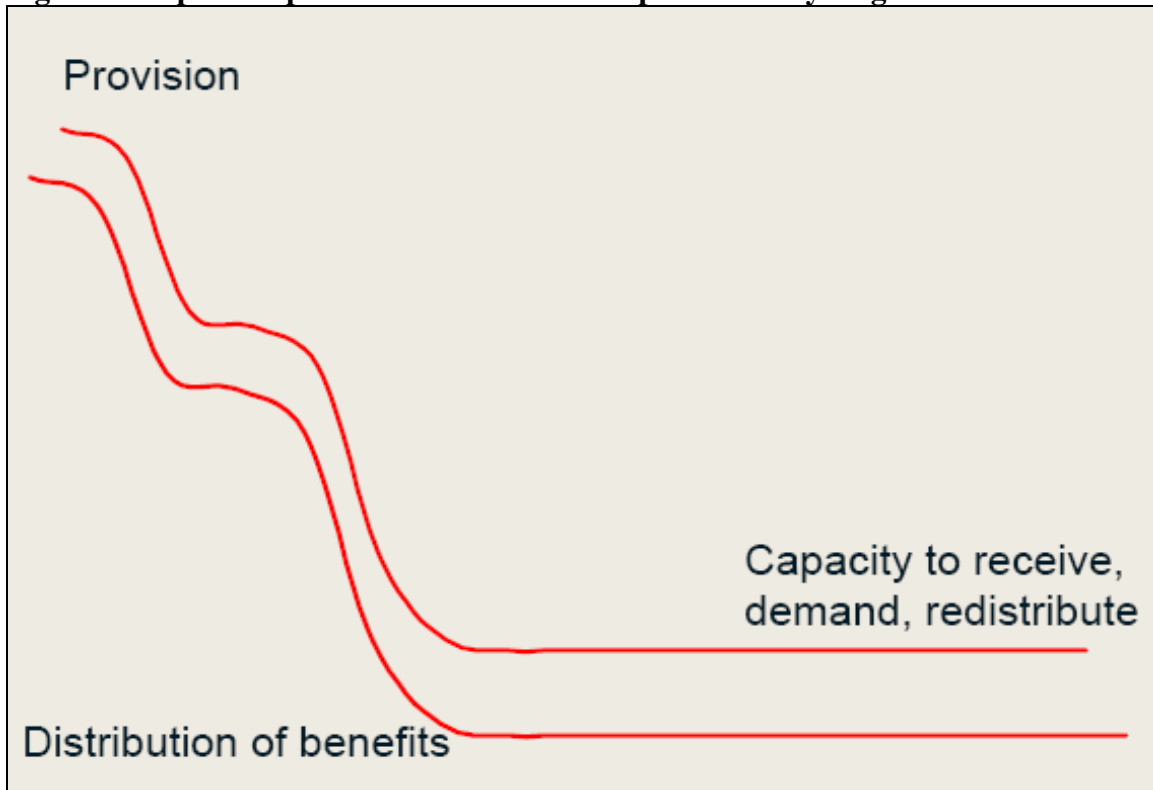
- considers SP to be a right and entitlement, and not just a matter of charity;
- places clear obligations on states to guarantee SP;
- can use a range of international human rights standards to justify SP, starting with those related to social security but broadening out to all human rights;
- highlights the core obligations and minimum standards that can be expected, as well as the specific requirements of vulnerable groups;
- can use a range of human rights principles to justify SP and also influence the design of schemes (e.g. equality and non-discrimination, participation and accountability);
- places citizenship, and the importance of understanding social and political contexts, at the centre of the justification and delivery of SP;
- as a result requires a focus on the ability of citizens to claim their SP entitlements;
- as well as a focus on accountability mechanisms, and institutional capacity, to guarantee the appropriate design and delivery of SP; and thus
- links demand-side with supply-side considerations, when SP can often appear be more technical and supply-side focused.

Such a framework is important to prevent inadvertent infringements of human rights, as well as actions that increase, rather than decrease inequality. Individualistic responses to children have the potential to exacerbate inequalities. Children who are easily identifiable and ‘reachable’ – often those in urban areas, and attending school or a health service, are more likely to receive attention. On the other hand, children who are more vulnerable, by virtue that they are further away from available services and facilities, or live in inaccessible areas, seldom receive much attention.

Improving the ability of citizens to claim social protection entitlements must occur in the same ways that AIDS activism has increased access to ARV treatment. If citizens are not empowered to reach out, demand and receive social protection and other entitlements, improvements in provision might further divide those that have from those with little or nothing. Figure 5 illustrates that increases in provision in situations of inequality – whether of health care, education or other services – can reproduce and exacerbate inequalities in the absence of social movements and other mechanisms to empower

disadvantaged and excluded groups to claim entitlements and to redistribute resources. As indicated in a later section of the document, increasing the capacity of individuals, families and communities to demand services is a critical role for civil society organizations.

Figure 5: Expanded provision needs to be complemented by heightened demand



(ii) From orphans to families and systems

Families provide care for the vast majority of children and, in the context of HIV/AIDS, it is families who try and shield children from the worst impacts of the epidemic. Once the family is appreciated for its central role and the starting point for intervention, it becomes difficult to justify efforts to help individual children in the absence of family strengthening. However, family-centred responses are not the norm. In fact, when interventions are directed at children, the family is often considered more as an impediment than the primary care environment for the child. Programmes are frequently based on compensating for family deficiencies – in food availability, economic resources for uniforms and school fees, gaps in protection for children, and lack of care.

If families were provided with support – income assistance, support for caregiving and the like – their children would be less likely to need support.

If families were provided with support – income assistance, support for caregiving and the like – their children would be less likely to need external support. Families would also be shielded from the humiliation of outsiders providing basic care for their children, on top of their own suffering, because they are unable to support their children.

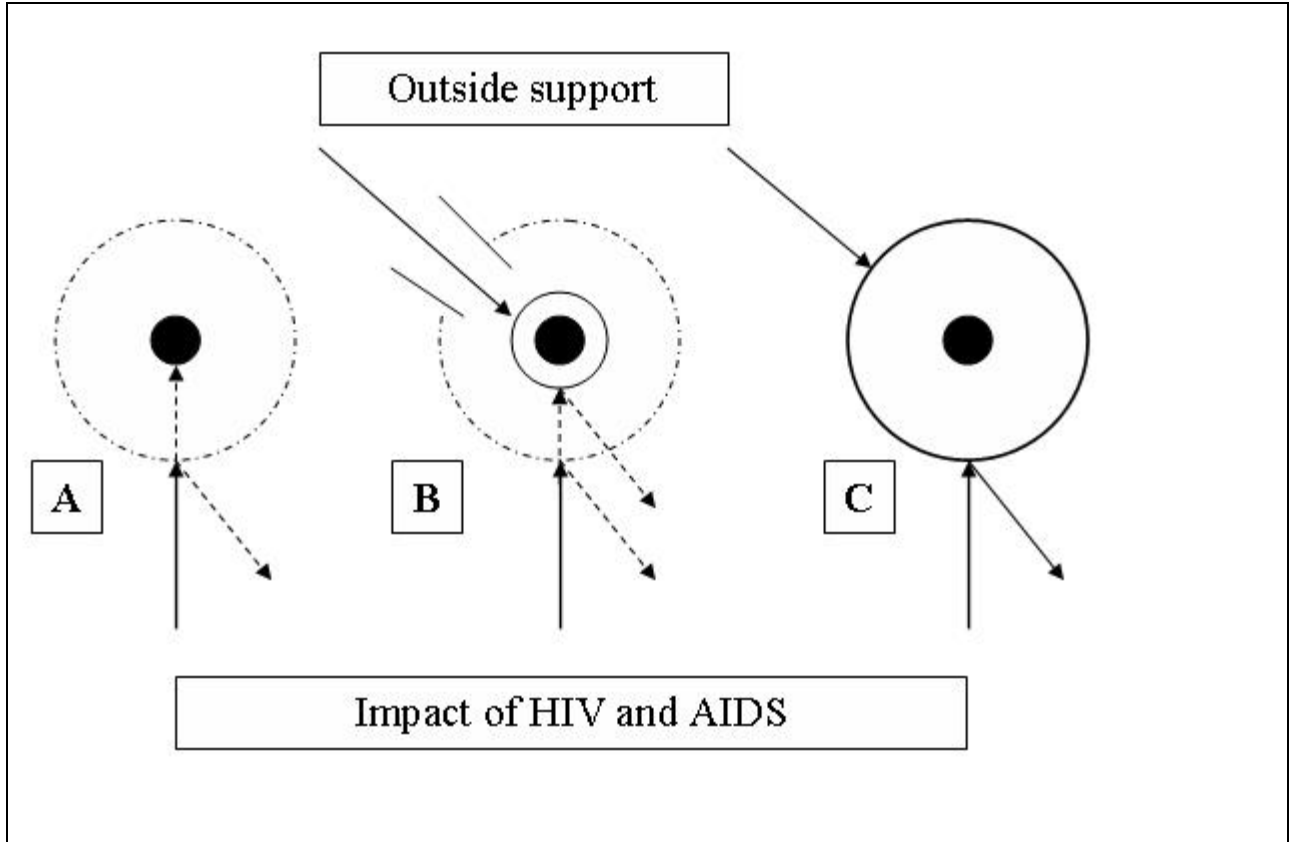
Some programmes attempt to protect children from their families. There are, of course, times when children need to be protected from family, but it is problematic to assume that this is generally necessary in the context of HIV/AIDS, or that it is necessary to protect a child from a family that is failing the child materially because of resource constraints.

Figure 6 outlines two approaches to responding to children. The larger circles in the figure represent the family and the smaller ones the child cared for within the family. The figure depicts three situations. In situation A, the family has some shortfalls and is unsupported. It can thus only partially absorb and deflect the impacts of poverty and HIV/AIDS on children in the household. Situations B and C represent two different approaches to providing support to children, one which skips the family and one which recognises and supports its fundamental role in the long term care of children.

In situation B, the outside support is directly to the child and seeks to provide an alternative means of protection to that available to the child from the family. The external agency and the family are, as it were, opposed in their relationship to the child, and the agency acts as though the support to the child needs to be protected from the family so that it can reach the child. For example, the child is fed by an organization external to the family, rather than food, cash or livelihood activities provided to the family, in case the resources are misdirected and the child fails to benefit from assistance. Family-centred responses can both strengthen families and work with families as the targets of assistance, rather than having the individual child as the focus. Isolating assistance to the individual, be they children or adults, can lead to missed opportunities and inefficient interventions.

In situation C, the support is provided to the family so that the household can better do what it is already trying to do – care for children. For example, money is given to the household to support the child's school attendance. The mother can buy a school uniform locally which costs less than uniforms sourced by an external agency, and she might use the money left over to supplement the food of a younger child in the family. This is an example of trying to strengthen the family to perform family tasks, including the care of the child identified as being in need of assistance

Figure 6: Possible relations between families and external agencies in supporting children



The provision of PMTCT services is a clear example of a missed opportunity to strengthen the family and enable prevention, treatment and mitigation resources to be more effectively used. PMTCT programmes tend to focus on the expectant mother and her newborn child. Having identified a mother as HIV-positive during the PMTCT programme, the importance of linking her into a treatment programme is obvious. This has become known as PMTCT+ (Plus). While this is an important and obvious linking of services, it still focuses on the individual woman. Some programmes also use PMTCT to reach out to her partner for testing, and linking them into a treatment programme if needed.

The provision of PMTCT services is a clear example of a missed opportunity to strengthen the family and enable prevention, treatment and mitigation resources to be more effectively used.

But PMTCT also creates an opportunity to identify other children who might have been exposed. They too could be tested and linked to treatment programmes if required. These examples of extending PMTCT services all occur within the health services. Thinking of

the mother as part of a family prompts further consideration of family support for disclosure, support during adult illness, and the early identification of children who may lose their mother and perhaps their father. The mother, and father if he is involved, can be linked to support programmes to enable the family to cope with the multiple impacts of HIV/AIDS, including assistance with child care, keeping children at school and planning for the future care of children. Services of the latter kind are often provided by CSOs and it is critically important that they be linked to government and other health, education and social services. Focusing on the family as the point of interaction draws attention to the need for services to be complimentary. Such opportunities to work across sectors are the focus of a later section of this document.

Other examples of services which can be expanded in a beneficial manner to take a more family-centred approach include adult treatment, voluntary counselling and testing (VCT) and home-based care. If, in each case, the individual is considered as part of a family then an opportunity is created to use the link to provide an entry point for other members of the family and other services. Such approaches have the potential not only to expand coverage of services but also to facilitate positive interactions and consequences. Having a partner on treatment may reduce drug sharing and increase compliance. Receiving services to support child care can reduce stress, increasing the benefits of treatment and enhancing the prospect of planned care for children.

Intervention of this nature need not only be expanded to families but can start with them. There is currently growing attention to the possibility of implementing cash transfer programmes as a means of strengthening families' capacity to respond to the needs of children in the context of HIV/AIDS. These programmes would typically involve the monthly payment of a relatively small cash amount to each family, with potentially some adjustment for the number of children. Such an approach recognises the caring role of the family and seeks to support it, rather than bypassing the family in an attempt to reach children directly. Cash transfer programmes are clear examples of attempts to generate situation C responses as depicted in Figure 6.

Many of the impacts associated with HIV and AIDS are also associated with poverty. Moreover, the ability of poor individuals, families and communities to respond to the challenges faced by HIV/AIDS is compromised by their situation. Given this backdrop, systemic responses are needed to address the complexity, scale and duration of impacts of the epidemic on children and families.

... systemic responses are needed to address the complexity, scale and duration of impacts of the epidemic on children and families.

The promotion of systemic responses typically focuses on state-led interventions. This opens up a particularly important issue: who does what? In contexts where community groups, local and international civil society organisations (CSO), local governments and national governments have been involved to greater or lesser extents it is important to

coordinate responses and ensure their complementarities as they are scaled up. The different actors have different strengths and weaknesses and a scaled response requires an appreciation of these to indicate the best uses of resources. A systemic government-led response does not negate the roles of other organisations and groups, but it may change them.

... it is important to coordinate responses and ensure their complementarities as they are scaled up.

(iii) Social protection and the role of government

Regular flows of income, as occur in cash transfer schemes (such as old-age pensions, household or family grants, food grants and child grants) are generally small, but they have been shown to have a number of positive impacts on children's well being in a variety of contexts. These include improvements in health indicators, both usage indicators and outcomes. There are also studies which show improved school enrolment rates and decreased poverty. The regular nature of the income flow has also been associated with the opportunity for better planning. Moreover, the income has been seen to increase household productivity and chances to invest in job search (DFID, 2005; Gertler, 2000; Rawlings, 2004).

The strong evidence of positive outcomes of cash transfer programmes has generated considerable interest in introducing them in a number of countries. The interest is growing in a variety of settings, but the possibilities of using the approach as a response to the impacts of HIV and AIDS on children has generated considerable excitement and a number of pilots are already underway, including in Kenya, Malawi, Zambia and South Africa.

The strong evidence of positive outcomes of cash transfer programmes has generated considerable interest ...

State capacity in a number of high prevalence countries is already strained. Skilled human resources are often in short supply and systems are under pressure. Cash transfers relative to many other interventions place a lower demand on human resources and management for delivery. Social work services, for example, require high levels of coordination among well trained personnel within a quality maintenance bureaucracy. Cash transfers, therefore present a means by which states can support families without burdening their delivery systems to the same extent, and perhaps with greater effectiveness. Of course, there are implementation challenges and questions of corruption. At the national level, the possibilities of corruption are little different from any other intervention as most interventions of all kinds start with a money budget. The

implementation challenges and corruption concerns at the sub-national level are important and are receiving attention.

A number of issues come to the fore in connection with cash transfers for vulnerable children, of which five in particular stand out. Firstly, social transfers are justified by human rights, as indicated earlier in the document; secondly, the appropriate amount for transfers in different conditions and what threats are there that they might offer perverse incentives is a question. Thirdly, appropriate targeting mechanisms need to be specified; fourthly, the role, if any, of conditions must be understood; and finally, we must consider how the introduction of a state-led cash transfer programme affects the role of other actors.

All five issues require substantial discussion. The first four have, however, already received some attention and continue to receive more. The last issue - who does what - has not been accorded the same level of direct attention although the issue clearly sits below the surface of the other debates. *Who does what* also links to systemic responses in general. The call for governments to play a bigger role in responding to children in the context of HIV and AIDS in a field with many established actors has generated some nervousness. For these two reasons the following section will examine this issue in more detail.

Cash transfers provide another avenue for the state to support children via the family.

(iii) Joining up efforts: Who does what?

The scale of the HIV and AIDS epidemic, particularly when considered against the backdrop of widespread poverty, calls for large scale responses. The strengthening and expansion of health and education services to children are an obvious area for increased state action. Cash transfers provide another avenue for the state to support children via the family. These systemic responses can be designed so as to improve the well being of all children while simultaneously providing additional support through cash to the most vulnerable children, as a result of HIV/AIDS, poverty or a combination of both. In many contexts the most vulnerable children are actually in the majority, as such a high percentage of children in southern Africa live in poverty.

As indicated, the current emphasis on systemic state-led responses has generated some anxiety among other actors, especially international and local CSO's. These actors have, to date, played a major role in supporting children, especially in the absence of substantial state intervention. The pressure now for the state to step in may be perceived as a pressure for these actors to step out. While there may well be a need for changes in the way both operate, the state and CSO's have a number of comparative advantages in relation to one another, suggesting that considered collaboration will lead to the best outcomes for children.

... considered collaboration ... between the state and CSO's ... will lead to the best outcomes for children.

Comparative advantages

The nature of states and of CSO's suggests certain advantages and disadvantages of each in terms of service provision. It is important to recognise these advantages and disadvantages so that resources can be directed efficiently and effectively. Much of the discussion in this section and the discussion which builds on it, are a consideration of the potential of each. We suggest ways in which the strengths and weaknesses which states and CSO's could and should have must be considered in a large scale, substantial responses. It is, however, recognised that in some situations states and CSO's may either or both lack the comparative advantages described. This is a challenge, and ways to work towards realising the advantages is an important area for debate and development. While it is imperative to aim for the realisation of advantages, we must also bear in mind how responses will take shape during transitions in the roles of CSO's and the state.

The state

The state has a number of advantages over CSO's. Foremost among these is its size and coverage. HIV and AIDS in the context of poverty in high prevalence setting present a national problem of very large scope. The need for a response is not isolated and the advantage of national reach is obvious. Furthermore, the state has continuity and longevity. The state can commit to providing services into the future and is not dependent on external budget decisions to the same extent as CSO's. Although a number of states are heavily dependent on donor support, the funding is generally more secure and committed over longer periods of time than CSO funding. CSO's can also be dependent on a few key individuals while the response of states is more robust.

The state has the opportunity to use redistributive taxes as a means of funding. If children have lost their parents or are in some way in need of support, the general assumption is that the care and support should come from the extended family and the community in which they live. The family arguably does have a responsibility towards children and so this expectation is not without basis, and extended families are indeed often the first to respond. Given the interaction with poverty, children in need of support by communities as a result of HIV/AIDS are more likely to be poor. As poor people tend to live in the same communities, the community is likely also to be poor. This results in the poor being asked to provide for the poor. The use of redistributive taxes spreads the cost burden more broadly than the immediate community, which is a more just strategy.

Finally the state has authority. It has the ability to implement legislation, enforce compliance and create policy environments.

To some extent the state's advantages are also its weaknesses. As a result of its size it is slow moving and lacks flexibility. When considering a nation in the design of responses, it is difficult to adapt to specific local contexts. It is in these situations that the comparative advantages of CSOs become clearer. The state has the reach to address problems, whereas CSO's have the capacity to reach out to individuals.

The state has the reach to address problems, whereas CSO's have the capacity to reach out to individuals.

Civil society organizations (CSO's)

CSO's, free of the bureaucracy, responsibility and size of the state, can be far more flexible. They can see a problem and adapt their services promptly. Not only can they be flexible, but they can also be creative. Seeing the possibility that something might work, they have the freedom to try it and find out.

Contexts differ and what works in one setting may well be far less effective in another. CSO's have far greater ability to perceive the need for adjustment and to make changes. They can develop services and responses which are only relevant in one particular context and adapt them for another. They do not have the same pressure to provide uniform services or to provide basic services to everyone in their catchment areas. This is true not only between communities but also within them. CSO's can respond to individual distress on a case-by-case basis which can be difficult and inefficient for the state to do. States can formulate budgets, create services and fund them, but the intermediary processes are costly, and quality and equity are problems.

Given the different advantages of these two types of service provider there is obvious scope for cooperation to maximise impact. As the state moves towards a systemic response, CSO's can choose a variety of roles, some of which are more considerate of the relative advantages than others. Some of these different roles are discussed below.

The role of CSO's in the shift to systemic responses

In what follows, we outline a number of different roles which CSO's can play and which make good use of their comparative advantages. These are:

- Provision of state services
- Demonstration projects
- Facilitation of receipt and benefit from state services
- Amplification of benefit from state services
- Linking services within government and between government and CSO's
- Context-specific and non-scalable services
- Activism and empowerment

Provision of state services

Unfortunately there are many instances where services which would traditionally be assumed to be state responsibilities are either absent or inadequate. Notable examples include failure to provide health, preschool care or education to all children. The void has often been filled by CSO's and, in particular, by faith-based organisations. In some countries in southern Africa, a considerable proportion of health facilities and schools are supported by faith organizations in one way or another.

Services can be provided in such a way that they can be linked into state systems or even taken over by the state.

The manner in which CSO's step in to provide, what should be, state services can have implications for the long-term provision of these services, especially if the state is planning on expanding its provision. This is most evident in the choice of models of provision. Services can be provided in such a way that they can be linked into state systems or even be taken over by the state. This has often been the case with church run hospitals. The church establishes the hospital to fulfil a need, but as state capacity improves so the church withdraws, sometimes financially, sometimes administratively and at times completely.

It is worth a CSO considering, when providing a service that the state would normally be expected to provide, if their model enables later collaboration or hand over. This links closely with the second role we outline, the role of CSO's in running demonstration projects. It is worth noting that CSO's have often taken on state services and that the state has not stepped in to assume its responsibility for considerable time. While some of these services may lend themselves to state provision, until the state is in a position to provide the services, CSO's should not be left unsupported, because the period of transition can be very long. However, transition should be uppermost in the consideration of state and CSOs.

Demonstration projects

It is not always universally agreed what services the state should be expected to provide or how they should or can be provided. Given this situation, three important possibilities present themselves for CSO's - the chance to try new things, the opportunity to experiment with how to do them, and the chance to break down state resistance.

... the chance to try new things, the opportunity to experiment with how to do them, and the chance to break down state resistance.

As described above, CSO's have the opportunity to be more flexible and creative. When new challenges present themselves, CSO's are well positioned to experiment with alternative approaches to addressing them. Some of these approaches may never lend

themselves to state uptake (and this is discussed later), but some may. It is the provision of services which the state arguably should provide that fall into this category. Considering later state involvement so that services may be expanded to take advantage of the coverage and longevity of state provision, may alter the design of CSO services when trying something new. Presenting projects as a demonstration of how approaches can work has the potential to link together the relative advantages of the different players. For example, not many southern African countries are in a position to implement cash transfer programmes, and there are many programmatic and logistic choices to make. CSO's can experiment with these on a small scale and document what is needed to expand them.

There are times when the state welcomes these demonstrations and is willing to take them up. There are other times when demonstration projects can be used to break down state resistance by undermining excuses given for non-provision. Faced with constraints, or as a result of unwillingness, state actors may write off the provision of certain services as impossible or likely to be ineffective. CSO's can challenge these perceptions if they deem them to be wrong.

If a model of implementation is followed which the state could never use then the project might be successful in the location it operates, but the knowledge generated will do little to stimulate the state.

When the state refuses to provide services which are, arguably, the state's responsibility CSO's can step-in, or step-in in a way, which shows that the state could provide the service, and a model of how to provide the service. If a model of implementation is followed which the state could never use, then the project might be successful in the location it operates, but the knowledge generated will do little to stimulate the state. If, however, a model is used which the state could well take on or replicate elsewhere, then the project can be used by government, or by civil society to pressure government to action. The latter was the strategy adopted by *Medecines Sans Frontieres'* (MSF) in their ARV therapy pilot programme in the Western Cape in South Africa. Amongst others, this enabled the Western Cape to be the first province to defy South African government policy by providing AIDS drugs to HIV-positive pregnant women in the public health sector.

Examples relating to HIV/AIDS and children include providing family-centred health services, using PMTCT or VCT as an entry point. CSO's providing these services in one area have the potential of providing learning for eventual uptake by the state - which could lead to associated improvements in coverage. The design of such programmes is neither obvious, nor are the problems which they may face simple to solve. The flexibility and creativity of CSO's gives them an advantage in the design and testing of alternatives.

Facilitation of receipt and benefit from state services

It can be difficult for the state to deal with individual problems. As large bureaucracies, they struggle to respond to individual needs. As a result even when services are provided, some individual cases may be overlooked or neglected because of difficulty of access and/or the failure of the state to respond to idiosyncratic needs.

The opportunity for facilitation to have a major impact is when state services exist but access is a problem. In these situations the ability of CSO's to respond at an individual level can have significant impact. For what may well be a small investment of resources, CSOs can facilitate access by children and families to the greater benefits (such as health and education) provided by the state.

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Cash transfers provide an important example of the potential of such projects. The provision of a monthly cash transfer has been shown to be highly beneficial, but access typically requires documentation and physical access to service providers. Very poor families may lack the resources to obtain the documents needed. They may also lack the funds to invest in accessing the transfer. It may require a number of trips to a government office to become registered for the transfer. If the family does not have the money to fund transport to the offices or they cannot afford the time away from their productive activities, then they may never be able to access the grant.

As a result, those who stand to benefit the most may well end up being those who are left out in particular. CSO involvement at the point of gaining access is an example of the good use of the comparative advantages of different players. The state provides the long term stable support, addressing the problem at hand. A CSO supporting families to access the grant provides the individual attention and flexibility which is not in state capacity. The CSO's small investment but targeted of resources results in long term benefit for the family.

Other examples of facilitation projects would include assistance to overcome barriers to health, education, legal and social services. The service lends itself to state provision, but dealing with the individual challenges faced by families does not.

Amplification of benefit from state services

The challenges faced by families are generally complex and access to a single service may not be sufficient to address them. What is more, accessing a service can have differential benefits depending on other interacting factors.

Health care, for example, works better when the person receiving the care is well fed. Supporting adults on ARVs to acquire quality and appropriate food is an example of how a CSO project can amplify the benefits of a state provided service.

Cash transfers, as mentioned, are currently receiving a great deal of attention both as a response to poverty and to the impacts of HIV and AIDS on children and families. The benefits of cash transfers have been well documented, but there are some pockets of resistance to them. This links back to Figure 6. It may be assumed, for example, that the problem is more than poverty; that the family does not have the best interests of the child at heart and that interventions need to guard against opportunistic and exploitative actions by family members. Many of those who resist cash transfers favour situation B in Figure 6, where support is provided directly to the child and that the protection comes from the service provider not the family. This is clearly not a sustainable option. In essence, this results from distrust of the poor. If families are implicitly perceived to have failed children by becoming HIV+, or by not pulling themselves up by their bootstraps and having sufficient funds to support their children, as outlined in an earlier section, they may not be trusted to distribute benefits to children.

There are a number of other reasons for resistance to give money to among the poorest people in the world, most of which are better dealt with elsewhere. One which does deserve mention here relates to the perception that cash transfers are being promoted in place of CSO responses.

There are a number of ... reasons for resistance to give money to among the poorest people in the world ...

It is indeed possible that the implementation of cash transfer programmes will displace some activities currently being undertaken by CSO's, and rightfully so. If families' economic position is improved, there may well be instances where they no longer need services previously offered to them by CSO's, such as help with school uniforms. Much of what CSO's do in the context of HIV and AIDS in southern Africa involves poverty alleviation⁸, and if cash transfers are more efficient at this, transfers will displace some of these services. However, this by no means negates the role of CSO's, but rather frees them to undertake other activities, many of which states can't provide, such as services and assistance to specific individuals, families and communities.

Before CSO's move off poverty alleviation and other activities that could better be provided by the state, there is the period of transition. It would not be appropriate to end services before the means to address the needs that prompted them are in place. More important to this discussion, is the possibility for CSO's to operate creatively within a cash transfer environment to amplify the benefits of the programmes.

... the possibility for CSO's to operate creatively within a cash transfer environment to amplify the benefits of the programmes.

⁸ Geoff Foster (personal communication, 2007).

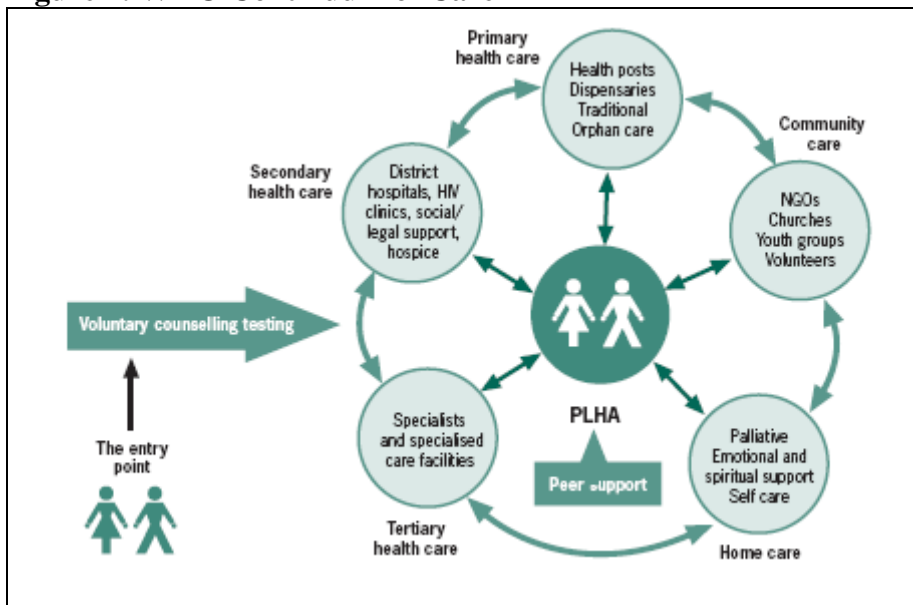
Providing cash to a household expands their choices and opportunities. Supporting families to take full advantage of these chances is an obvious space for CSO activity. Finding ways to use the funds for the best value current consumption or as leverage to generate more consumption is a very context-specific consideration. There are innumerable possibilities for complimentary programmes to amplify the impact of what is generally a small amount of money.

Under normal circumstances, the more capital a household has, the more the productivity of the household increases. Cash provides one part of that capital; CSO's have the possibility to support the human capital side through skills development and information sharing. An obvious example here would be for CSO involvement in income generation projects which utilise the security offered by the grant. The possibility for amplification in this field are challenging but exciting.

Linking services within government and between government and CSO's

Richter and Foster (2006) stressed the importance of creating a continuum of care for children affected by HIV/AIDS along the model of the World Health Organization Continuum of Care (see Figure 7). This model requires various government systems, such as education, health and social welfare to work together, as well as with community and other civil society groups and resources.

Figure 7: WHO Continuum of Care



CSO's can play a critical role in facilitating and maintaining linkages, enabling beneficiaries to move between services and other sources of support. In this way, CSOs can also build the capacity of both government services and the work of local community-based groups.

One of the dangers of CSO's not working in this collaborative way is that they can deplete government services of staff and capacity, through more attractive salaries and working conditions.

Context-specific and non-scalable services

The discussions thus far have focused on the role of CSO's in interacting with state services. The routes described show the many possibilities for services from both sides to be designed in a way that compliment each other and maximise the benefits for children and families.

It is, however, worth noting that there are areas of response in which the state is unlikely to ever have significant involvement, beyond providing a supportive legislative, policy and funding environment.

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Problems which are highly context-specific and require a great deal of consideration of the local environment in their design and implementation do not lend themselves to state involvement on the ground. Highly specific or specialised interventions are difficult to take to scale and by their nature are best run as local projects. Examples include psychosocial interventions with child sex workers, child soldiers or other groups who require very specific psychosocial, and material support, and assistance with re-integration.

Services which are needed but difficult to scale often require dedicated CSO's to take up the challenge. It is important to recognise what the needs on the ground are, as well as the inability of the state to respond. This justifies support for the work of CSO's when they are clearly the most efficient providers. The provision of psychosocial support to traumatised children is very important but also highly specialised. The challenges faced by children in different contexts vary, and the stigma they face takes different forms. The support they receive from community members and extended family is not always the same. CSO's have the ability to be highly adaptive and can support local responses and assist with the introduction and extension of new supports in collaboration with community groups.

The state, however, is the ultimate duty bearer. Recognising the comparative advantage of CSO's does not absolve state inaction. Rather, it changes the nature of action required. CSO's in these situations are the most efficient and effective service providers, but the need for a supportive environment and financial support is often best met by the state. In the interim, however, local and international donors are important sources of financial aid for these activities.

Activism and empowerment

The state and CSO's have been discussed thus far as if they were entirely independent actors. CSO's, however, have a role to play with the state, as well as alongside it.

CSO's working close to communities may see problems before the state does or before the state is willing to acknowledge the problems. For this reason, CSO's have a role to play in conveying this information; but information sharing is often not enough. The state may resist responding for a host of reasons and the need for activism is frequently apparent.

The role of CSO's in amplification does not end with the amplification of benefits from state services, it continues with the amplification of the voices of those who face the challenges of poverty and HIV and AIDS on a day-to-day basis. To date the response to children has been overwhelmingly undertaken by families and communities with little outside support. Supporting the empowerment of those most affected and amplifying their demands on the state is critically important if responses are to be meaningfully improved.

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As indicated in Figure 5, CSO's can capacitate families and communities to receive and demand services through collective action and social movements.

The amounts of money involved in all aspects of the response to HIV and AIDS have increased substantially in recent years, especially with the contributions of the Global Fund and PEPFAR. While again lagging behind, the money directed towards children has also increased.

With increasing funds comes increasing pressure to show impact. Excessive monitoring and evaluation can become counter-productive, but it does draw attention to impact. While small programmes focused on specific aspects of children's needs may work in a particular area, larger amounts of money increase the pressure to show broader, substantial, and sustainable impacts. It is clear that to have that larger impact requires larger and more systemic responses. Projects can take us only so far.

5. Summary and conclusions

The HIV and AIDS epidemic interacts with the context in which it plays out. In southern Africa and other highly affected areas, this is typically a context of high poverty, high levels of migrant labour and family dislocation. Interactions between HIV/AIDS and poverty present new challenges for children and their caregivers while exacerbating those which they were already facing.

Given the scale of the epidemic in the region and the scale of the pre-existing challenges, it has become increasingly clear that the response to children affected by HIV and AIDS cannot be considered in isolation. The early focus on parental loss and children without family care led to an undue focus on bereavement and replacement care. With such a narrow and intense spotlight, challenges faced prior to death are missed – as are similarities in many of the challenges post-death with the challenges faced by other children in difficult situations.

It is now much clearer that orphan care projects alone will be ineffective in making a meaningful difference to the large numbers of children living in very difficult situations in southern Africa. There is an obvious need to recognize that, given the scale of the interacting problems of HIV/AIDS and poverty, resources have to be used efficiently and effectively. A family environment is, and always has been, the most efficient and effective means of providing care for children. There is no shortage of human resources as unemployment rates in the region are among the highest in the world. But there are other shortages, not least of which is a critical shortage of money. Cash transfers to poor households as a foundational intervention to improving the wellbeing of all children living in poverty makes sense. Poverty is a problem itself and makes other problems such as HIV/AIDS far worse. By addressing poverty, both its impacts and the impacts of interacting challenges can be reduced.

While a central part of the response, money alone is not the solution and the promotion of cash transfers should not be done in such a way to present them as ‘a solve all’ solution. There are other aspects of the broader context which influence the current living conditions of children and their opportunities to realize their future potential. Free access to health, education and social services are critical examples. Strengthening the delivery of these and other services to all children is an important part of the response.

Such systemic responses to children are gaining support as the core response to HIV and AIDS to reduce the impact on children. While support is increasing, resistance is still apparent. Some of this resistance stems from a lack of trust in the poor. Outsiders may see the family as an impediment and want to avoid any spillover of support to the family from efforts to support the child. This misses the importance of a strong family in the care of the child and in the future of the society.

Other concerns stem from a lack of faith in governments to deliver systemic responses. In the transmission phase, this is an important concern to consider as CSOs often provide

services in the absence of government services. There remains a need to support such efforts until state provision is available.

Finally, concerns and resistance appear to result from a view that systemic response might replace project responses. Taking a step back, we think all would agree that more needs to be done and that there is place for multiple actors. CSOs may not be best placed to provide direct poverty alleviation and provision of health and education services in the long run. But such systemic responses are by their nature impersonal. There will be numerous examples of where children fail to benefit from services, where families will abuse provisions and where benefit may be minimal as a result of other factors in children's lives. States in highly affected regions such as Southern Africa are not equipped to deal with such situations and there is an obvious space for the creative and facilitative role of other players - a large space at that.

The challenges are great and the need to work together drawing on each others strengths and covering for each other's shortcomings is paramount. A coordinated large scale response is urgently needed.

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