

# **A literature review on child carers in Angola, Nigeria, Uganda and Zimbabwe**

Save the Children UK

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## 1. Purpose

The purpose of this review is to support a process of exploratory child-led research into the needs of children who are carers in Angola, Nigeria, Uganda and Zimbabwe, with the eventual goal of identifying desired policy and programme responses. It provides a synthesis of findings and issues raised in the available literature on child carers, specifically in the four countries, and comments on the fit between existing policies and current knowledge.

## 2. Executive Summary

In the four countries under review, the literature on ‘child caring’ is very thin, and there is no evidence of interventions of any scale designed to respond specifically to this issue. Thus, we have no country-specific empirical data on the long-term outcomes of a caring role for children, nor precise information on the interplay of factors underlying risk and resilience. This review draws on the patchy but growing body of literature on child and family well-being in the context of AIDS in these and other countries in sub-Saharan Africa. Findings therein point to:

- the processual nature of ‘caring’ that evolves alongside illness, death and impoverishment;
- contextual features that impinge on the way children, and their family members, respond to the demands of care;
- factors that build resilience in children with care responsibilities, particularly those who live with chronically or terminally sick relatives;
- possible consequences to short and long term well-being.

The scale of ‘child caring’ remains unknown, but is likely to be widespread and unevenly distributed. Children are more likely to be caring in regions where HIV rates have been high for several years and are still climbing, local sources of income are few (prompting healthy adults and children to migrate for work), proportions of single-headed households are high, health and social services are minimal (including ART access) and communities are, by default or design, relied upon to provide ‘home-based care’ to sick members.

Existing data suggest that children as young as 8 years take on the care of sick adults and siblings, and that these roles can continue for several years, perhaps for a series of sick or frail adults. Too little is known about the psychological impacts of emotional care and the assumption of responsibility (‘parentification’) by young children in African contexts. Older children whose caring roles undermine their school attainment recognise this long-term cost to their well-being.

Girls appear to have primary care responsibilities for siblings or sick/frail adults more frequently than boys. But gender divisions of labour are very sensitive to socio-cultural preferences (for example for gender matching in caring) and the sheer scarcity of human resources. This means that the growing proportion of boys who are full-time carers can be overlooked within local neighbourhoods, and policy provision.

Close scrutiny of research investigating care dynamics within families and neighbourhoods reveals that:

1. Children are performing a physically, mentally and emotionally demanding set of tasks during a period in which their lives are undergoing profound unwelcome change;

2. The experiences and implications of living with a parent or other close relative with acute, debilitating illness, plus those of bereavement and grief, need to be integrated into our analysis of 'care';
3. We should not assume a linear relationship between AIDS sickness in the home, children's care roles, orphanhood and further care roles for children;
4. Caring, for children and adults, is a two-way relationship even when aspects of the care role have been reversed. Unwell adults (who are being cared for by children) continue to try to care for these children in significant ways. Greater understanding of the roles of 'child' and 'parent' is called for, in order to gain insight into the way reciprocal caring can bolster resilience.
5. The quality of relationship between child and parent-figure is the best predictor of child mental health. Factors that stand to improve adult quality of life (e.g. ART, health care, reliable income) raise the standards of adult care of children, improve the quality of their relationship, and thereby have important indirect benefits to child well-being.
6. Children are likely to assume caring responsibilities at the point when a household is in severe economic decline, and has minimal (or no) human capital with which to engage reciprocally in social networks. Adult sickness may attract stigma related to AIDS, or to the inability of the household to contribute to social networks. Social isolation puts immense strain on the child-adult relationship, and poses a risk to livelihood because food and other basic goods are not shared.
7. Child carers often manage to stay in school but their attainment suffers owing to sporadic attendance, exhaustion and failure to complete tasks. Policies that focus only on improving enrolment amongst OVC will not address this problem. Evidence from other countries that health shocks improve parental investment in education begs questions about the appropriate means of bolstering parental efforts to support their children through school.
8. The caring role may strengthen children psychologically and socially in ways not available to those who witness debilitating illness in the home while others perform care. The younger siblings of 'child carers' may be highly vulnerable in this regard, especially in the context of likely future bereavement, re-location to a relative, or remaining with an older sibling whose ability to care is compromised.

Factors that build resilience in children who care, as well as those who live with sick relatives or are orphaned are:

- a. The quality of relationship between child and adult as an end in itself and as a mediator to children's inclusion in social networks;
- b. The provision of health care or social grants;
- c. Capacity within social networks to provide food, sustain livelihoods and ensure children and adults feel included in the community.

Striking parallels in the mechanisms undermining well-being for children in these three scenarios include:

- a. Economic impoverishment due to difficulties generating income or resources;
- b. Invisible compromises to children's emotional well-being and mental health, and the risk that these are neglected in policy and intervention;
- c. Severe adult illness and its potential to mediate relationship with child, and thus child's mental and physical health;

- d. Lack of knowledge amongst children about nature and likely course of illness; their exclusion from decisions around where they live, schooling etc;
- e. Gender and age-based discrimination, and exploitation.

The data currently available point to some unique aspects to children's caring roles in terms of well-being outcomes and the mediators in these:

- a. Heightened interdependence between child and sick adult as a result of the reciprocal nature of care;
- b. Raised sense of responsibility, especially at an emotional level and in terms of meeting daily household needs,
- c. Anticipating loss of a parent, or another close relative, often without full knowledge of the illness, its transmission or its implications for the rest of the family;
- d. Excessive time demands on children that hinder their ability to complete homework, attend school regularly and move through the grades.

Three out of four of the above mechanisms, and a majority of the more general protective factors listed above, operate at the level of interpersonal relationships. This finding suggests the importance of policies and interventions able to support the relationship between children and their 'caring' adults, who may in time become those for whom children care.

Child caring is not given specific attention in any of the four countries' policy documents, but remains a hidden, sometimes hinted at, component of AIDS-related vulnerability. Where mentioned, children's care roles are defined in relation to younger siblings in 'child-headed households'. Several national policies highlight children living with sick adults as 'vulnerable', and thereby of high priority.

The strengths of the policies lie in their focus on improving access and quality of basic services to adults and children, and in this sense provide a robust foundation to resourcing child carers. Four matters of substantive concern arise:

1. Absence of strategy to address psychosocial well-being: Several policies draw attention to this as a priority area, but do not specify the means of addressing it. This implies limited knowledge of how to provide the nature and scale of psychosocial support required.

2. Inconsistencies and contradictions around rights to parental care: Nigerian and Ugandan policy for OVC contain explicit statements regarding the need for family reunification or 'alterative family care' for children in 'child headed-households'. In Uganda, the second target group of 'vulnerable children' includes those who live with sick parents. There is a stated goal of ensuring that children live in 'caring families', but this quality is not defined. It remains possible that policy is (perhaps unwittingly) supporting the removal of children from homes where they are caring for sick parents. In Uganda, children's constitutional rights to know and be cared for by their parents stand to protect children in this regard, but require integrating within existing OVC policy.

3. Inclarity around the definition of child caring as 'child work': Only in Uganda has there been investigation of child work in the context of high AIDS rates. Even here it is unclear whether the activities contained within caring and the conditions under which children are performing these, are those that are locally regarded as 'work' or qualify as 'hazardous

labour' according to ILO standards. The legal and practical implications of defining child caring as child work have not been adequately considered.

4. Approach to service delivery: Nigeria's approach is one that identifies OVC then targets them specifically with direct assistance, one that has been tried and largely rejected in other African settings owing to its failure to respond to more general vulnerabilities found in a large portion of the young population many of whom will become 'OVC'. Uganda and Zimbabwe advocate a more integrated approach to enhancing service provision. Angola's policy provision is less elaborated with respect to AIDS and prioritises approaches consistent with post-conflict rehabilitation. There are likely to be valid reasons for this, however the document is not supported by evidence that links post war recovery and rising AIDS rates in terms of their respective or interactive effect on care in the home, and child well-being.

More pertinent, but less visible here, is the degree of political commitment to these and other policies that stand to protect children and their immediate caring relationships, especially in countries where long-held practices forefront other ideals (e.g. the dual legal system that exists in Zimbabwe and tendency for traditional law to hold sway, often to the detriment of women and children).

In light of the paucity in knowledge on the topic of child caring in Nigeria and Angola, and its scant coverage in Zimbabwe and Uganda, an obvious recommendation is for further research. But large-scale prospective and longitudinal studies of the kind needed to thoroughly investigate the dynamics and outcomes of child-caring are not practical, because they are labour and resource intensive, and would need to be repeated across diverse areas. Given the predictive picture emerging from this review, I conclude by recommending area-specific appraisals and give suggestions as to their design.

### 3. Note on available evidence and sources

Published primary data on care roles performed by children in these four countries varies from non-existent (in Angola and Nigeria) to patchy in coverage and limited in scope (in Uganda and Zimbabwe)<sup>1</sup>. In terms of the region, there are only two quantitative studies of outcomes for children living in households with sick adults in sub-Saharan Africa, one in Kenya (Graff Zivin et al. 2006) and one in South Africa (Cluver, Gardner et al. in press). The few other known studies in the developing world are qualitative; two from Zimbabwe (Robson 2000; Bauman et al. 2006) and one from Tanzania (Evans and Becker 2007). Importantly, no comparative or prospective longitudinal studies have been conducted (although one is underway in South Africa, Cluver et al; 2008), meaning that we cannot draw precise conclusions about the nature and impact of child caring in a particular setting.

In light of this scenario, I have consulted research on child well-being and caring more broadly, including the impact of AIDS-related illness on households, and on care by adults, in a range of settings within sub-Saharan Africa. These studies provide important insight into general features of the regional cultural, socio-political, economic and epidemiological landscape that stand to influence child caring very directly, and include some area-specific

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<sup>1</sup> Further in-country searches may reveal illuminating grey literature on the topic (for example NGO reports and advocacy material) in English and other languages.

factors. In this way, the review draws attention to the most glaring gaps in knowledge and suggests their implications for current policy and within the prevailing socio-political climate.

#### 4. Defining and researching 'child carers'

The children whose roles and lives are the focus of this review share many experiences related to poverty and the presence of HIV/AIDS with the vast majority of children in their neighbourhood, and country. However the literature points consistently to certain key distinctions that relate firstly to the nature or quality of the care role they perform, and secondly to the magnitude of that role (Becker 2007, see below for more detail).

Thus, the first goal of this review is to summarise existing knowledge on children in sub-Saharan Africa whose care roles go beyond, not only what adults (locally and more broadly) would normally expect of children but what many children would expect routinely to do within the home. Critical gaps in understanding are identified. The second goal is to examine existing provision for child carers within national policy and plans, and to raise issues in aligning policy and approaches in intervention to best serve the interests of these children.

Existing evidence points to children in this region assuming a dominant role as caregivers in the following circumstances:

1. Living with HIV-infected parents, who have chronic and debilitating illness, and may be approaching death;
2. Living with and caring for increasingly frail grandparents, who may have formerly been caring for the child;
3. Heading households and caring for younger siblings, usually as older children or young adults.

Policy discourse, and indeed much of the scholarly literature, has tended to group children with HIV positive parents who have been, are now, or may become primary carers to sick parents or other relatives, under the broad category OVC or 'Orphans and Vulnerable Children' (Cluver 2006). Greater recognition is now being given to the distinct mechanisms of risk and their implications for child well-being amongst some sub-groups within the OVC category. Research and policy have focused specifically on HIV positive children and orphaned children over the last five years. Only very recently has attention begun to be paid to child carers, and thought given to the implications of this role and the settings in which it is performed, as well as to the likelihood of care responsibilities being on-going or repeated presence in children's lives.

Recognition of children's caring roles remains uneven in both academic and policy spheres, posing challenges to the collation of knowledge and any efforts to assess how the 'care' scenario is encompassed in general provision for children and families. Where such recognition is emerging, the spotlight is firmly on the scale of widespread chronic, debilitating and distressing illness caused by AIDS, and its broad-reaching implications for families and entire communities. Thus, a focus on child caring, firstly illuminates for the first time a period of heightened risk for large numbers of children who continue to live with parents and relatives, secondly helps us understand the nature of the process entailed in 'orphanhood' in different contexts, and thirdly calls into question the appropriateness of existing and envisaged responses to HIV-affected children.

Lucie Cluver, principal researcher in the first prospective and longitudinal study of child caring and impacts on well-being in South Africa, notes that “available developing world literature tends toward a focus on deficits and impairments, with a relative neglect of protective factors in young people’s lives, and potential positive as well as negative outcomes that may result from a caring role.” (Cluver, 2008) The study she has designed draws on developmental literature that emphasises cumulative factors as better predictors of children’s long-term outcomes than single-stressors (Rutter 1999, 2005 in *ibid.*), and foregrounds the social-contextual, family and structural factors that can buffer children against environmental stressors (Bronfenbrenner, 1979 in *ibid.*).

Other prominent researchers in this field have called for an approach concerned with the resilience of young carers rather than their vulnerability in order to better explain *differences* in experiences and outcomes *between* young carers within and across countries, and to challenge researchers and policy makers “to consider new ways of understanding children’s caregiving, as not so much an example of vulnerability, but as an active expression of resilience” (Becker 2007 citing Evans, 2005; Newman, 2002).

## 5. Scale of the issue

According to a recent comprehensive study of available literature on the topic, “many children in sub-Saharan Africa are increasingly likely to have significant caring responsibilities for parents and relatives with HIV/AIDS” (Evans and Becker, 2007 citing Ogden et al., 2004; Robson and Ansell, 2000). That said, the truth is that we do not know how many children can be defined as ‘carers’ in these four countries, or elsewhere in the region because we have no official figures or other reliable data (Ogden et al., 2004; Robson et al., 2006: 97 in Becker, 2007).

The scant available quantitative research from specific countries points to rising incidence of child caring. A large survey in Tanzania conducted in the early 1990s found that about 4 percent of 7-14 year olds were reported to have engaged in caring for sick relatives in the previous seven days (Ainsworth et al., 2000: 22, cited in Robson et al., 2006: 97), and that subsequent increases in the number of children affected by the AIDS/HIV pandemic are likely to have pushed this percentage up significantly in recent years.

In the absence of baseline figures, all that can be said is that similar increasing incidence of child caring is likely in the countries under review owing to high (and in some cases, rapidly rising) HIV prevalence, parallels in the nature and levels of poverty of the majority of the population, in-access to services, and thus in the impact of AIDS-related sickness on family dynamics. In all four countries, health and social services are unavailable to a large portion of the population, meaning that terminal care is usually provided at home with little or no professional support and varying kin or neighbourly assistance (see below). Children’s majority status in the population<sup>2</sup>, plus their relative health and availability in the home, positions them as care resources even when their families perceive them as requiring care themselves.

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<sup>2</sup> Census data for 2000 show that 42.7% of the population of Sub-Saharan Africa is aged 0 to 14 years; in Zimbabwe, for example, this figure is 43.9% (UN Populations Division, 2003, quoted in Robson et al, 2006).

Table 1 shows us that rates of adult sickness and death are very high in all four countries, although the large differences between low and high estimates, indicate that true prevalence and death figures cannot be achieved. What is clear is that in all countries there are between half a million and 2 million adults with HIV (and in Nigeria, perhaps up to 4 million), very few of whom are likely to receive treatment and care by the state or civil society organizations (see below). Even in urban Soweto, South Africa (where a large proportion of people are income poor but access to services is good relative to the vast majority of the region), a survey comprising 4912 households found that just under half (44%) of all households contained at least one sick adult and that just under a quarter (22%) of all adults were categorized as being sick (Gray et al. 2006). Studies like this indicate that even if plans for rolling out health and social care are realized, the demand for care in the home is likely to rise over the next decade and as working-age adults fall sick and die, a larger portion of the care burden will fall to the older and younger generations.

Trends in prevalence rates in each country can help predict the demand for care of unwell adults that will be placed on children over the next two decades. Importantly, the variable but often protracted period between infection and debilitating illness can mean that even when HIV rates have stabilized or are declining, rates of AIDS-related illness and care needs will continue to rise. Declining HIV rates are well documented in Zimbabwe (UNAIDS, 2005), and also observed in Uganda, where rates fell from 15% in 1991 to 5% in 2001 (UNDP, 2005). The UNDP attribute the decline in Zimbabwe to changes in sexual behaviour through the use of condoms and a reduction in the number of sexual partners (*ibid*). And while this UN body asserts that the in clarity of causes of the Ugandan decline, the country's second National Strategic Plan for HIV/AIDS (2008-2012) gives data showing rising rates of new HIV infections, and points out that the reversal of Uganda's prevention success may not be as 'recent' as many assume: "Stagnant and worsening HIV trends in Uganda actually date from 2002", and that sexual transmission is the major source of new infection (UAC 2007: vii). Elsewhere in southern Africa, HIV rates are expected to rise (UNAIDS, 2005) and data indicate similar trends in Nigeria.

Table I: National HIV-related data indicating rising demand for care of sick adults

<b>Country</b>	<b>Angola</b>	<b>Nigeria</b>	<b>Uganda</b>	<b>Zimbabwe</b>
Total population, thousands (UNFPA, 2007)	16900	137200	30900	13200
Numbers of people age 15+ living with HIV/AIDS, thousands *	200 / 450	1600 / 3800	780 / 1000	1000 / 2000
Percent of population 15-49 years living with HIV/AIDS *	2.3 / 5.3	2.3 / 5.6	5.7 / 7.6	13.3 / 27.6
Numbers of deaths; adults and children, thousands*	18 / 47	120 / 330	54 / 130	120 / 250
Orphans, Children (0-17 yrs) orphaned by AIDS, 2005, estimate, thousands	160	930	1000	1100
Orphans, Children (0-17 yrs) Orphaned due to all causes, 2005, estimate, thousands	1200	8600	2300	1400
Orphans, Orphan school attendance ratio, 1999-2005	90	64	95	98

Source: Population, HIV prevalence and death data from 2005, cited in the 2006 World Health Organisation Report on the global AIDS epidemic. Orphanhood data from 'State of the World's Children 2006'. UNICEF.

Key: \* low estimate / high estimate

The orphanhood figures deserves some attention for two reasons. First, they show the range in underlying causes to orphanhood, which stand to influence the dynamics of family life upon which child caring occurs. Angola has very high rates of non-AIDS related orphanhood: In 2003, these were estimated at 1 million, almost 10 times the number of children orphaned by HIV and AIDS, pointing to the lasting legacy of the civil war. In contrast, AIDS is estimated to account for three quarters of orphans in Zimbabwe where the epidemic is more established and its effects more pervasive.

Second, we know that not all orphans have performed a care role, and that child carers comprise a potentially much larger group of children whose parents are alive, but sick. We also know that, depending on capacities of kin networks, a small but varying portion of orphaned children have care responsibilities for their younger siblings. In order to be more reflective of the pool of potential carers, these figures would need to be stratified by age in order to exclude those under five years (who are unlikely to have cared for a parent or to have care responsibilities for younger siblings) and to isolate numbers of 'single orphans' (because these children are likely to have a remaining parent who is HIV infected and may now, or in the future, require care).

National level data would of course need to be supplemented with provincial and district data not only on orphanhood (and causes), but on other key demographic variables. These

would include numbers of children who live apart from one or more of their parents (e.g. in the care of grandparents or other relatives), and are therefore unlikely to be directly witnessing this parent's sickness or contributing to their care. Such a scenario may change the nature and effectiveness of their resilience and vulnerability to AIDS-related adult sickness. Sub-national data on adult access to anti-retroviral therapy, and to broader health and social services, are also key to understanding the consequences of HIV infection on individual health, household economics and the implication on children as family members under a particular set of pressures.

Indicative but dated information on health provision include:

- In 1997, less than one third of Angola's population had access to health services<sup>3</sup> (National Strategic Plan on HIV and AIDS), contributing to very poor knowledge of HIV transmission particularly in remote rural areas.
- Between 2003 and 2004 there were approximately 1,000 people per nurse in the four countries being reviewed (WHO Health, Nutrition and Population online database).
- In Uganda, where the health service is relatively well-resourced, there were 20,000 people per doctor in 2003 and 1,095 people per hospital bed in 1995 (www.UNDPuganda: Uganda Facts and Figures).
- In 2000, only 0.5% of PLWHAs in Uganda had access to antiretroviral therapy (Kikule, 2002).
- In 2002, the Zimbabwean government declared the lack of access to ART a national emergency and in 2004 launched a national ART programme. In 2005, 48 health facilities were offering ART services in Zimbabwe. About 20,000 patients were on treatment programme by the end of December 2005, with about 13,000 in the public sector institutions and 6,000 in private institutions (Chakanyuka, 2005 cited in Makwiza et al, 2006). Prior to this, ART was provided by the private sector, two research projects and one mission hospital, thereby reaching only a small proportion of those requiring treatment.
- In 2002, Nigerian government-run health-care services were described as "barely functioning" after years of neglect during repressive dictatorship and military rule as well as widespread corruption (Hargreaves, 2002). Half the population are unvaccinated for routine diseases. By 2001, the 3.5 million HIV infected people were without access to the most basic of care. "A poorly structured health service that relies on vertical programmes for HIV, tuberculosis, and malaria, means that coordination is chaotic, and already scant resources fail to reach the lower levels in which they are needed most." (ibid.)
- In mid-2005, only one person in 10 in Africa in need of antiretroviral treatment were able to access them (UNAIDS, 2005; WHO and UNAIDS, 2005 cited in Makwiza et al, 2006).

It remains the case that each country has a specific historical and political trajectory, upon which HIV has moulded changes in the landscape of illness and poverty. That said, the commonplace under-provision of health care and social services results in a majority experience (not denying differences here for the urban elite), of delays in rollout, patchy provision, medication supply shortages and extremely low rates of HIV-testing, all of which contribute to continuing high levels of parental AIDS-illness and death (Nattrass 2006 cited in Cluver ESRC proposal).

Robson et al (2006: 107), who have extensive empirical research experience in Zimbabwe, Lesotho and Malawi, argue that the existence of young carers "may be seen in part as an

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<sup>3</sup> The reason for poor health service access is not so much remote rural living (42% of the population are urban, ibid.) but the damage to infrastructure during the war and associated transport and communication problems.

outcome of reduced state healthcare provision and the promotion of policies advocating home care for individuals with HIV/AIDS.” (Becker, 2007, Global persps)

These and other trends in policy and service design for the care of AIDS-sick adults and affected children are examined in the final section of this review. Gaps and contradictions within policy and intervention plans indicate dimensions of caring that are either taken for granted (and remain unsupported), or are genuinely invisible to policy makers.

## 6. Who is caring where?

The gender and age dimensions of child caring in sub-Saharan Africa, and where possible in the four countries under review, are presented here.

### 6.1 Gender

Existing research in sub-Saharan Africa indicates that women and girls perform the majority of care in the home, whether this is for young, old, healthy or sick residents (Robson et al., 2006:100). Some older literature suggests that boys are brought into a caring role only when there are no girls available to do so. However, recent studies point to the variety of contexts in which boys are drawn into care. For example, when a man needs care and his wife is absent (a common scenario in contexts of high mortality rates and mobility in marital or partnering relationships), boys are given the caring task owing to cultural preferences to match genders of carers and recipients of care.

Gender matching of caregiver and care recipient is considered preferable in a variety of developed and developing world contexts (Becker, Aldridge & Dearden, 1998, p. 20). The case of a boy in Lesotho reporting caring for his aunt is described as “unusual because a boy reports taking care of a female relative” (Robson et al, 2006:99). Studies in southern Africa suggest that “only where there is really no-one else available to care will it fall upon a child to look after an adult of different gender” (Robson & Ansell, 2000, p. 181; Robson, 2000, p. 66 in Robson et al, 2006:99).

Thus, the nature of gender relations in the region mean that girls do more caring than boys, and may be organized into care roles outside their own homes. In northern Uganda, where girls aged 5-12 are in demand as domestic servants, relatives arrange for orphaned girls to move to an urban branch of the family who desires domestic assistance and these girls engage in domestic and child care tasks in return for food and lodging (Oleke et al., 2006:276). Most of these girls do not attend school. In such a scenario, girls in Uganda may find themselves caring for young children in a setting where they have even less power because they are part of a transaction between family members.

These trends notwithstanding, a combination of cultural preferences for gender matching and sheer absence of alternatives mean that boys often step into a care role and perform other domestic duties usually carried out by girls or women. Such situations pose challenges to the prevailing social construction of gendered childhoods (Robson et al:101), meaning that there is a danger of overlooking boys’ experiences and needs both in local neighbourhood responses and the level of national and regional policy development.

For example, while survey data on child carers in Tanzania showed that girls were more likely than boys to have their schooling disrupted, another finding indicated that the nature

and impact of boys' caring activities are being ignored (Robson et al, 2006: 102). When boys who lived in non-two parent households were asked questions about school attendance, nearly a quarter (23.1%) said that caregiving at home meant their school attendance was irregular. But none of their parents or guardians reported this when they were asked survey questions. The researchers suggest that parents may be genuinely unaware of the time demands on boys related to care, or be unwilling to admit that these 'feminine activities' are being undertaken by boys.

The two contrasting pictures of the gender and age profile of child carers that emerge from Zimbabwean work serve to illuminate the diversity in demographics and dynamics of care that can occur in a relatively small area and within a broadly similar cultural setting. Robson's (2000:66) early work on dimensions of child caring in high-density, low-income residential areas in Harare and Chitungwiza, reflected the strongly female gendered care roles; girls between the ages of 15 and 17 were doing the majority of caring. Contrary to their expectations, Bauman and colleagues found that older children and girls in urban Mutare were not more likely to take on the responsibilities for personal care, household chores and emotional support to their mothers, than younger children and boys (Bauman et al. 2006).

## **6.2 Age**

Anecdotal evidence from various African countries suggests that children who care are often young because older siblings tend to leave home to find work or seek survival on the streets as family poverty deepens (UNAIDS, 2000 cited in Becker, 2007, global perspectives). Thus it is not uncommon for children between 8 and 11 years old to have primary care responsibilities, and four-year-olds were found to be contributing significantly to parental care in Ingwavuma, a deep rural area of South Africa (Barnard 2002). In parts of Uganda, where older girls are in demand as domestic servants (Oleke et al., 2006), their younger siblings assume care roles at home. This sibling dynamic shows the importance of investigating the social dynamics driving the supply and demand of domestic or other labour (for example class, rural/urban living or ethnicity), in order to identify where very young children begin caring.

There is some evidence from Mutare, Zimbabwe that children over 13 years perform more emotional care than their younger siblings (Bauman et al 2006:66). Counter-intuitively, this study also showed that having an older sibling or adult in the household did not mean that child care-giving was less frequent or intense.

Without country-based longitudinal data on child caring, we cannot tell how early caring affects the likelihood of being a carer in later childhood and early adulthood. We do however have evidence from certain southern African countries about how families respond to adult AIDS-related sickness and death, the ideals and realities of succession planning and the movements of children thereafter. These studies alert us to the probability of children performing a series of care roles for parents, siblings, grandparents or other relatives, and to the likelihood of them moving house in between each care role (see Becker 2007 and section 8 for more on care as a process). Age-based analysis of care is therefore important. Very young carers are likely to have different competencies and vulnerabilities to children in their teens. But, older children who care may have built up certain strengths, and carried or exacerbated certain risk factors, through the fact that they have been caring for many years.

### **6.3 Diversity and change in the socio-political landscape**

Definitive statements of intra-country patterns of child caring, and the socio-political reasons underlying variation in prevalence or their associated risks are not possible without the necessary empirical research. Nevertheless, available studies flag the following factors that stand to shape the nature and extent of child caring, and the conditions in which children perform caring:

- post-conflict migration;
- mobility in the extended family and the urban/rural diaspora;
- socio-cultural change, increasing economic heterogeneity;
- synergistic relationships between AIDS and chronic poverty;
- attitudes, beliefs, family and inheritance practices associated with ethnicity, religion and interaction with other worldviews.

A detailed analysis of evidence pertaining to each factor and reasons why it is likely to be relevant in the four countries under review is found in Appendix 2.

### *7. What does caring entail for children?*

Very little data exist on the range of tasks and responsibilities encompassed in the role of child carer in the four countries. We have some evidence of the nature of children's caring roles in Uganda (Luzze, 2002) and Zimbabwe (Bauman et al. 2006; Robson 2006), and find strong parallels between findings here, in other sub-Saharan countries and those conducted in the developed North. For example, Evans' and Becker's recent comprehensive review (2007) of research on child caring in Tanzania and the UK finds that, despite very different socio-economic, cultural and policy contexts, children caring for parents with HIV in share many similarities in terms of their everyday caring responsibilities, needs and aspirations. The range of caring tasks children typically perform in African settings are:

- Household chores - cooking; cleaning; washing dishes; laundry; shopping; fetching water; tending livestock; cultivating crops and vegetables;
- Health care - reminding parent/relative to take their medication; caring for parent/relative in hospital; assisting with mobility; preparing special nutritional food;
- Personal care - washing/ bathing parent/relative; assisting to eat, dress and use the toilet;
- Child care - bathing siblings; supervising and accompanying them to/from school;
- Emotional and practical support - talking and comforting parent/relative, being a confidante (reported in Zimbabwe by Bauman et al. 2006); helping adults to remember appointments;
- Income generation activities – begging; casual farm work; selling produce; domestic work; working in a shop;
- Attempting to resolve financial problems by making small investment and production decisions (noted in Uganda, by Luzze 2002).

#### **7.1 Distinctive features of child caring**

While it is certainly the case that children living in poor households commonly take on many of the above tasks, some children at certain points in their lives assume a role and status in the home that encompasses most or all of the above in large volume. Thus, as stated in the introduction, child carers are distinguished in the eyes of researchers by “the extent of their

caregiving, its nature, the time involved and the outcomes for children's development, social and economic participation." (Becker, 2007) Other scholars with extensive research experience in the region argue that it is also "the intimate care...that most clearly distinguishes the labour of young caregivers from the usual work young people do in Africa with respect to household chores' (Robson et al., 2006: 100)

Comparative research shows that child carers in resource-poor African settings shoulder a much greater social and emotional responsibility for their sick parents than those in wealthier settings where medical and social services are readily available. Only 12% of mothers and children in New York said that children were responsible 'very often' for the care of their mothers when they were sick, as compared to 39% of mothers and 26% of children in Mutare, Zimbabwe (Bauman et al 2006:63).

The root of this difference is broadly understood: Across the developing world, the work of adults and children in families is relied upon to perform tasks that are in large portions undertaken by welfare departments, health services and state social security in developed countries. Social organization of this nature "is underpinned by a value system which emphasises the obligations owed by children to their parents in terms of contributing to the household and providing care during sickness or old age" (Laird 2005: 462, in Becker, 2007). While these general expectations may be common across sub-Saharan Africa, there is likely to be considerable variation in the moral obligations of children towards their parents and other relatives:

- Are there age or gender dimensions to these obligations?
- To what extent does failure to fulfil these responsibilities attract censure and penalty both from kin and the wider community?
- Do local adults distinguish child carers from their peers, and if so, how?

These questions are important in terms of understanding any social consensus upon which special vulnerabilities are locally defined, and responded too.

Some studies provide information that is indicative of general attitudes towards and ideals regarding childhood. For example, in Mutare, Zimbabwe, three quarters of the 50 AIDS-sick mothers questioned felt that their children had too much responsibility, and 80% of child carers also replied affirmatively to the question (Bauman et al., 2006). And in a 2004 study of child labour and HIV/AIDS conducted by the ILO and the Ugandan government, one question posed to household heads was: "Is there a 'care burden' or a marked increase in domestic work and household chores imposed on children due to the HIV/AIDS pandemic?" But, as far as I am aware, there is no research on these aspects of the inter-generational care relationship in particular cultural contexts. It is nevertheless an important area of enquiry for

- a) understanding the outcomes of caring: Expectations of children that are held within neighbourhoods and families stand to influence the psychosocial implications of being a young carer, and children's notions of whether they have 'succeeded' or 'failed' in that role;
- b) developing interventions that effectively strengthen local resilience, for example by supporting adults in their efforts to respond to children's needs and to bolster their well-being.

## 7. 2 What are child carers not doing?

The volume of tasks children are expected to perform can demand both time, and a high level of physical, mental and emotional energy. An Australian study found that unlike non-caring peers, young carers spend most of their time either providing care or thinking about the person with care needs (Carers Australia 2001b:9 in Becker, 2007).

Two Zimbabwean studies indicate the sheer time demand placed on carers and the resulting opportunity costs for children. Adult carers of AIDS patients at home spent 2.5–3.5 hours a day providing direct patient care (Hansen et al., 1998, p. 757, cited in Robson et al, 2006: 105), and when a sample of 50 child carers in urban Mutare were asked whether care interfered with things they wanted to do, “78% reported experiencing some impact on participation in after-school activities, 63% reported inability to do homework at least once in a while and 90% said they miss socializing with friends” (Bauman 2006:64). A Ugandan study of child work found that of the children living in AIDS affected households, 13% spent up to 4 hours per day caring for the sick. Sixteen percent reported working both day and night, the majority of whom were girls who were therefore exposed to the risk of sexual abuse (ILO and Ministry of Gender, Labour and Social Development 2004:38). In view of similarly stretched familial resources and scant health or social services, parallel time-related pressures and outcomes for child carers are probable in Angola and Nigeria.

## 8. Care as a process involving two-way relationships

Critical to our understanding of how children’s changing roles and the burden of care affect their short and long term well-being is the prior recognition of processes of change in one or more facets of care over time. Such changes are often gradual, but can be sudden.

Literature from the region points to the following stages of this process and resulting experience for children:

- The likelihood of witnessing parental illness, experiencing deeper poverty, and feeling the implications of both in terms of heightened distress and anxiety in the family, *before* beginning to care, and *during* their period of care;
- Starting off the care role through support to one or more other carers in the home;
- Significant changes, even ‘role reversals’ in their relationship with a parent or another relative to whom they have close emotional bonds, [often referred to as ‘parentification’ in medical discourse, and studied as a particular psychological response with consequences for well-being, see for example Bauman, 2006];
- Continued efforts by sick or frail adults to persist in caring for children at an emotional level (Thomas, 2006);
- Witnessing a severe decline in parental well-being, including distressing symptoms of ill-health, and being unable to halt this process;
- Witnessing or hearing about parental death, being moved to the second parent, grandparent or another relative, adjusting to new care figures and living environment;
- Repeating the care role, this time for frail grandparents and the associated anxiety of losing another adult ‘carer’ (Clacherty 2008)

By spelling out the stages of caring roles that respond to AIDS-related illness, we soon see that children are performing the physically, mentally and emotionally demanding tasks listed earlier during a period in which their lives are undergoing profound change, and in which

they witness, and are part of, familial efforts to manage the steady erosion of long-standing (but increasingly fragile) economic, social and emotional securities. Against this backdrop, the 'task' of caring given or assumed by children would appear to be about much more than providing various forms of practical, economic and emotional assistance. Rather, children are part and parcel of responsiveness and mobility within the domestic and kin spheres, often due to undesirable circumstances. Their roles are integral to the sustenance and re-forming of kin relationships through such processes (see Roalkvam 2005 cited later in the review), but their power to influence family plans and their outcomes may be minimal.

The vast majority of existing research has investigated child caring as a phenomenon that has grown in scale, and potential severity, as a direct result of the AIDS pandemic. One consequence of the recent focus on child caring is that we have negligible evidence of the nature and scale of child caring before HIV rates rose so dramatically. Many other chronic and debilitating illnesses have affected, and continue to affect, adults in poor African neighbourhoods, and we can expect children to play a caring role in the absence of other adults. There is a risk that we over-interpret the 'process' described above and assume progressive, linear relationships between the presence of AIDS, illness, caring roles and impact on child well-being (see box below). It is therefore important to recall that children's caring roles arise from other sets of needs than AIDS complications or even other kinds of illness, and that a caring role may never be performed by children prior to, or after, orphanhood.

The dangers in assuming linear relationships between AIDS-related sickness and child outcomes are highlighted in a recent study of the incidence of so-called 'child-headed households' and the consequences for child well-being (Meintjes et al. under review). Drawing on two national surveys, these researchers found that while numbers of orphans have risen steadily in the period between 2001 and 2007, numbers of child-only households have not increased. Moreover, over 90% of children living in child-only households to date were shown to have at least one living parent. And "in 2006, 65% of children living in child-only households in South Africa had two living biological parents, and 81% had a living biological mother." (ibid.) Their findings directly contradict the picture of rising numbers of child-headed households commonly presented in policy statements (e.g. Dept of Housing, 2006) and scholarly debate (see Bequele below), and show the fallacy of assuming that orphanhood is the primary or only driver to child-only households.

*"The grandmothers bury their own children first and then they have to look after their grandchildren. And when grandmothers die, given the fragmentation of the extended family, there is no one coming up behind. So you have the phenomenon of child-headed households."* (Bequele 2007:2)

Arguments like that above are readily used to pique listeners' responses but not only are they based on a series of assumptions like those just described, but they give no recognition of children as engaged in a caring role, or in active in shaping their circumstances during adult sickness and after their death.

Knowledge about what happens after a child has cared for sick adult remains very poor. The reliance on, at best, retrospective sampling (i.e. studies of orphans) or, at worst, anecdotal evidence often drawn from very different economic, political and socio-cultural contexts is reminiscent of the manner in which the circumstances and life-chances of 'street children' were defined in the 1980s. Scenarios put forward range from former-carers' inclusion in other branches of the extended family, to their total abandonment and likely entry into military service or begging, street living and delinquency (e.g. Bequele 2007:5).

Recent research on the dynamics of 'care' by adults and by children in southern Africa highlights the two-way nature of the care relationship (Bray and Brand 2007; Thomas, 2006), in which each person assumes aspects of the material, social and emotional responsibilities, the precise nature and degree of which shift over time. The 'give and take' of care relationships that involve children and their implications for carer well-being are often overlooked because there is an implicit assumption within usual constructs of care that adults set the rules, even when children are providing some level of care.

Children as young as five were observed to be defining the parameters of care, including their expectations of their sick parents, in a poor settlement on the outskirts of Cape Town (Bray and Brandt, 2007). And research in Namibia found the well-being of child carers to be symbiotically related to the sick adult's perceived ability to continue caring for their child, or to ensure that others will do so (especially if she is the child's mother) (Thomas 2006:3183). These findings point to the mutual interdependence of child carer and parent (patient) emotional well-being. In practical and policy terms, they alert us to the significance of factors that can improve the quality of life of sick or elderly people independently of the child carers' efforts, and of the role these can have in reducing negative impacts on child well-being.

## 9. How does caring affect child well-being?

This section presents the scant available data on well-being outcomes for children in sub-Saharan Africa who care for sick or elderly adults, or young children (often following parental death). I draw heavily on relevant studies of adult carers, of children who live with AIDS-sick parents and of the consequences of orphanhood owing to the plausible (usually un-identified) inclusion of child carers in their samples, clear overlaps in children's experience and circumstances, and the shared possibility of becoming a carer in the near future.

### 9.1 Physical health

Owing to its primary focus on psychological and educational outcomes, the existing literature on child carers can only indicate the possible risks to physical health inherent in the caring role. The literature on adult carers, children who live with sick adults and child orphans is more instructive on this topic.

Research with adult carers in Namibia found that when the health of their patient deteriorates, women and their children cease to enjoy eating, do not "eat normally" and therefore have less energy for daily activities (Thomas 2006:3179). These findings demonstrate the compromises to well-being associated to living with a sick adult that have already been made prior to any caring role that may be assumed, as well as the impact on nutrition of an emotional response that is as plausible amongst children as it is amongst adults. Moreover,

there are strong socio-cultural pressures operating on carers that dissuade them from eating adequately: In the Caprivi region, “the failure of a woman to reduce consumption during caring may be interpreted by others as displaying a lack of care and respect for the ill person” (ibid.). The age at which girls assume such ‘womanly’ status, and whether all children would be expected to show this kind of ‘respect’ for sick adults, are relevant questions for child caring in this context that were not answered in the Namibia study.

Strong socio-cultural norms that prioritise ‘respect’ as a concept around which social relationships are organized and their salience in structuring interaction between adults and children, have been documented in a number of regions of South Africa (Bray et al. forthcoming; Dlamini 2005). These indicate the probability that similar cultural pressures to demonstrate respect are exerted on children, although the particular means through which one is expected to do so are likely to vary within and between countries. This small body of literature alerts us to the possibility that under-nourishment, vulnerability to opportunistic infection and physical weakness in children who care may not result from economic impoverishment alone, but from the interplay between poverty, socio-cultural norms and psychological responses to severe illness in the home.

One of the few quantitative studies of the effects of adult illness on child well-being was conducted in Soweto, a large township in South Africa with very high rates of adult sickness (Gray et al, 2006). The presence of a sick adult was found to adversely affect children’s vulnerability to disease, likelihood of full immunization, frequency of hunger and exposure to abuse. However this study investigated very young children and could not distinguish the extent to which negative child outcomes were a result of children’s vertical HIV-infection.

The mediating role played by the severity of adult sickness, including its responsiveness to treatment, on child health is evident elsewhere. A trial of antiretroviral treatment in Kenya showed that HIV-positive caregiver access to medication resulted in improved nutrition and growth amongst their children (Graff Zivin et al. 2006).

Two studies in Zimbabwe (Nyamukapa et al. 2006; Watts et al., 2007) and one in Tanzania (Ainsworth and Semali 2000) found compromised physical health amongst orphans as compared to non-orphans. There is also indicative evidence of the greater likelihood of malnutrition amongst orphans in disparate southern African countries (Ainsworth and Semali 2000; Lindblade et al. 2003; Gray et al. 2006; Cluver and Orkin in review), and in South Africa of higher rates of HIV prevalence in orphaned children (Operario 2007).

What remains unclear are the precise mechanisms that underlie these differences, and thus whether orphanhood *per se* (i.e. parental death and the new care environment) is directly causal or whether these risks were established beforehand, perhaps during parental sickness and/or the child playing a caring role (Cluver et al. 2008 ESRC proposal). One of the Zimbabwean studies found evidence of intra-household discrimination and concluded that the poorer physical health and nutritional outcomes amongst orphans and AIDS affected young children cannot be explained by greater exposure to extreme poverty (Watts et al. 2007). As mentioned above, it does however remain possible that under-nourishment began during parental illness through children’s emotional reactions and culturally-informed responses of carers (as found in Namibia), or because more food and money for medicines

are being allocated to the sick person and less of each are available to other household members.

Causal pathways for higher HIV rates in South Africans also remain unclear (Cluver 2008). Recent work suggests three possible routes: One is extreme poverty that increases children's vulnerability to transactional sex (Halperin and Epstein 2004). Another potential route is early sexual debut: sick and frail parents may not be as able to monitor and prevent risk behaviours as their healthy counterparts (Operario et al. 2007). The third possibility is direct infection via the provision of medical care without protective gloves (Lindsey et al. 2003), and is thus directly linked to children's caring role.

Children caring for AIDS-sick adults are exposed to HIV infection through personal medical care and through accidents in the home. While the chances of transmission are slim, the risk remains because children lack knowledge about the nature of the illness (Robson et al. 2006:100), and of how they can protect themselves. In the absence of accurate knowledge, children (like adults) may develop mis-perceptions of the disease and of their vulnerability to infection, leading to resentment against an ill relative and the absence of protective behaviour. This trend was noted amongst adult women carers in Namibia, as was the lowering of carers' guard against infection in periods of stress resulting from their long-term care (Thomas 2006:3180). In contexts where cultural norms exclude children from 'adult knowledge', children are arguably more vulnerable to infection than adult carers, as well as to the potential psychological implications of being unable to adjust their expectations regarding the progress and outcome of the illness.

## **9.2 Mental health and two-way emotional support**

The most comprehensive investigation of the impact of caring on the psychological well-being of children was carried out in Mutare, Zimbabwe and New York (Bauman et al. 2001). Within a sample of 50 AIDS-sick mothers and their children who performed major caring roles in Mutare, two-thirds of children showed signs of clinical depression and 80% said they had too much responsibility. The absence of any control group, for example siblings in the home who were not caring, make it difficult to pinpoint exactly the association between feeling overburdened with responsibilities and mental illness such as depression. Studies in South Africa amongst children living with AIDS-sick parents have shown severe compromises to psychological health in the form of mental distress and poor cognitive abilities (Gwandure 2007), and psychopathology (Cluver, Gardner and Operario, in review). Co-residence with a sick adult who is notionally at least a child's 'carer' may in itself incur risks to child mental health, owing to children's heightened distress, as well as to the poor mental health of sick adults and their resulting limited caring capacities (HIV positive mothers showed high rates of depression and deficits in infant care (Stein et al. 2005 cited in Cluver et al. 2007).

Research amongst AIDS orphans has identified disadvantaged mental health outcomes in Uganda (Atwine et al 2005), Ethiopia (Bhargava 2005), South Africa (Cluver and Gardner 2007) and Zimbabwe (Nyamukapa, C., et al). Few studies have investigated causal pathways. But in South Africa, caregiver sickness has been found to mediate levels of psychopathology amongst orphans (Cluver, Gardner et al. in press), and sickness of a surviving relative linked with distress amongst a qualitative sample (Cluver and Gardner 2007). The fact that AIDS-orphaned children reported higher levels of psychosocial problems than children orphaned

through other means in a large quantitative study (Cluver and Gardner 2006; Cluver, Gardner et al. 2007) suggests that the chronic and debilitating nature of AIDS-related illness in adulthood may have a particularly eroding effect on child mental health. The researchers point out that reported levels of psycho-social problems were also mediated by stigma, poverty and reduced educational access (discussed in sections below). And the presence of psychopathology increased dramatically when two or more stressors were present and mutually interactive, for example the “cumulative stressors of stigma and poverty raised risk of disorder from 19% to 83%.” (Cluver et al. 2007)

There are however indications from a variety of contexts of mechanisms that further raise the likelihood of depression *when children are caring*, namely children’s provision of emotional support, their perceptions of overly onerous responsibility and the inability to provide ‘adequate care’. In an earlier study in the USA, Bauman et al. (2001) found that daughters who provide emotional support to an ill parent have extremely high rates of depression, but their ill parents are unaware of the emotional cost their daughters bear. Interestingly, their subsequent comparative study did not produce the expected correlation between child depression and maternal designation of their emotional support, suggesting that mothers in Zimbabwe and the US may select children to confide in based on their emotional stability and are therefore aware of the implications of placing such a demand on them (Bauman 2006:67).

There is some evidence to suggest that ill adults depend more heavily in terms of emotional support upon child carers in poor African settings than in better resourced settings, and by implication that children experience a greater sense of responsibility for the emotional (and perhaps physical) health of adults in their care. When AIDS-sick mothers in Mutare, Zimbabwe were asked to name people who provided emotional support (e.g. people in whom they confided, who really understood what their life was like), 39% named the child carer as someone who provided emotional support (as compared to only 18% of their AIDS-sick counterparts in New York) (Bauman et al., 2006:64). In contexts where health or social services are largely absent and social networks stretched to capacity, sick parents may seek emotional support from their children because there is no-one else who can provide it.

Culturally validated notions of children’s roles and capacities may also play a role, for example in guiding adult opinions of what is spoken about with children, and what can be expected of them in response to an adult sharing their concerns and confidences. In the aforementioned study, it is interesting that mothers in Mutare were more likely than New York mothers to say they talked to children about problems as if they were another adult and that they talked to them about finances, but their children were less likely to feel that their mothers talked to them like an adult than their mothers reports suggested (ibid.:65). This discrepancy, plus the finding that far fewer Mutare mothers than New York mothers reported sharing of intimate secrets with their children, suggests that particular cultural norms guide the nature and level of communication between adults and children in Zimbabwe, and shape children’s experiences of their relationship with the adult for whom they are caring.

The precise effects of an exaggerated responsibility for a sick relative’s emotional and/or physical well-being on a child’s well-being are difficult to determine. Psychologists writing in the US argue that inhibited development and depression are both possible outcomes when

children take on the parenting role (Wallace, 1996 cited in Bauman et al. 2006), as are delayed development, guilt and low self esteem (Barnett & Parker, 1998 cited in Bauman et al. 2006). Culturally-informed constructions of childhood, including consensus within a community about the roles, duties and capacities of children stand to mediate children's experiences of what is analytically referred to as 'parentification'. But children's subjective definition of 'too much responsibility' is immune to these variables as it connotes a level of responsibility that is much greater than that which is locally expected or even acceptable.

Indicative findings that call for further research into these mechanisms include the much higher depression scores among children in Mutare who said it was 'very true' that their mothers complained they did not do enough, compared to those children who reported that this was either somewhat true or not true (Bauman 2006:67). Perceptions of 'too much responsibility' may include a combination of feeling over-burdened by the sheer volume of tasks and knowledge that one's parent does not appreciate one's efforts.

Research that has investigated the effects of living with a sick adult and on child caring *per se* consistently points to the quality of parent-child relationship as the strongest predictor of child mental health (Thomas 2006; Bauman et al. 2006:68), and that the defining power of this mediator stands across very diverse socio-cultural or economic contexts (*ibid.*). Scholars in this field alert us to the inappropriateness of placing any blame for poor child mental health on sick parents, or the manner in which they conduct their relationships with their children. The focus of attention should rather be on the conditions under which adults are coping with sickness, and in which adults and children are attempting to offer care.

Small-scale ethnographic research in Cape Town suggests that the administration of anti-retroviral drugs in impoverished neighbourhoods can place an additional responsibility on child carers. A study that investigated relationships between mothers on ART and their young children observed instances of five year olds taking it on themselves to remind mothers to take their medicine twice a day and to drink a glass of water with it (Bray and Brandt 2007). The assumption of these medical responsibilities may exacerbate a child's sense that their sick parent's health depends largely, or solely, on their abilities. Young children may not know enough about how the virus and the ART works to fulfil this role appropriately and 'adequately', especially in cultural contexts where efforts to protect children include withholding information about life-threatening illness and death.

### **9.3 Economic security and household livelihood**

In Ingwavuma, a deep rural area of South Africa, over half the 25 child carers studied were trying to earn an income for their family (Barnard 2002). The sample is small but indicative of severe income shortages in homes containing an AIDS-sick parent and of efforts by children to address these.

Literature from the sub-Saharan African region indicates that children most often assume a major caring roles in situations where there are no suitable adults to perform this role, or transferable assets to 'trade' in ways that can pay for labour (Robson et al. 2006). Hence their households are by definition 'labour poor', less able to produce their own food or to engage reciprocally in kin networks, and much more vulnerable to severe impoverishment. The implication of these labour and illness dynamics are that children are likely to be caring in a period when household poverty varies, and may be deepening rapidly. Research in the

impoverished agrarian Caprivi region of Namibia showed that ill people and their (adult) carers often returned to livelihood activities during periods of remission (Thomas, 2006:3178). But these periods became shorter as the immune-system weakened and dependency increased. The study reminds us that in households where the ill person contributed a large portion of the available labour, his or her incapacity to work severely erodes the household's ability to access and mobilise assets, and their illness therefore has a profound impact on household livelihood security. In some settings, land or property is sold in order to raise money for hospital bills and medical treatment (Bequele 2007; speech given at conf in Kampala, Uganda), perhaps owing to the way health services are structured. This is another mechanism through which children's economic security can be eroded, particularly when adult sickness is chronic and debilitating as is often the case when caused by AIDS.

The role of specific types of income stream accessible in a particular national or local setting has also been detected in a recent analysis of South African household survey data on children in child-only households (Meintjes et al. under review). These children (a portion of whom we can surmise are caring for their younger siblings) were found to experience greater income poverty relative to those living in all mixed-generation households. Three quarters of South African child-only households rely on remittances as their main source of income, a finding suggesting their income poverty is driven by the relative unreliability and irregularity of remittances, plus very low access to regular monthly income through formal employment and state social grants (ibid.). A remittance economy is likely to be an important backdrop to domestic care dynamics in settings where labour intensive industries, such as mining, are clustered in one particular area. One can also anticipate high rates of HIV in populations working in, and living near, mines, and a much more widespread ripple effect of labour migration and declining health in the earning population amongst their relatives living in distant areas of the country.

This small handful of country-specific studies points to the importance of mapping the demography of labour, income generation and remittances alongside vulnerability to HIV infection in a particular area, paying particular attention to age and gender. By identifying the flow of economic resources in this way it becomes possible to see where the main breadwinners are likely to fall ill, and where children who care and their younger siblings are highly vulnerable to impoverishment.

Empirical studies in rural eastern Zimbabwe (Howard et al. 2006) and rural Tanzania (Hoffman et al 2008) point to the economic fragility of households which have fostered orphaned children, the high levels of physical, emotional and financial stress experienced by foster carers (for example grandparents), and the lack of social support available to families who are struggling most with impoverishment. For these reasons, researchers recommend the provision of direct financial assistance to adults who have informally fostered children whose parents have died, including the provision of free schooling (Howard et al. 2006) and pensions (Hoffman et al. 2008).

A recent piece of action-research in Tanzania demonstrated the significant economic, social and emotional impact of pensions to families comprising older people and their grandchildren (Hoffman et al. 2008). In so doing, it demonstrated the enormous potential of a minimal but reliable and regular income for older care figures to protect child well-being. Pensions were found to make a marked improvement not only to children's nutrition and educational outcomes, but to the quality of relationship between children and grandparents because they reduced stress in the home. The data showed that children felt more loved when their grandmother was able to meet their material needs, reciprocity was sustained and conflict between the generations was reduced (Hoffman et al 2008:7), as evident in the following quote:

*'If you get home and you find food and you eat you become energetic again and help. Then there is no fighting with granny. You are happy to get water because she got food for you.'*  
Grandchild of pensioner in Tanzania

The underlying argument here is that by bolstering the financial capacity of fostering relatives to provide adequate care, stress in the home is reduced and relationships between adult carers and children are strengthened (ibid.:7). Should children have been carers to their now deceased parent, or later assume a caring role for the relative who has fostered them, economic supports like these as well as other means of strengthening the relationship between children and carers are of critical importance in light of the fact that the quality of this relationship is the strongest protective factor in children's long term mental health.

As mentioned earlier, economic poverty and resulting food/resource shortages in the home can be a significant mediator in the relationship between childhood experiences of caring, adult sickness or death and their physical and mental well-being. For example, the section above cites the influence of poverty in the relationship between AIDS-related orphanhood and high rates of psychosocial distress in children orphaned by AIDS (Cluver and Gardner 2006; Cluver, Gardner et al. 2007).

Loss of property is a potential additional risk factor for children caring for one parent, particularly the mother, when the father is absent or deceased: A recent review of childhood vulnerabilities within Southern Africa points to the widespread practice of property grabbing after the death of an adult that persists because "traditional laws on inheritance usually take precedence in practice over formal laws... and these usually relegate women and children to a lower status than men" (Save the Children 2006). In Zimbabwe, women are treated as minors under the law and barred from inheriting property<sup>4</sup>. Customary laws of inheritance also exclude children from being appointed heirs intestate (when parents die without leaving a will). Marital and non-marital children are treated differently in relation to custody and access to inheritance, the latter often facing greater difficulties in accessing rights to education. A contradiction in state policy underlies the continuation of these practices: The Zimbabwean Constitution under section 23 contains a general prohibition against discrimination yet allows for discrimination in matters of customary law and does not specifically prohibit discrimination in the private sphere (UNICEF 2004:10 cited in ibid. 2006:12). The review's claim that "women and children are frequently left destitute with little hope of recourse" (ibid.) is not supported by empirical

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<sup>4</sup> Although formal law in Zimbabwe would permit women to inherit, the Supreme Court has refused to accept that African women can acquire new rights that they did not have under customary law (ibid.).

evidence. It is however plausible in a region where 34% of households are female-headed. Poor enforcement of any existing legislation underlies these processes of disempowerment and impoverishment, as does the unlikelihood that women and children are aware of their legal rights or have the resources, skills and confidence to challenge the accepted custom (ibid.).

Some have warned of the consequences of the chronic impoverishment of children in AIDS affected families prior to parental death, however these warnings are given without empirical data to substantiate them:

*“...long before they are left to fend for themselves, they resort to legitimate and not-so-legitimate means in order to meet their survival needs: employment in hazardous work with its accompanying physical and psychological risks and exposure to various forms of slavery and prostitution; getting engaged in petty jobs; selling the family assets; and engaging in begging and, sometimes, in anti-social activities. Girls marry at early age or are prostituted. And boys may join illegal military service or city gangs.”* (Bequele, 2007: 5).

Unsupported, and potentially exaggerated, claims are designed to draw attention to the plight of children. The problem is that they can easily become ‘truth’ through their repeated use in scholarly or policy-related rhetoric (For more on this trend see Bray 2003, Meintjes & Bray, 2004; Meintjes & Giese, 2006.). In the four countries under review, it remains the case that the relationship between economic and social capital, and the responses of children and surviving relatives to desperate impoverishment, are poorly understood and deserve much more attention.

#### **9.4 Educational outcomes**

There is a larger literature on the impacts of caring on children’s schooling that is indicative of longer-term educational outcomes than on other aspects of their well-being. That said, Caring appears to greatly reduce children’s abilities to stay in school in certain contexts: Of the eight full time carers interviewed in Zimbabwe, only one was still in school (Robson, 2006). The lack of quantitative work on this topic means that the scale of premature exit from school as a direct result of caring activities remains unknown. Studies from different parts of Africa suggest that the chances of dropping out are slightly greater amongst child carers, but caring has a greater impact on regular attendance, timeliness and the completion of homework in South Africa (Barnard, 2002), Zimbabwe (Bauman et al., 2006:64), Namibia (Thomas 2006:3183) Tanzania (Robson et al, 2006: 101), Uganda (ILO & Government of Uganda, 2004) and Western Kenya (Skovdal et al, forthcoming).

These findings indicate that children are attempting to combine their schooling and care responsibilities, and that many ‘succeed’ in terms of persisting to attend. However, irregular attendance and incomplete homework, perhaps combined with exhaustion in the classroom, are likely to undermine the quality of their learning experience and thus their educational chances. Children in their late teens caring for sick adults in Western Kenya reported that their greatest source of anxiety in relation to their care role was their irregular school attendance and its likely impact on their overall well-being in the long term (Skovdal et al, forthcoming).

In her research amongst adult carers in Namibia, Thomas (2006) notes that the national school policy forbids children to miss school in order to care for a sick family member. It is therefore difficult to envisage any support from teachers or other services for child carers who miss periods of school or struggle to keep up (see section 12.3 below).

The orphanhood literature contains a body of recent research utilizing longitudinal data and demographic modelling showing that parental death has a significant negative effect on school enrolment and educational attainment, particularly amongst older children, in Uganda (Yamano, Shimamura and Sserunkuuma 2006), South Africa (Case and Ardington 2006) and elsewhere in the African continent (Case, Paxton and Abledinger 2004). Significantly, longitudinal studies in Tanzania (Ainsworth, Beegle, and Koda 2005) and Kenya (Evans and Miguel 2007) found that school dropout often occurred *prior* to the death of the parent; and posited these to result from changes in the household income, increased expenditures on health, and shifts in labour demands following the onset of the parent's illness. The precise re-allocations of labour including potential caring roles for children were not investigated. A different study in northern Uganda illuminates labour dynamics operating in a specific area that impact education (Oleke et al., 2006). Very few of the girls aged 5 to 12 years working as domestic servants for relatives in the city attend school, in part because their work throughout the day is seen as payment for bed and board (ibid.: 276).

Living with a sick carer was also found to have an adverse impact on school attendance in Soweto, a large impoverished urban neighbourhood in South Africa (Gray et al, 2006). Conversely however, a comprehensive quantitative and qualitative study in Malawi found that women's real and perceived anticipation of future health shocks have a positive effect on their children's school enrolment and educational attainment (Grant 2008). This study identifies the high value placed on education by parents, a sentiment that is prevalent throughout southern Africa and documented in AIDS-affected populations in Lesotho (van Blerk and Ansell 2006) and South Africa (De Lannoy 2005). Grant found that "women were motivated to invest in their children's education when they anticipate future AIDS-related poor health", and "education was cited by parents as the most common strategy for protecting the well-being of their children", particularly in the event of parental death (ibid. 1622). Grant's discovery of a close link between parental knowledge of their likely future health status (that accompanied HIV testing and knowing their status) prompts her to conclude that interventions targeting health uncertainty, such as HIV testing programs, may make a significant contribution to maintaining children's educational attainment in communities affected by HIV/AIDS.

### **9.5 Social well-being and psycho-social outcomes**

The literature on the social well-being of child carers indicates serious compromises to psychosocial outcomes that arise from the opportunity costs entailed in time-consuming caring tasks, and from social isolation triggered by one or more factors including the long-term nature of AIDS-related illness, the capacity of social networks to offer support to children, culturally informed practices of reciprocity within social networks and stigmatizing attitudes towards people affected by AIDS.

Loss of friends and social isolation were reported by young carers in Zimbabwe, as was the fact that adults usually decided that they should leave school and did not consult children (Robson et al, 2006: 104). The same study found that short term caring can have profound

social outcomes, stigmatization and isolation reported in Zimbabwe once 'care role' ceases upon death of recipient: "They were carers for a matter of weeks, or months, and more often than not the death of their care recipient sooner, or later, brought freedom and relief from caregiving, but also deep personal sadness at the loss of a ...close relative, as well as grief and possibly feelings of regret or guilt. They may also have to face stigma and judgmental attitudes if it is known that the care recipient died of AIDS." (ibid.:105).

These scholars report that AIDS remains powerfully stigmatized in Zimbabwe, as in much of sub-Saharan Africa. The prevalence and impact of AIDS-related stigma varies over space and time, the latter probably explaining why Kaleeba et al. (1991 cited in Robson et al 2006) report high levels of stigma in Uganda, whereas Akintola (2004) asserts their significant decline over the last decade: "Many of the people interviewed in Uganda indicated that though stigma exists in the country, it is not as pronounced as it used to be years back" and that "Most of the staff of the organisations interviewed stated that stigma is virtually non-existent." (ibid.:30) That said, marked urban/rural differences appear to persist: Anecdotal evidence is given of urban immigrants in Uganda refusing to contact their families in the rural areas because they were ashamed to go back home with a disease instead of achieving a better life in the city (Akintola, 2004:30). As a result, they faced isolation from families and the prospect of death in the city rather than the possibility of returning to their natal villages.

Research amongst adult carers in the Caprivi region of Namibia (where HIV rates are 43%) showed that stigma can also be caused and exacerbated by prevailing attitudes towards dependence and reciprocity, with carers' feelings of being tainted or discounted by others tending to increase at times when patients were too sick to be able to contribute to livelihood and familial activities (Thomas 2006:3175). Women carers became lonely and isolated, firstly because they were less and less able to invest in social capital networks, and secondly when they were adversely impacted by stigma directed toward the ill person. And because caring takes place within the private sphere of the home, these women considered it unusual and even futile to speak with others about their loneliness and anxiety (ibid:3181). This study highlights the importance of contextualising stigma and "recognizing that the fatigue and burden of care (entailed in AIDS-related sickness) challenges the household's ability to provide treatment and support" and thereby further contributing to discriminatory attitudes and social isolation (ibid.). Moreover, the psychological vulnerabilities identified by women carers highlight the potential emotional burden on children and its consequences for their long-term mental well-being (as discussed in section 9.2).

The terminal nature of AIDS can also play a role here: In both Namibia (ibid.) and Uganda (Ntozi, 1997), adult carers reported that support networks became less forthcoming when HIV/AIDS was known or suspected since caring is considered a 'waste of time' when the patient will not recover. In the case of child carers, the question remains as to whether prevailing attitudes towards children and their vulnerabilities act to counter these with efforts to engage with and support children who care.

One study in Nigeria documents positive attitudes amongst Muslim men towards parentless children and the fostering of children after orphanhood (Ohnishi et al 2008, see appendix 2). In the Caprivi region of Namibia "taking in orphans plays a key role in 'closing' the stigma and tension and facilitating the re-establishment of key social support networks" because orphans are considered a future source of labour (Thomas 2006: 3185-6). What is not made

clear is whether these sympathetic and supportive attitudes begin before a parent dies, or whether they are specifically attached to orphaning.

Ethnographic research indicates that positive attitudes towards vulnerable children, particularly orphans, do not guarantee children's inclusion in and protection by a network of kin or neighbours. Roalkvam (2005) studied a small group of children caring for their younger siblings in child-only homes in a semi-rural area outside Harare in Zimbabwe. She found them to be highly socially isolated and self-sufficient, and argues that social institutions, such as the practice of lobola (financial exchange at marriage) and inter-lineage kin relationships, have functioned to protect children in cases of parental death for many generations. The reason why, in her estimation, there are so many child headed-households that receive little or no support from kin networks is the combined effect of the scale of HIV and AIDS-related illness that puts unprecedented pressure on these institutions, and the fact that adults die in the prime of life when the very kin relationships that should ensure children's protection are still being made (for example lobola may still be left unpaid, thereby creating ambiguity in who has responsibility for children whose parents have died).

A very different picture of social inclusion is portrayed by a recent analysis of child-only households in South Africa showing that three-quarters of these households rely on remittances from relatives, indicating their inclusion within and dependence upon broader kin networks. It is worth noting that the latter study is representative of the general picture within South Africa because it drew on data collected by two national household surveys over a seven year period. It is not possible to tell the extent to which findings in the Zimbabwean ethnographic work are locally specific. However, a second qualitative study in Zimbabwe showed orphaned children to have weaker family ties and drew two conclusions. The first was that the strength of kin networks was highly variable over space and time, but always under immense strain. The second was that while alternative social institutions existed (including neighbourly and peer networks), children did not have the knowledge or social capital to engage reciprocally in these in ways that would provide them material support and greater social capital.

It is not only cultural notions of childhood vulnerability that stand to influence the extent to which children caring for sick adults or younger siblings are included in and protected by social networks. Culturally-informed perceptions of the motherhood role can also play a part in this relationship because these can lead to anxiety amongst sick mothers regarding their inability to fulfil this role adequately, and resulting compromises in the quality of care available to their children. As noted earlier, the quality of relationship between adult carers and their children, even and especially when adults are sick, is a primary mediator in child outcomes.

Ethnographic work in Namibia (Thomas 2006) and South Africa (Bray and Brandt 2006; Bray et al., forthcoming) finds that motherhood in both places, as in much of sub-Saharan Africa, is accorded significant status and value. AIDS-sick mothers in Namibia expressed concerns regarding the health and care that their children were receiving, and their inability to provide adequately for them whilst they were ill (Thomas 2006:3183). Xhosa-speaking women living in poor neighbourhoods outside Cape Town who were on ART and intermittently unwell recognized that their anxiety around ensuring the health, nourishment and schooling of their children during periods of sickness, and once they had died, undermined their mental health and compromised the care they were able to give their children (Bray and Brandt 2006).

Some reported that they no longer had the mental energy to play with their young children, and others were hesitant to engage with their teenagers around issues of well-being because they were uncertain about whether and how to disclose their status, or fearful of their teenager's response. At the same time, when mothers with AIDS were physically well enough, they responded to their personal priorities to care for their children pro-actively and practically, for example enrolling children in better schools (as noted in Malawi, see the preceding section), and making agreements with their own parents or siblings about the child's future home.

Deteriorating health rendered women in Cape Town disempowered with regards to their ascribed role in the family and community, which increased the possibility of their emotional withdrawal from their children. This research suggests that the emotional connections between children and their sick mothers may be complex and fraught prior to and during a period where the child takes on more caring responsibilities. Should sick mothers experience greater physical pain, social isolation and loneliness – all of which are likely in the context of stigma, witchcraft and/or widely dispersed homesteads (see Thomas 2006:3185), their deteriorating mental health is likely to increase the psychological burden on child carers considerably.

#### **9. 6 Positive impacts of caring**

I round off my analysis of child outcomes by summarising documented evidence of the benefits to children of playing a caring role in sub-Saharan Africa. My intention is that this will enable an approach to child caring that is based on an interrogation of resilience which, as Becker (2007) suggested, stands to facilitate research, policy and programming decisions that are responsive to existing strengths and carefully target factors that undermine these.

The benefits to child well-being brought by caring that have been identified in research to date are primarily social and emotional, with implications for positive mental health and life-skills. Child carers and their AIDS-sick mothers in Mutare, Zimbabwe, like their counterparts in New York, agreed that the child can handle their assigned chores, and most also agreed that the child is more capable than peers because he or she has responsibilities for chores (Bauman et al. 2006:63). Growing up, becoming strong, taking on responsibility, contributing to the household and having the opportunity to mature were some of the benefits of caring listed by children caring for sick adults in Zimbabwe (Robson et al, 2006) and Western Kenya (Skovdal et al, forthcoming) and those caring for young children in South Africa (Donald & Clacherty, 2005). Others were learning new skills (e.g. listening, patience and home nursing skills) and enjoying close loving relationships with care recipient in which they shared stories and life experiences, and developed attachments. These studies also identified emotional maturity and pride in caring amongst the young carers, as well as benefits for young carers' households. Children with a primary care role usually perform the spectrum of domestic tasks that would require labour regardless of whether there is illness in the home. This means that other household members are free to work for an income.

Comparative work in Tanzania and the UK concluded that many children felt they had gained from their caring responsibilities in terms of closer relationships with their parent/relative with HIV, siblings and other family members and felt that they had become more independent, mature and had developed greater emotional resilience and knowledge and understanding about HIV/AIDS (Evans and Becker, 2007).

Children's subjective analyses of the benefits of caring convey a significant contributor to their *current* well-being: positive perception of one's own position comprise an important component of well-being that is often overlooked. That said, Robson et al (2006:104) point out the possibility that children who identify the positives are, consciously or sub-consciously, enabling their basic psychological survival in a bleak and onerous scenario. Listing the benefits of caring allows individuals to "resist, subvert, or even contest, their exclusion" (ibid. 2006: 106), but their longer-term implications remain unknown.

The extent to which perceived benefits translate into measurable *long-term* benefits in other dimensions of well-being, for example life skills and psychological health, is more difficult to measure because studies to date have relied on cross-sectional data. Existing research does however point to significant change over time in children's experiences of caring and their perceptions of its costs and benefits. Firstly, and particularly when AIDS underlies sickness, the care recipient's health fluctuates and often deteriorates rapidly (Thomas 2006). Secondly, as children grow older, care-related disruption to their schooling (see above) is likely to have a more serious impact on their long-term well-being (a key concern of older child carers in Western Kenya, see Skovdal et al, forthcoming). Thirdly, the capacity of kin and neighbourly networks to support children fluctuates over time and is vulnerable to environmental conditions, such as drought (ibid.)

We still do not know, but perhaps should not under-estimate, the manner and extent to which positive experiences in the current caring role can independently or interactively protect children in the long term. It makes intuitive sense that children are better able to cope with bereavement and the changes in domestic arrangements that may follow if they have enjoyed close and trusting relationships with their sick relative, validation of their caring role by kin and neighbours, and access to material or emotional support through social networks. In this way, the caring role may strengthen children psychologically and socially in ways not available to children who witness chronic and debilitating sickness in their parents while someone else cares. The younger siblings of children caring for sick adults are potentially highly vulnerable in this regard, as well as to the reduced capacities of the sick adult and older sibling to provide adequate care.

A number of studies point to the characteristics of children's domestic environment and individual personality that mediate whether caring is both perceived to be largely positive by children, and has no serious harmful effects on current well-being. The strength of parent-child relationships, and in the case of orphans their ties with wider family and neighbourhood were proved critical in Zimbabwe (Robson et al 2006) and South Africa (Henderson 2006). The "quality of the community and its ability to share resources" made a difference in Western Kenya (Skovdal et al, forthcoming). All three studies identified the role of children's resourcefulness in influencing outcomes, in particular their different abilities to negotiate community support. Such findings re-enforce the picture of child carers as part and parcel of the broader social fabric, both creative contributors to protective relationships and vulnerable to the reduced capacities of individuals and their connectivity. These findings suggest that resilience in child carers can be bolstered through the strengthening of key social relationships (and in certain settings, increasing children's knowledge of potential sources of support).

## 10. Analytical summary and policy implications

In preceding sections, I have purposefully distinguished between research data on child carers, children living with sick parents and orphaned children for three reasons. The first is to avoid conflating these experiences and mis-representing any causal pathways related to well-being. The second is to enrich our knowledge of the contexts in which these occur (by drawing on as large a body of material as possible). And the third is to start building an understanding of the parallel and differing impacts of each experience on child well-being, and hence to sharpen our focus on where 'caring' fits.

Looking across the three scenarios represented in the whole data set, consistencies are evident in the defining characteristics of 'protective' or ameliorative mechanisms, by which children can experience positive outcomes despite exposure to extreme stressors (i.e. whether these are associated with caring, living with a sick parent, and/or orphanhood):

- a. The quality of relationship between child and adult is critical as an end in itself (i.e. to children still feeling cared for, for the successful negotiation of role reversals as adult health declines), and as a mediator to children's inclusion in social networks
- b. The provision of health care or social grants is very rare, but when available plays a critical role in sustaining adult care roles and strengthening inter-generational relationships when older people are ill or frail
- c. The capacity of social networks to provide food, sustain livelihood and ensure children and adults feel included in the community.

There are also striking parallels in the mechanisms that undermine well-being across the three scenarios. These, unsurprisingly, are experienced where the above protective factors are absent, or too weak:

- d. Economic impoverishment due to difficulties generating income or resources
- e. Invisible compromises to children's emotional well-being and mental health, and the risk that these are neglected in policy and intervention;
- f. The nature and severity of adult illness (particularly when a child's notional 'care-giver') is a mediator to child mental and physical health. As adult health declines, so does their capacity to care which undermines the quality of relationship between child and adult (point a above);
- g. Lack of knowledge; children living with sick adults, whether caring or not, generally have little, or no, knowledge of the illness of the person they are caring for and are generally not consulted about decisions (e.g. whether they are withdrawn from school, Robson et al. 2006:100);
- h. Gender and age-based discrimination, and exploitation.

The data currently available point to some unique aspects to children's caring roles in terms of well-being outcomes and the mediators in these:

- a. A heightened interdependence between child and sick adult as a result of the reciprocal nature of care;
- b. Raised sense of responsibility, especially at an emotional level and in terms of meeting daily household needs, which begs questions about 'parentification' and its

implications (positive ones may include raised self-esteem through an active care role, and negative implications could entail diminished self-esteem through feelings of failing to provide 'good enough' care);

- c. Anticipating loss of a parent, or another close relative, often without full knowledge of the illness, its transmission or its implications for the rest of the family;
- d. Excessive time demands on children that hinder their ability to complete homework, attend school regularly and move through the grades.

With the exception of the last, all four of these mechanisms operate at the level of interpersonal relationships, thereby suggesting the importance of support to the relationship between children and their 'caring' adults, who may in time become those for whom children care.

A key finding of recent research in 6 sites in Zimbabwe was that, "while many orphaned teenagers desire direct communication with adults about parental illness and death, adults themselves—whether the sick parent, other relatives in the household or a caregiver following parental loss—are often ill-equipped to identify and manage children's distress positively" (Wood et al, 2006:1923). This team of researchers suggest that the most effective way of creating an enabling environment for orphans, is to build the capacity of key adults in orphans' lives, particularly surviving relatives, caregivers, and teachers so that they are able to address emotional issues relating to parental loss constructively. This would entail a shift away from usual psychosocial support approaches that target children, to one that is more inclusive of the adult generations. A similar logic motivated a major initiative by the Christian Children's Fund in Angola to enhance the capacities of adults to recognize and respond to war-related trauma in children, and thus to bolster these children's psycho-social well-being (Wessells and Monteiro, 2000:179).

### **10.1 What influences the relationship between children and their sick parents?**

The question that now becomes important is what can best protect and bolster positive relationships between children and their parents or parent-figures in times of extreme economic stress and debilitating illness? Two broad answers are suggested in my analysis and explored in this section. First, inclusion in social networks and second, spaces to talk and to grieve.

Psychologists agree that social support networks are essential in creating an environment which protects children's health and promotes their development, whether the stressors are high rates of serious illness or the after-effects of war (Wessells & Monteiro, 2000). Support networks within the family, school and wider community play a role in bolstering children and their close relatives' resilience and mitigating the negative impacts of young caregiving and HIV/AIDS on households. The extended family is often assumed to be the primary social network that offers protection and emotional support to parents and their children.

Following their research in Rwanda, Thurman et al (2006) suggest that "although advice, guidance and comfort are free commodities, communities strained by genocide, HIV/AIDS, mistrust and decreasing resources may be less willing to provide care and protection to vulnerable children in their midst" (ibid.: 227). The effects of conflict and/or severe economic hardship in Angola, Uganda and Zimbabwe may have influenced the social fabric in similar ways (See Roalkvam 2005 in appendix 2). In such contexts, family-centred

interventions may not be ideal in supporting the parent-child relationship, and interventions targeting villages or sections of its population may prove more productive in re-building social capital. In targeting youth, one could build on the positive function of strong peer relationships in offering support. And should caring adults be available to serve as mentors to child carers, these relationships could be stabilized and bolstered, thereby promoting resilience (Masten & Coatsworth, 1998 in Thurman et al 2006).

Very little work exists on understandings of grief and bereavement among African children, or on adults' responses to orphans' psychological difficulties (Wood et al, 2005). Research in six urban and rural sites in Zimbabwe found that teenagers' experiences of loss are highly complex and dependent on developmental stage, resilience, quality of care, and social support networks (ibid.). In addition, they often include a progression of experiences from the onset of a parent's or caregiver's illness, through to the aftermath of death. Factors that rendered AIDS-related bereavement especially complicated and difficult to accommodate amongst teenagers in Zimbabwe stand to exert a powerful influence in the other 3 countries under review, because they relate to the progression of HIV-related sickness and to stigma that emerges in various ways across the region. These factors include the grief a child may feel prior to the actual death in the form of 'anticipatory loss', their witness of debilitating illness, the compromised parenting that accompanies this illness, and the greater likelihood that AIDS-related death is more stigmatized and likely to lead to premature death of parents (ibid.:1924). Amongst a group of 193 children from the Rakai district of Uganda who were subsequently orphaned, the majority reported feelings of hopelessness or anger when their parents became sick, and were scared that their parents would die (Sengendo and Nambi, 1997). Arguably, children who care for very sick parents until their death, and then assume responsibility for younger siblings, have an even closer encounter with these trajectories.

Death, in South Africa (Posel 2004; Dawes et al. 2004) and Zimbabwe (Wood et al. 2006), is considered to be an inappropriate topic for children, meaning that in many homes the subject is not discussed in their presence. In urban Zambia (FHI, 2003), many children described not being allowed to visit the graves of parents, nor even in some cases knowing where their parents were buried. The exclusion of children from conversations and actions that deal with matters of illness and death caused Zimbabwean teenagers' to harbour frustration and anger against relatives who knew the facts but chose not to tell the truth (Wood et al.; 1928). One problem that results from this veil of silence around death is that children internalized their problems, which then manifest in physical symptoms like headaches and stomach aches. This then fed the adult tendency to interpret children's silent responses as positive signs of coping, and to remain unaware of the distress and psychological turmoil that is occurring.

Broad-based psychological understanding of bereavement suggests that "constructive grieving involves accepting the reality of the loss, experiencing its pain, adjusting to a changed environment, and relocating the deceased within one's life, including 'memorialising' the person." (Wood et al:1931). The quality and extent of family and community support following bereavement also impacts on child well-being (Wild, 2001), and the age of a child influences their response to death as well as their communication needs (ANECCA, 2004 in ibid.). For these reasons, the team who conducted research in Zimbabwe advocate psycho-social interventions that involve children and adults in conversation, for example the memory box or book work begun in Uganda in 1997 that is now being rolled out through

local initiatives supported by REPSSI (a regional non-profit organisation aiming to mitigate the psycho-social impact of HIV and AIDS on children).

The Zimbabwean evidence of very limited adult awareness of the effects of grief on children, and of equally limited adult confidence or skills in discussing death and grief with children, points to a situation in which bereavement and its psychological consequences for children (and adults) are largely neglected, and stand to seriously undermine long-term well-being. Parallel empirical work has not been done in other countries, but it can of course be the case that children are 'told' about sickness and death in other indirect means, for example through songs, the actions of relatives or household rituals (Henderson, work in progress; Dawes et al. 2004). Perhaps the intensity and prevalence of AIDS has created a situation where children are coming face to face with ill and dying relatives much more frequently, and these forms of diffuse knowledge sharing are not sufficient to convey the information that they need to understand and manage their situation?

Where culturally-validated preferences to exclude children from discussions of illness or death persist, and stigma adds further pressure on everyone to maintain silence, it is probable that unresolved grief and related frustrations are a significant risk factor to all children who witness parental illness and death. As yet, we do not know enough about the various spaces (in discourse, song, story, ritual) available to children and adults in which to communicate about illness and death, nor whether these encourage or allow children to ask questions or express feeling.

While attitudes and practices that shore up silence between generations appear pervasive in the region, there is preliminary evidence from South Africa of challenges to, and changes in, so-called 'traditional' ideas about the age at which children are able to understand the meaning of illness and death, and the appropriate age at which a child can be part of discussion on these topics (Dawes et al 2004). Xhosa-speaking mothers in a poor peri-urban township outside Cape Town said that their perceptions of when and how to communicate with their own children are changing having witnessed a 'surprising' level of awareness and understanding of AIDS amongst very young children in the neighbourhood. The indications are that these shifts in perception and behaviour are prompted in part by much higher rates of adult illness and death (that children cannot fail to observe and therefore prompt some kind of explanation), as well as the more visible presence of AIDS-related services and a greater willingness amongst adults to discuss the disease and its implications more openly.

These findings alert us to the possibilities for significant changes in social attitudes and behaviour towards children that arise in response to the profound impact of large-scale illness, death and/or the injection of services related to these phenomena. In the same way, what might at the outset appear like very entrenched attitudes towards children who care may in fact be moulded quite rapidly by changes in socio-economic or epidemiological trends, state policy or service provision.

## 11. What do national policies say about child caring?

This section provides an overview and analysis of where and how child caring fits into key policy and legislation in each country. I have focused on policy pertaining to children and HIV/AIDS, and in countries where little is yet developed for children, have turned to

broader AIDS policy. [The overview is not exhaustive as certain policy documents were not available electronically.]

In all four countries, the development process for national policy and plans for orphans and vulnerable children was accelerated by the Rapid Assessment, Analysis and Action Planning Process led by UNICEF in 2005, which aimed to scale up and improve the quality of the response to orphans and vulnerable children at national level and to fulfil commitments made by national governments through the UN Declaration of Commitment on HIV/AIDS. Save the Children (2006) reviewed this process within Southern Africa (including Angola and Zimbabwe) and noted achievements in relation to policy formation. The critical gap was found to be enforcing child protection and human rights laws, the absence of which was making orphans and vulnerable children more susceptible to poverty, stigma and discrimination. Governments attributed lack of enforcement of laws “to shortages of funding and lack of trained staff” (ibid.:2).

### **11.1 Angola**

Angola’s first National Strategic plan on HIV/AIDS was formulated in 2003 and designed for a 5-year period. The document recommends a revision in 2005 in light of predicted sharp increases in numbers of infection in an environment where people are highly mobile (but I could find no evidence of this revision). In summarising the impact of AIDS on the family, the NSP portrays children as recipients of care who place demands on adult time, lower productivity and contribute to increased impoverishment (p15). It then acknowledges the absence of data on the impact of HIV and AIDS on children or on family dynamics (ibid.). I am unaware of any major pieces of research commissioned by the government on this topic. Later the document suggests that educational outcomes are likely to be compromised, in part due to children, particularly girls, being required to stay at home to care for sick relatives or do domestic tasks (ibid.:21).

Care assistance to people living with HIV/AIDS is listed as one of the government’s priority areas (ibid.:27), but the NSP then acknowledges that in 2002 only one hospital had an HIV referral unit, and that this could not deliver even the basic sanitary and medical care. Specific plans as to how to improve HIV-related health care from this gravely low base are not given, nor is any mention made of ‘care assistance’ of psycho-social nature. Oblique references are later made to the work of NGOs in post-conflict psycho-social care that are suggestive of state assumptions or hopes that this role will continue and will address AIDS-related psycho-social outcomes (ibid.:31).

At its 37<sup>th</sup> Session in 2004, the Angola committee on the rights of the child commended the establishment of the National Policy for Orphans and Vulnerable Children to address immediate consequences of the armed conflict. It drew attention to a wide range of scenarios placing children at serious risk, but in no part of the summary document were children affected by HIV and AIDS mentioned. The persistent lack of a comprehensive national plan of action for all children in Angola was noted (<http://www.speakafrica.org/angola>).

According to UNICEF’s Inter-Agency Task Team on Children and AIDS (Kluckow, 2007), a National Plan of Action (NPA) was initiated in 2005 (1 year later than other 3 countries), and progress made in 2006 included the Government taking ownership and leadership within

the Rapid Assessment, Analysis and Planning process led by UNICEF (Kluckow 2007). The NPA was due to be approved during a stakeholders meeting to be in early 2007, and a monitoring and evaluation plan was to be drafted with assistance from UNICEF's Eastern and Southern Africa Regional Office. At the time of writing, this National Plan of Action had not materialised.

In terms of the nation's broader commitment to children's rights, Angola is a signatory to the UN Convention on the Rights of the Child and the African Charter on the Rights and Well-being of Children, but is the only country in Southern Africa not to have ratified the ILO Convention 182 on the Worst Forms of Child Labour. Significant challenges are apparent in aligning the state legal with international conventions that define children as those under 18 years of age. For example, in the 1975 Angolan Constitution, the term 'children and young people' is used without any age definition (Save the Children 2006:11).

The different, arguably 'slower' approach, taken by the Angolan government to policy development regarding children and HIV/AIDS can be linked to the prioritisation of post-conflict rehabilitation (including for example the development of a National Policy for Separated Children), lack of capacity in government policy departments and may indicate an absence of political will in this area. At no point do these policy documents make any reference to the probability that children's vulnerabilities relating to HIV/AIDS and those relating to post-war recovery are likely to be highly interdependent.

## **11.2 Nigeria**

Nigeria, like Uganda and Zimbabwe, developed a National Plan of Action (NPA) for Orphans and Vulnerable Children (OVC) through the UNICEF assisted process that began in 2004 and was officially launched in 2007. The NPA begins by trying to define vulnerability but, by combining standard definitions (used in the 2006 Save the Children analysis of childhood vulnerability in Southern Africa) and the views of children consulted, a long list of specific childhood circumstances are produced. Many of these have no evident link with HIV or AIDS, but they are incorporated into the scope of this policy document (perhaps because their identification by children is felt to give them due weight). Child caring is not mentioned, although both the standard definition and the list drawn up by children includes children living in households with terminally or chronically ill parent or caregiver, or with an elderly or frail grandparent or caregiver.

The implication here is that co-residence with sick or ailing relatives is the risk factor, although no supporting data appear available. Later in the document raised risks of domestic abuse and exploitation are mentioned for children whose parent is chronically ill (as well as those living with a relative, or who experience conflict in the home), but again, this assertion appears based on cumulative anecdotal evidence rather than empirical data. The onerous burden of domestic work born by a proportion of children who live with relatives is briefly mentioned. But acknowledgement that children may have a primary care responsibility for a sick or ailing relative is only made in a long list of diverse and ambitious recommendations pertaining to psychosocial support ("Skills building especially for Children affected by HIV and AIDS to cope with the role reversal of becoming caregivers and /or household heads should be given priority"), and in a paragraph about compromised access to education ("Children, particularly girls, living in households with chronically ill parents are taking on the role of "carers" and also shouldering the burden of the household tasks.")

Interestingly, those living in child-headed homes feature in the children's list of 'vulnerable children', but the NPA does not make any later reference to their caring roles or possible implications on well-being.

The NPA largely consists of long lists of 'findings' (derived from scant and non-referenced literature and a small consultation exercise with children and adults) and associated recommendations. These read rather like an extensive wish list, the items upon which are not grouped or prioritised. The costed "minimum care package for OVC" represents an attempt to prioritise. Tellingly, this includes educational support (financial assistance to keep children in schools), provision of basic material needs, health care and income support. The reader will recall that Nigeria has a much lower school attendance rate amongst orphans than the other 3 countries (see table 1). State health policy in Nigeria does not support free services for orphans and vulnerable children. One of the many recommendations made in the NPA is to "review health policy and consider providing health care services free to OVC".

The NPA makes no provision regarding the negative psycho-social impact of AIDS-related caring or orphanhood. Moreover, all the proposed interventions are directed at individual children, rather than at adults who care for them, families, communities or social systems. The specific targeting of orphans or other vulnerable children on the basis of AIDS related household problems has been critiqued owing to the possibility of increasing stigma and discrimination. The only exception to this in the Nigerian NPA is a proposed business grant to "OVC caregivers at household level".

Co-ordination of NPA processes and implementation at a national level is, at least on paper, tightly defined. The Federal Ministry of Women Affairs chairs the implementing body (the National Stakeholders Forum) which incorporates a large number of government departments, INGOs and civil society bodies. State and local government level co-ordination mechanisms are however almost non-existent, and NGO actors are described as operating largely independently without co-ordination.

The Nigerian NPA describes the broader legal and policy framework for the protection of vulnerable children as "uncoordinated and out of step with the country's obligations to international treaties and conventions on child rights". The 2003 Child Right's Act (modelled on the principles of the UNCRC) is operative in federal law, but has yet to be passed by the majority of states in the country. Moreover, this document does not have a section specifically addressing issues affecting children in the context of HIV and AIDS. Very frankly, the NPA for OVC asserts that "Even in states where the Bill has been passed the capacity and commitment to translate this into concrete action that can be monitored and evaluated is entirely lacking".

Nigeria's Guidelines and Standards of Care was also produced in 2007 by the Federal Ministry of Women's Affairs with contributions from a variety of international NGOs, UNICEF, national NGOs, and other agencies. This document also reads like a long 'wish list', and advocates supporting family and communities to provide the best possible care in each setting.

This document states that the priority target groups for state assistance will include, but not be limited to the below. A careful look at this list quickly tells us that children who care do not constitute a ‘priority group’ *per se*, but that they could experience one or more of these risks either alongside, or owing to, their caring role:

1. Children suffering abuse and neglect, including sexual abuse and exploitation, physical violence, emotional and psychological abuse and neglect.
2. Children involved in hazardous labour in both formal and informal sectors, including slavery /bonded labour and child trafficking.
3. Children in need of alternative family care or family reunification, including child parents, children in child headed households, the homeless, unaccompanied children, and children in institutional care.
4. Children affected by armed conflict and other forms of organized violence, including abducted children, children in displaced camps and refugee settlements, children in organized crime networks or gangs and children recruited by rebel groups.

Pertinent here is the absence of any discussion of care as ‘work’; the guidelines include a highlighted reminder to its authors to define ‘hazardous labour’<sup>5</sup>, but there is no indication in other Nigerian policy documents that caring may be considered here. Rather, care is presented as a demand on time that prevents children from attending school, or as incurring a ‘role reversal’ between children and a parent or guardian (the precise meaning within diverse Nigerian socio-cultural contexts or its psychological consequences are not explored).

### 11.3 Uganda

Accompanying Uganda’s second National Strategic Plan on HIV/AIDS (2008 to 2012) are plans, guidelines and standard forms needed for performance measurement. This cluster of documents, all “produced in a participatory, consultative way” illustrate the much more comprehensive portfolio of HIV-related policy documents than found in Angola or Nigeria. Acknowledged in the document’s preface is the inclusion of a stronger evidence base supporting the anecdotal knowledge relied on previously in Uganda (and evident in attempts to frame policy in Nigeria and Angola).

The Ugandan NSP makes explicit that prevention of new infections is the policy priority, while at the same time “ensuring massive commitment to care, treatment and social support”. It proposes to increase “the proportion of OVCs receiving public support to 54%” noting that prioritising prevention would in the long term reduce sickness and death rates, and numbers of OVC. Data and associated policy statements refer primarily to ‘orphans’, noting their forced entry into paid work, early marriage or household headship, and their increased likelihood of early sexual debut (a concern that appears to be linked to the onus on preventing new infections). Stating that ‘no family has been left untouched’, the NSP then cites “girl children (who) often have take up the burden of illness care, leading to a high

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<sup>5</sup> I recommend that the final version of the NPA is checked in the unlikely event that the definition of ‘hazardous labour’ has been extended to include caring.

drop-out from school<sup>6</sup>” and higher incidence of “early marriage, discrimination, property grabbing and disinheritance” for children in AIDS-affected families. No supporting data are given for any of these trends, confirming the research gaps noted earlier in this review.

Increased support for OVCs is noted as a key achievement of Uganda’s first NSP (ibid.:14), but it is unclear whether this amounts to more than increased school enrolment driven primarily by universal primary education.

The second NSP lays out its goal to show positive change in the way individuals, households and communities cope with the effects of HIV and AIDS that stand to impact on child carers. Increased provision of quality psychosocial support to infected adults and OVC (particularly women and children), access to basic services, and provision of non-tuition related educational costs for OVC are listed as key objectives towards achieving this goal. While these objectives appear valid, important and time-consuming groundwork has yet to be done, for example to document existing psychosocial support mechanisms in order to identify gaps, and to provide appropriate policy recommendations and guidelines in this area. Moreover, precise mechanisms for achieving these are not yet clear. How, for example, will the non-tuition costs and essential needs related to formal schooling be met for OVC? If this process entails the selection of certain children, on what grounds will this be made and will child carers be included?

The institutional mechanisms established in Uganda appear stronger than those of most other countries in the region. A comprehensive legal and institutional framework for protecting children was established in the early 1990s through the development of the 1993 Ugandan National Programme of Actions for Children (UNPAC) based on the UN CRC, and the 1996 Uganda Children Statute.

Moreover, the political priority given to AIDS is indicated by the Ugandan AIDS Commission’s location within the Office of the President. Recently, the government adopted institutionalized co-ordination mechanisms for managing HIV and AIDS at sub-national level, involving political and technical leaders (UAC 2007:33), but the efficacy of these mechanisms is still low owing to multiple and serious institutional challenges within districts, including lack of equipped personnel, guidelines, adequate infrastructure and financial resources. The annual Joint AIDS Review (JAR) provides an important participatory forum in which all state and civil society actors can come together to review the performance of the previous year’s response to AIDS.

Acknowledging the large gaps in knowledge around the mechanisms and impacts of AIDS, and particularly regarding the effectiveness of responses to date, the Ugandan NSP proposes its potential role to drive and co-ordinate the research agenda and defines priority research areas as risk factors and drivers of the epidemic, social support, and care and treatment. The nature and impact of child caring would theoretically be covered by the latter two foci, but the NSP does not specify whether and how it will be able to take these forward.

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<sup>6</sup> This sentence is drawn directly from the opening section of the 2004 report on child labour and HIV/AIDS (ILO and Ministry of Gender, Labour and Social Development, Government of Uganda). The report does not provide evidence to support this conclusion.

Uganda's first National Orphans and other Vulnerable Children Policy was drafted in 2004 with assistance from UNICEF and USAID, and is held in the Ministry of Gender, Labour and Social Development. It is an explicitly rights-based document that foregrounds principles of respect, participation, age-appropriate responses and assuring that family and community are the first line of response.

Child carers are identified as a vulnerable group (and thereby within this policy) only in the context of some orphans becoming household heads (ibid.3). The policy states that its primary focus is on "the most vulnerable children who are without families and may not be orphans, with the intention of re-integrating them back into the family", and secondarily "on the most needy households of adults and children that may or may not contain an orphan". Children caring for sick or frail adult relatives fall outside the first priority group but are likely to be encompassed in the second. Consideration of the processes linking adult illness, care by children and orphanhood (discussed in section 7) appear to have been overlooked in this policy document, as in others in the four countries under review. One of the proposed policy strategies is however to "promote awareness of the impact of vulnerability on male and female children who are care givers", suggesting some awareness of the carer role and variation in its implications for child well-being.

The subsequent National Strategic Programme Plan for Implementation 2006-2010 (NSPPI) was developed in consultation with a range of state and civil society actors during 2004. It also asserts the priority focus on "vulnerable children needing re-integration into caring adult-headed families", and includes those living with child-headed households (along with street children, unaccompanied working children, children displaced through conflict and those living in failing institutions). The second priority, "vulnerable households", stands to encompass provision for child carers given that one target population is "households with orphans and other vulnerable children in which the head of household, caregiver or children is chronically ill or living with HIV/AIDS and the poverty status of the household is in the neediest category as determined by the community in which they live".

Research evidence analysed earlier in this review suggests that services to support the physical, economic and psycho-social well-being of sick adults stand to significantly enhance the well-being of child carers. Thus, the strength of the Ugandan NPA and accompanying NSPPI lies in their few, concrete objectives that are orientated around the provision of basic services for vulnerable children *and* their families, namely:

- To ensure that the legal, policy, and institutional framework for child protection is developed and strengthened at all levels;
- To ensure that orphans, vulnerable children and their families access basic essential services package;
- To ensure that resources for interventions that benefit orphans and other vulnerable children are mobilised and efficiently utilized; and
- To ensure that the capacity of duty-bearers for orphans and other vulnerable children to provide essential services is enhanced.

The Ugandan Constitution (1995) provides special protection to children in general and vulnerable children in particular, including specific mention of the rights of children to know and to be cared for by their parents or guardians, access medical treatment, and be

protected from all forms of exploitation and abuse. There is a logical link between this provision and the NSP focus on 're-integrating' children into family settings. Of concern however, is the undefined specification that these should be 'caring' families. Might families in which the only adult 'care-giver' is chronically sick, and a child is looking after this person, be defined as 'uncaring'? And might this policy unwittingly support the removal of children from such households, thereby undermining or even preventing the relationship between child and parent/guardian that research shows to be so critical to child well-being? The constitutional provision cited above can be used to avoid this risk, precisely because it accords children rights to "know and cared for by their parents or guardians" without placing conditions on their capacities to care.

The policy recommendations made in the joint ILO and Ugandan government report on child labour and HIV AIDS (2004) include steps to link the draft child labour policy with the NPA for OVC. Currently, there is no obvious synergy. Achieving this aim will require a re-consideration of caring as a form of work by those working with the NPA, as well as attention to the interpersonal nature of care (and its resulting social and psychological benefits) in the finalisation of child labour policy. If caring is defined as 'hazardous work', then it may follow that child carers fall by default into the category of children needing to be 're-integrated' before the appropriateness of this response is examined very carefully.

Further recommendations of relevance to child carers are to support 'orphans' to keep them in school, and to strengthen special educational schemes such as Complimentary Opportunities for Primary Education (COPE) catering for children who have to work to survive (and in doing so to ensure that there is a balance between school and work and protection from hazardous work).

#### **11.4 Zimbabwe**

Zimbabwe has a plethora of policies and legislation relating to children and AIDS: The National Orphan Care Policy and the National AIDS Policy were both adopted in 1999. There is also a National Strategy on Children in Difficult Circumstances (not available to me, but should be consulted). Legislation includes the Children's Act (amended in 2001), the Children's Protection and Adoption Act and its Amendment, the Guardianship of Minors Act, the Maintenance Act, the Child Abduction Act and the 2004 Education Act. Policy and provision for children during the late 1990s appears to have been strong. The National Orphan Care Policy established a partnership between government ministries and private voluntary organisations, the community, faith based organisations, traditional institutions and local and international NGOs. These partners collaborated to advocate on children's behalf and respond to their needs through Child Protection Committees that were established at all levels from village through to national. The more recent NPA for OVC seeks to support this framework, but makes no comment as to how the recent socio-political landscape has affected these structures.

The precise authorship of Zimbabwe's 2004 National Plan of Action for Orphans and Vulnerable Children is not clear, nor is the source of its instigation. The document refers to support from the Social Services Action Committee of the Cabinet (SSACC) and a national stakeholder conference prior to its completion. The first of its stated strategies is to establish a National Secretariat to co-ordinate implementation and monitoring, but no

indication of where this will sit within the government structure is given until the appendices. There, it is stated that the mandate for this policy lies with the Ministry of Public Service, Labour and Social Welfare, which provides chairmanship to the SSACC, and will host the Secretariat at national and provincial levels.

When reading this document, one gets the sense that even more is left unsaid about the challenges of the political climate than in other contexts. The first page draws attention to Zimbabwe's strong legislative and policy framework support children and identifies very poor mobilization and co-ordination of resources as serious barriers to their implementation. Implicit here is the absence of political will to invest money or human resources in this, and perhaps other, social policies. The NPA does make direct reference to the problems arising from the country's dual legal system. As noted in section 9.3, customary law often holds sway, and serious contradictions can arise with statutory law regarding the rights of women and children that result in discrimination. The NPA is an explicitly rights-based document and spells out its guiding principles that align with articles in the UN Convention on the Rights of the Child. No mention is made of whether and how rights-based thinking, policy or programming on children operates in Zimbabwe.

The first page of the NPA also points to the country's corpus of civil society organizations providing services to children (200 were identified in and around three large cities) and recommends their increased co-ordination. It makes no reference to the possible effects of the recent political climate on the operation of these organizations.

The list of children defined as 'vulnerable' is long and contains many broad circumstances with no direct link to HIV and AIDS (children in remote areas, married children etc). Child carers do not feature<sup>7</sup>, but children with one or two chronically ill or deceased parents are on the list. Interestingly 'child parents' are included but children in child-only homes are not (perhaps because the latter are assumed to be orphaned). Reference is made to a UNICEF/USAID situation analysis of orphans and vulnerable children which found widespread "psycho-social distress, grief, stigma, discrimination, isolation, economic deprivation, loss of educational opportunity, burdensome domestic responsibilities, and fear for their own future". The analysis concluded that this group of children are the most vulnerable population in Zimbabwe (where AIDS rates are exceptionally high, and access to basic services seriously compromised by the "current socio-economic situation").

Children's caring roles receive scant attention in the NPA. When outlining a broader objective to increase health and nutritional education to OVC, a footnote specifies that the Health topics should prioritise children as care-givers to family members with HIV/AIDS.

Aside from the mobilization of resources and strengthening of co-ordination mentioned above, the NPA's core objectives are oriented around fulfilling the basic rights of children, namely to:

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<sup>7</sup> Similarly, child carers are not identified directly within broader government policy despite stated aims to 'support home-based care of HIV people' and 'improve protection for children in difficult circumstances and prevent situations that give rise to children in difficult circumstances' (Government of Zimbabwe 1992, 26, 66 cited in Robson 2000).

- Increase child participation where appropriate in all issues that concern them from community to national level, considering their evolving capacities;
- Increase the percentage of children with birth certificates by at least 25% by December 2005;
- Increase new school enrolment of OVC by at least 25% by December 2005, while ensuring retention of OVC in primary and secondary schools;
- Increase access to food, health services, and water and sanitation for all OVC by December 2005;
- Increase education on nutrition, health, and hygiene for all OVC by December 2005; and
- Reduce the number of children who live outside of a family environment by at least 25% by December 2005 (this includes children living without adult guidance, children living on the streets, and children in institutions).

The various ways which child carers (assuming that they are identified as ‘vulnerable’, or that implementation is in practice broad based), stand to benefit from efforts towards meeting these objectives is made evident in preceding sections of this review. In short, greater access to services, including for sick adults, could ease the burden of care; a basic identity document could be critical to future legal status or eligibility to inheritance, efforts to bolster school retention could assist child carers whose responsibilities in the home are very time consuming. And education on health issues, including the nature of the virus, transmission and prevention, could better enable children to protect themselves from infection while giving personal medical care, and adjust their expectations around the patient’s life chances thereby bolstering their resilience to future bereavement and change in their intimate, domestic sphere.

The one possible exception relates to the final objective. The potential positive or negative consequences on children caring for very sick adults, or highly dependent children, depends on the way in which “living without adult guidance” is interpreted. Clearly, children who are caring for their siblings in child-only homes fit this category, and action may be taken (possibly against their will) to place them in relatives’ homes, institutions or a combination of the two (thereby splitting the siblingship). ‘Living without adult guidance’ would appear to exclude children who live with and care for very sick or elderly relatives. However, if the broader legal framework is referred to, it is possible that more conservative notions of ‘guidance’ or ‘proper care’ may come into play and sanction the forced separation of sick parents and their children, and the consequent undermining of that very significant relationship during a critical period of illness.

There are components of the legislative framework that could be used to support the removal of children from homes where parents have chronic and debilitating sickness. The Children’s Protection and Adoption Act provides categories of children who need care (i.e. a replacement of their current domestic sphere) and includes those whose parents do not or are unfit to exercise proper care over them. And the Children’s Act (amended in 2002) includes the “power to bind over person having custody over a child to exercise proper care” which includes “being maintained in domestic circumstances detrimental to the child’s welfare”. In such scenario, the court may...”order the parent or guardian of the girl, child or young person to enter into his own recognisances, with or without such sureties and in such amount as the court thinks fit, that he will due care and supervision of the girl, child or young person.” This makes it possible for the court to insist on a legal agreement (perhaps

with money attached) with a guardian to take proper care of the child, and only on this basis is the child allowed to remain with him or her.

It remains very unlikely that cases for removing children from homes where they are caring will be brought to bear, in part due to poor implementation of policies and laws. There are however unresolved contradiction regarding the motivation to protect children, and at the same time uphold the rights of those who care to remain in a home where care could be argued to be 'compromised' on many fronts.

In its profile of the HIV/AIDS situation, alongside infection, death and orphanhood statistics, the NPA for OVC cites a 1999 survey showing that almost 40,000 children, including 26% of 10-14 year olds, in Zimbabwe are working<sup>8</sup> (MoPSLSW, CSO and ILO 1999). Owing to the absence of any discussion of child caring as a possible form of work, the inclusion of this figure is presumably meant to indicate the impacts of HIV and AIDS on the economic predicament of families and children. The definition of 'working children' used in this survey and document is 'Children under 15 years who work for money outside their own homes' (Gwaunza et al. 1994, 7, 18), meaning that child carers who remain at home and are unpaid do not qualify. The implications of defining child caring as 'child work' are considered in section 12.3. At this point, it is important to recognize that government policies aiming to reduce numbers of 'working children' are unlikely to affect the circumstances or well-being of child carers, because child caring – where recognized – is regarded as a welfare rather than a labour issue.

## 12. Critical Policy Issues

The aim of this section is to flag components of existing policy that do not marry with knowledge emerging from the body of research discussed earlier in the review. It is however difficult to pin-point these inconsistencies very precisely because the policies analysed above are inadequately referenced and do not appear to be informed by in-country research.

### 12.1 Responsiveness to country-specific and intra-country variation in children's circumstances and needs

One of the drawbacks of INGO driven regional initiatives to develop national policy is the possibility that a general 'blue-print' emerges and is adopted by countries without due attention to:

- a) the particular demographics of illness and poverty that stand to impact on care resources in the home: Who is getting sick where? How present and 'healthy' are the older generation?
- b) Variation in cultural dynamics that denote care roles: What do these mean for boys/girls? For younger/older children?
- c) The effects of war and displacement: How similar or different are the dynamics of care in immigrant communities?

More developed national policies (in Uganda and Zimbabwe) emphasise the provision of basic health and social services to all OVC, but just *how* this is to be achieved, and whether

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<sup>8</sup> . The absence of any reference to 'child caring' as work in any policy documents would imply that this survey did not investigate or record incidence of child-caring, perhaps because it did not fall within a pre-defined list of possible occupations in which children are engaged. The methodology and findings of the 1999 joint ILO and government report would be worth consulting.

such provision extends to adults in their home, is not made explicit. There is plentiful evidence that, if the state pursues the (cheaper) model of 'home-based care', for sick adults and/or vulnerable children, children living in communities where social and emotional resources are very stretched will shoulder a large portion of this 'community-caring' responsibility. Robson et al (2006) point out that such policies may be "genuinely motivated as a 'virtue from necessity'", perhaps in the context of little awareness of how they place additional demands on already over-stretched people. These researchers also point out that enthusiasm for 'home-based care' may arise from and sustain a different agenda, namely to use discourses of 'community' and 'participation' as a means of masking the need to address the larger question of why home-based care is all that is available to poor people, and consequently to question the macro-economic logic of state institutions and INGO partners.

The policies imply that children and their families are without services because these are too few and too remote. No mention is made of the possibility that other issues of access and quality may be at play, for example expense, stigma or barriers to women and children?

### **12.2 Health care models: Supportive or blind to children?**

Extensive analysis of health care systems in the four countries was beyond the scope of this review. However I have been alerted to a number of features of existing services and the models being rolled out in response to AIDS that appear to influence the support available for child carers.

For example, hospitals in Uganda typically offer semi-comprehensive care, which includes nursing and medical care, counselling, health education, and material and financial support. Importantly, volunteers from within communities are relied on for referrals, but professional medics and social workers provide the actual care. Uganda is the first and only African country so far that has made palliative care for people in the terminal stages of AIDS and cancer part of its national health plan. This decision was based on an increase in the incidence of cancers associated with HIV/AIDS (known as AIDS-defining cancers) and low levels of ART access.

Akintola (2004) states that "a major feature of most of the care organisations in Uganda is the professionalization of care", in other words a system where patients are provided with specialised medical care as well as support services by a team of medical professionals that usually consist of medical doctors, nurses, and other paramedics as well as religious personnel. In this model volunteers may identify sick people and provide some basic care, but they are supported by mobile medical and social teams. It is therefore one that appears to be responding appropriately by supporting the very low resource base of community members – adults and children alike – who are fit and available to care. But we do not know how broad-reaching it is. Does this model extend across the country, or is it only available in certain locations?

This approach is a far cry from the negligible health provision available in Angola, Nigeria, Zimbabwe and large portions of Uganda. Here, as elsewhere in southern Africa, home based care models can be blind to the existence and role of child carers, thereby creating a situation where a system that has been designed specifically to support local care networks, masks the presence of many vulnerable children. For example, staff working for a home-based care programme in Kwa-Zulu Natal, South Africa, spoke of a decision not to train

children to be caregivers, explaining that children are usually sent out when this training is being done. But, problems arise because “it is children who actually care for the sick when the volunteers leave despite the fact that they do not have any training.” (Akintola, 2004:28)

### **12.3 Rights-based approaches to child caring**

Defining an appropriate ‘rights-based’ approach to supporting child carers may be more difficult than first appears. The language of rights in respect of children who care is noticeably absent in the policy documents. The relative invisibility of child carers is a large part of the explanation. But the inherent tensions in defining and arguing for the rights of child carers may also play a part.

Care, by children, is on the one hand considered part and parcel of belonging to a family:

*“The understanding that care is given free of charge is at the heart of informal caring relationships, in contrast to professional, paid-for caring arrangements. Informal caring activities are often hidden, part of the private domain of the family, founded on love, attachment, duty and reciprocity, not on monetary exchange” (Becker and Silburn, 1999 in Becker 2007).*

Yet, on the other hand, care by children can be conceptualized as work, and even hazardous labour:

*“Recognising these activities as care work is to politicise and to make public the activities, roles, value and outcomes that characterise unpaid, family and hidden caregiving, and to identify these issues as concerns for social and public policy, and for social development.” (Becker, 2007)*

The latter is perceived as problematic because it violates children’s rights to protection and education. But if such ‘work’ is outlawed, children are denied their right to live amongst their family and fulfil a role therein, even if this ‘family’ comprises a sick parent.

### **12.4 Defining child caring as ‘child work’?**

Discussion of care by children as child ‘work’ is largely absent, except in Uganda where the ILO worked with the government to investigate the impacts of HIV on child work, including whether there is a ‘care burden’ or a marked increase in domestic work and household chores imposed on children due to the pandemic:

*“Of the 929 children from different households surveyed, 35% said they were involved in cooking or cleaning the house, and 5% said they performed child care but none reported care for a sick or frail relative.” (ILO 2004:24)*

This finding raises questions about possible factors that discourage children from reporting their involvement in the care of sick relatives, and about the possibility that children do not see care as ‘work’ and therefore did not report it in this section of the survey.

### **12.5 Rights-based approaches, cultural concordance and prioritization?**

As could be expected, none of the policy documents mention more fundamental philosophical similarities and differences in the way a rights-based approach frames childhood, and child-caring, as compared to culturally-informed values and attitudes that structure social life, and particularly inter-generational relationships, in the four countries.

Nor do they grapple with the dilemma that arises when the fulfilment of one right necessitates the violation of another. More worrying perhaps is that existing research has not engaged sufficiently with these issues either.

The 'right to education' is often given paramount status and can, intentionally or otherwise, undermine other rights of children who care. For example, Namibian school policy forbids children to miss school in order to care for a sick family member, presumably in an effort to discourage parents from keeping their children at home to help out. No-one has studied the precise effects of this policy, but it is plausible that teachers give minimal or no support to children who do miss periods of school because they are caring, thereby severely undermining their educational chances.

Contrastingly, children's rights to information and to a say in decisions affecting their lives are given no attention whatsoever, despite mounting evidence that ignorance is one of the main factors undermining children's resilience when caring.

### 13. Moving from policy to action

Globally, less than 10 percent of children orphaned and made vulnerable by AIDS are receiving some kind of public support (UNICEF, 2006 cited in Becker, 2007, Global perspectives). And perhaps more importantly, such support tends to be clustered, leaving large areas of some countries devoid of any such assistance. This figure indicates that support is available to an even smaller proportion of children who are caring for sick relatives. Why then, is this the case?

- An absence of the necessary synergy between community-rooted responses and international and national political will;
- Psycho-social health has been recognized as a priority, but little has been achieved in terms of planning and realizing the scale of psycho-social interventions;
- A background of chronic and deepening poverty, capacity limitations and political indifference at all levels (Phiri and Webb: 2002)

These factors beg the question of what is the most intelligent way of supporting child carers, amongst other vulnerable children? One possibility is to define and describe child carers as a specific group of children with particular vulnerabilities, and thereafter lobby for particular policy provision for this group. Another is to put energy into lobbying for provision, for example critical state services, and supporting state or civil-society efforts to resource children and adults with appropriate social and psycho-social support.

#### 13.1 Debating the case for 'new policies'

On the basis of their extensive comparative study of child caring in Tanzania and the UK, Ruth Evans and Saul Becker (2007) recommend the following for policy and practice:

*"There is a need for greater recognition of children's caring responsibilities in families affected by HIV from the local to the global level, and the development of policies, services and support to meet the specific needs of this group of young carers, within the broader category of children affected by HIV/AIDS orphans and vulnerable children."*

Becker (2007) also draws attention to the “creeping use of the ‘image’ of the AIDS-affected child as a caregiver, with Save the Children, for example, issuing a 2006 Mother’s Day appeal which described how ‘millions of children...have had to become “mums” themselves, giving up their own childhoods to care for younger brothers and sisters’ (Save the Children, 2006).”

Policy statements around child well-being are often reactive to the way social problems are defined in the media, international organizations and even ‘research reports’. Consequently, such statements are insufficiently scrutinizing of the empirical evidence available (Bray 2003; Meintjes & Bray 2005; Meintjes & Giese 2006). We have seen this occur in well-intentioned efforts to support street children, child workers and orphans over the last thirty years. Without careful attention to the facts, and acknowledgment of gaps in our knowledge, there is a risk that ‘child carers’ could become another badly defined, and therefore poorly responded to, ‘group’ of vulnerable children. The following sentences are taken from the executive summary of the ILO and Government of Uganda 2004 report on child labour and HIV/AIDS:

*“Several reasons were floated by the HIV/AIDS affected children for not attending school fully. The main reasons were the need to support the family. Other reasons included, lack of school essentials, and looking after a sick relative. It is clear that HIV/AIDS impacts heavily on the orphans by assigning them adult roles thereby making their future uncertain.”*

Use of the term ‘orphan’ to describe child carers is an illustration of the mis-information that can be conveyed in official research reports and lead to inappropriate policy responses (in this case, for example, narrowing the focus to children who have lost one or both parents).

The value of careful empirical research is shown in a recent analysis of reliable South African national survey data collated from 2000 to 2007 (Meintjes et al. under review). The study found that child-only households were not as common as assumed: Just under half (43%) consisted of only one member, of whom two-thirds were boys and the vast majority (84%) aged 15 years or over. In only 12% of child-only households was the oldest child under 15 years of age, the legal age at which work is permitted in South Africa. Thus the picture that emerges is not one that is wholly, or even largely, about young children caring for their siblings as a result of parental death. Cultural norms, high rates of labour-related mobility, spatial disparities in educational quality and chronic housing shortages are also reasons why children live without adults in the home.

These findings lie in stark contrast to those foregrounded in a recent fact sheet produced by the South African Housing Department. The fact sheet begins with reference to media reports of large portions of households (up to 65% in some neighbourhoods) being headed by children, and attributes the apparent increase to AIDS-related orphaning. One obvious flaw in calculations used here was the inclusion of statistics on household headship by 18 and 19 year olds who are technically adults. Moreover, these figures were derived from the 2001 census, a source that was found inappropriate in a later empirical study owing to the high numbers of implausible households that imply frequent mis-recording of age (Meintjes et al. under review).

In the case of child headed-households, there are clearly discrepancies between empirical research findings and the ‘story of vulnerability’ associated with a particular group that becomes common knowledge through repetition. This particular example could be repeated in relation to other categories of children seen to be ‘at risk’ and therefore raises a serious concern about the way in which state responses are targeted:

*For example, the South African investigation of numbers and characteristics of so-called ‘child-headed households’ revealed a serious “risk that policies, programmes and interventions which conceive of children in child-only households primarily as groups of young orphans will fail to address many of the reasons underlying the existence of this household form, and provide inappropriate mechanisms of support or intervention.” (Meintjes et al. under review).*

In light of the ways in which ‘information’ about a particular group becomes demanded (once that ‘particularly vulnerable group’) has been identified, then produced in the absence of scholarly processes, and then circulated amongst key actors, I would like to raise a note of caution against defining ‘child carers’ as a group with very specific polity needs.

### **13.2 Examples of effective programming**

While it is well beyond the scope of this review to identify and document interventions for children who care, I wish to report that in none of the literature did I see programme responses directed specifically at child carers. There are however examples of initiatives that clearly have direct or indirect benefits for children who care and/or live with sick or frail family members. The girl child network, for example, already responds to key needs (knowledge, socialisation, building self esteem, safe space to report and discuss abuse) and could plausibly integrate a means of identifying child carers, and responding to their needs. Such a model could serve well in contexts where many more girls than boys are full time carers, although the (perhaps more difficult to conceptualise and run, opportunities for boys to gain such support should not be overlooked.

#### Financial assistance to economically vulnerable or elderly foster carers

Pensions provided to grandparents in Tanzania were found to enhance the material and psycho-social well-being of children in the care of grandparents, (who may themselves have recently cared for a dying parent):

*“The most prominent change in social relationships [following the receipt of a pension] was evident in households where older people cared for grandchildren. The increased ability to meet the children’s needs eased worries and improved the relationship between the generations.” (Hoffman et al:2008:6)*

The increased capacity to fulfil basic needs encouraged a positive inter-dependence within the relationship between child and elderly carer, and thus bolster the quality of this relationship before the point at which the care roles might reverse. Should this occur, children and their ailing grandparents are more likely to cope with new roles if a grandparent has been able to provide what is deemed ‘adequate’ care in the past.

These striking findings point to the role of pensions or other forms of regular cash grants, either prior to, or alongside, state efforts to improve ‘cost-free’ access to health, social and education services. Challenges lie in defining eligibility and time-frames, as well as ensuring

that cash transfers do not become regarded as an acceptable alternative to systemic changes in service provision and thereby derail these processes.

#### Group support and education on caring

A number of small-scale initiatives in South Africa have produced guides and a working model as to how to support child carers. The NGO 'Sinosizo' in Durban runs support groups for girls and boys who have lost parents, or who care for their sick parents. They use their "Life skills guide for children" which contains chapters that inform children how to take better care of themselves, and those under their care. Similarly, Ekupholeni Community Psychological Support Centre initiative in Johannesburg runs a support group for young caregivers in child headed households, and has produced a guide that covers these topics and extensive information about HIV and sexuality.

The small pilot project run with funding from Symphasis in North West Tanzania (Madoerin 2009) is another example of group support and education. What is interesting about this project is that it involves support for both ill adults and their children. The adults and children meet once a week in separate but co-ordinated groups and also in joint groups where the adults and children spend time talking to each other. The project is documenting the weekly sessions and will produce a simple manual that outlines both the psychosocial support and educational activities that have been piloted.

#### Effective psycho-social support for child carers in Tanzania

VSI (Vijana Simama Imapara) is a children and youth organization established by the Swiss-funded NGO Humuliza (operating in North West Tanzania to provide comprehensive support to children and young people, and focus particularly on psychosocial support as part of the REPSSI network). VSI is organized in 20 clusters and currently has 2200 active members, and is managed by the child members who have acquired leadership skills to take on responsibilities. One of its core principals is children's freedom to choose the way forward. Child members meet to build friendship and trust, and experience actively helping each other, for example in the building of a house. Through these processes they learn their strengths and weaknesses, and build up self-confidence.

One indication of their success is the construction of a community project by 20 young orphans from VSI in the lowlands of Mubunda. This group of homeless youth moved from the Nshamba plateau to Mubunda in 2004 in order to form a cooperative where they are applying improved farming techniques to meet their needs. Humuliza co-ordinator, Kurt Madoerin, reports that they have achieved this with limited guidance from the organisation.

In a recent impact evaluation, a community leader reported benefits to children and to older members of the community: *"It has helped orphans gain a group identity and a forum to solve their problems and make friends. It also makes them self-reliant in that they feel comfortable about sharing ideas and participating in income-generating activities such as agriculture, animal keeping and small businesses. It has also indirectly benefited elderly and disabled people and provided houses for the homeless."* (Madoerin; personal communication; Clacherty and Donald, 2005).

According to Kurt Madoerin (the sociologist engaged in this work in Tanzania for many years), offering psycho-social support of this nature to orphans or children with sick parents can facilitate processes of self-determination in children, and enable increased appreciation

of children's potential and resources amongst younger and older generations alike. Learning from this initiative and other efforts to support child-led processes has been synthesised in a practical guide recently written by Madoerin and published by REPSSI titled " Mobilising Children & Youth into their Own Child- & youth- led organizations" (see [www.repssi.org](http://www.repssi.org)).

#### Information and psychosocial support for girls through a network of clubs

Founded in 1998, the Zimbabwean Girl Child Network (GCN) is a girls' rights activist development organization with a membership of approximately 30,000 girls across the country. The main goal of GCN is the empowerment of the girl child as well as the eradication of all forms of abuse and practices that impede the full physical, emotional and spiritual growth and development of the girl child. GCN uses a human rights-based approach to address gender inequalities in education and in all social, political and economic spheres of life. GCN is a community-based, grassroots organization that has several strategic program areas from education and training to advocacy and community development.

The network functions through girls clubs which create a space for girls all over the country to meet with trained volunteers to break the silence in a safe and supportive environment. The clubs' flexible structure has five elements: identifying needs; mobilizing and developing strategies to go public on incidents of rape; leadership development of the girls; and developing and empowering the community. As a consequence of empowerment through the girls' clubs, more and more girls, averaging eight per day, are reporting incidences of rape

#### 14. Conclusions and recommendations

Child caring, only recently featuring large on the research and policy agenda, remains poorly understood in the four countries under review. There are some signs that the cumulative, interactive nature of stressors on child well-being are being investigated and understood, however studies in this vein tend to impute outcomes without empirical evidence of cause. Many 'conclusions' are predictive, or rely on association rather than proof of cause, for example:

*"The care that older siblings can provide for younger children is likely to be inadequate because of the increased poverty of the household and the lack of maturity and experience of the caretaker, leading to poor health, hygiene and nutrition; absence from school, and developmental delays. The loss of material, emotional and developmental support from an adult exposes children to the distress which results from lack of affection, insecurity, fear, loneliness, grief or despair. It limits the possibility of a successful childhood, which, in turn, affects the future as adults." (ILO & Government of Uganda, 2004)*

The only extensive comparative study of child caring to date (conducted in New York, USA and Mutare, Zimbabwe) concludes that "child caregiving is not, in and of itself, necessarily hurtful to children, but there is some cause for alarm in certain situations – when the child is unable to participate in usual activities including school, when the child is alone and has no adult support and when the child does not feel appreciated." (Bauman et al. 2006:68).

The limited evidence available paints a picture of child caring in Angola, Nigeria, Uganda and Zimbabwe as a response to a mutual interaction between prevalent debilitating illness, household impoverishment and the absence of basic services. In this context, the responses

of adults in extended families and neighbourhoods to children who have large practical and emotional responsibilities are likely to be seriously compromised by the scale and nature of demands placed upon them. It is this reduction of adult capacity that appears to pose the greatest risk to children because it weakens the capacity of social networks to resource those most needy. It is this reduction of adult capacity that appears to pose the greatest risk to children.

For this reason, any further research on this topic should extend to analyzing how these factors work together to challenge resilience within the domestic sphere, to influence the designation of care roles within families, to understand what is expected of and by children, and to situate these very carefully in time and space.

In a variety of settings in sub-Saharan Africa, resilience within the family is evident in the very fact that children assume a care role, and the combined effect of experience and responsibility may strengthen their well-being. But we do not understand enough about whether and how existing social, economic and cultural mechanisms bolster resilience within the four country settings. An exhaustive study of such dynamics would not be possible owing to their variability over small areas. But any location-specific piece of research should include a contextual look at through the lens of resilience, in other words focusing on what children define themselves as able to achieve well, and on domestic dynamics (in which children are carers) that function despite the odds stacked against them. Factors identified that enable children to be 'good carers' and achieve at school are likely to mirror (but may not entirely overlap with), those that act to protect poor children in neighbourhoods where adult illness is prevalent. It is these that deserve support in the design of general OVC programming and anything aimed specifically at 'caring'.

The prospective and longitudinal approach to research on child caring currently being taken by Cluver and colleagues in South Africa promises to reveal synergistic relationships between factors that support and undermine child well-being when there is severe illness, frailty and dependence in the home, and when children take on a spectrum of responsibilities. The study is necessarily ambitious in scope<sup>9</sup>, and well-supported in terms of scholarly and financial resources. Research of a similar scale and scope would be difficult to achieve in at least three of the four countries under review (Uganda being the possible exception), therefore begging the question of whether a similar framework can be used to support more focused, rapid assessments of critical gaps in local knowledge. Having conducted this review, I suggest that it should be possible to identify areas within each country where child caring may be a component of AIDS-related vulnerability, and indeed indicative of longer processes of compromise to child well-being, using indicators flagged in this document and in-country knowledge of area-specific characteristics.

Envisaged here is firstly an area-specific profile of current resilience and risk amongst children living in homes most vulnerable to AIDS-related illness, paying particular attention to aspects of well-being identified in the South African study. Secondly, an analysis of contextual factors as laid out in appendix two (including migratory patterns, income sources

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<sup>9</sup> The qualitative component of the study involves 800 children in 2 provinces (rural and urban dwellers in each), and the quantitative longitudinal component involves 6000 children in 4 provinces (again, with a spread of rural and urban residents).

and constraints, access and quality of service provision) would assist in building a predictive picture of child caring, and any very particular strengths or vulnerabilities that arise from the care role, co-residence with a sick adult, economic responsibility in the home and/or grief and bereavement.

Any area-specific study such as this should include the mapping of support services for adults and children in order to understand service provision, and to glean access to grey material documenting responses to pressures by communities and families, and their impact on child resilience. For example, the Nigerian NPA for OVC refers to “A small number of examples of best practice which engage men, women, boys and girls in communities to identify and take action to support the most vulnerable children by using local resources and taking collective action e.g. community farms, kitchen gardens, community feeding centres” but gives no further details on their location, approach or targeting.

This review points very clearly at the value of generalised support to children and families in income poor neighbourhoods with high HIV infection rates, thereby adding to the established critique of orphan-focused initiatives. The broad body of evidence analysed herein suggests that the degree and strength of continuities and stabilities that existed before parental illness and that persist during illness have a substantial influence on child well-being after they are ‘orphaned’. And for those children who take on a caring role, whether for a matter of weeks or years, the available data suggest that these very same factors stand to influence their resilience to the demands of caring, particularly emotional ones such as witnessing parental illness, grief, and worry about the future. I therefore recommend attention to the means of enabling appropriate psycho-social support within families (i.e. bolstering the means to earn, to meet basic needs and thereby protect mental health), and considering specific psycho-social support to children and adults to facilitate communication about illness, loss, grief and future planning.

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## Appendix 2: Diversity and change in the socio-political landscape

Again, while definitive statements of intra-country socio-political trends in child caring or their associated risks are not possible without the empirical research, there are passages within available research reports that flag the roles of:

- cross border and post-conflict migration
- mobility in the extended family and the urban/rural diaspora;
- socio-cultural change, increasing economic heterogeneity,
- synergistic relationships between AIDS and chronic poverty
- attitudes, beliefs, family and inheritance practices associated with ethnicity, religion and interaction with other worldviews

### Cross border and post-conflict migration

Many residents of Uganda have migrated from neighbouring war-torn countries such as Sudan, Rwanda, the democratic Republic of Congo, as well as from the northern part of the country which has been ravaged by war. Many immigrants settle in Kampala, find jobs in factories and marry others who have fled conflict and are far from home. They live in very poor conditions in one- room shacks, distance from home and support networks means there is usually nobody to take care of them; and when they die, it is difficult to trace their families. Research shows that volunteer care-givers and care-organisations report experiencing greater physical and emotional stress in their efforts to support people in this situation when they fall ill (Akintola, 2004:27). Stigma and shame also contributed to the additional burden of care placed on these volunteers arising from weak social networks and the absence of kin. The study did not enquire into the nature of children's caring roles, but it is likely that children are more readily called upon to care where other relatives are too distant, and that they may have little support is available through kin-networks.

Migrant children, carers or otherwise, are unlikely to benefit from any service provision given that children who have crossed international borders (within Southern Africa and potentially across the sub-Saharan African region) “are not accorded refugee status and are treated as illegal immigrants in the countries in which they arrive” (Save the Children 2006:4).

In responses to widespread and large-scale population movement in the Great Lakes Region (arising from conflict, natural disaster and socio-economic difficulties), a number of regional initiatives<sup>10</sup> have been instigated to target mobile populations and complement national responses, for example that of Uganda (UAC 2007:11). The necessary political environment and systems to maximise outputs of these initiatives are yet to be developed.

In countries where portions of the population survived serious conflict, the consequences of war are likely to work alongside poverty and sickness, to create particular contexts of care and challenges for children in this role. In Northern Uganda, where 3.9 million people were living in absolute poverty in 2004, between 20,000 and 30,000 children were abducted at some point over the 20 years of the armed conflicts in this area, one in five lost either one or both parents to the conflict, and one in three young men and one of six young women have been abducted at some point in their lives (UNDP Angola: Facts and Figures). The

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<sup>10</sup> These include the Great Lakes Initiative on AIDS, the IGAD region IRAPP project, and the EAC-AMREF Lake Victoria (EALP) HIV and AIDS programme.

psycho-social consequences of these experiences, nor their interaction with contemporary poverty and disease, have not to my knowledge been. But the loss of parents and trauma of orphanhood through war, the physical absence of parents available to care point to levels of social and emotional fragility in both parental and child generations.

After almost 30 years of civil strife, relative peace and stability in Angola has only been achieved since the 2002 Luena peace agreement. The legacy of this conflict is a plethora of critical health, social and psycho-social issues affecting tens of thousands of people. The focus of INGO and state attention has therefore been on responding to mine-related injuries, reuniting those separated from families (including large numbers of children), the repatriation of refugees who fled to neighbouring countries, and psychosocial support to help children cope with the effects of violent conflict (e.g. work done over many years by the Christian Children's Fund). According to official figures, there were an estimated 105,000 physically disabled people in Angola, including some 70,000 mine Victims (ICRC Annual Report 2007:78). And in 2007, 18,575 people, including many unaccompanied children, who were either seeking or being sought by their relatives (ibid.). The urgency of these post-conflict needs have understandably eclipsed attention to health and social impact of HIV and AIDS. However organizations like the ICRC (International Committee of the Red Cross) who have worked to assist physical rehabilitation and other post-conflict scenario are now moving out of Angola (ibid.).

The paucity of research studies suggests that we know very little indeed about the social consequences of HIV and AIDS in Angola, or about how the psycho-social impacts of decades of war play out in familial and neighbourhood responses to chronic illness.

In the absence of any published empirical data child caring in Angola, it should be pointed out that the effects of war and efforts towards the rebuilding of communities are likely to form a unique backdrop to the impact of AIDS on children's roles in families and homes. HIV and the demands of caring are imposing themselves on children and adults who are already traumatized, missing relations and likely to have minimal emotional and mental resilience.

In post-conflict Rwanda, stigma faced by youth appears to be exacerbated by the deep-seated social problems surrounding the genocide, as well as circumstances surrounding parental death or absence. "Over half of the youth heads of household (51%) reported feeling isolated from the community and nearly as many (47%) felt no one cared about them. This left many (57%) with the impression that the community would rather hurt them than help them. Over half of the respondents stated that people spoke badly about them and/or made fun of them and a striking 86% reported feeling rejected by the community." (Thurman et al. 2006:226)

#### Mobility in the extended family and the urban/rural diaspora

The responses of families to AIDS in Lesotho and Malawi include the movement of children between kin homes, sometimes over large distances (Ansell and van Blerk, 2004). Decisions around such moves consider various factors; the skills of the children concerned and where they can be best utilised, the needs in families including care for the sick, perceived obligations on the part of extended family members to meet the needs of children, and children's personal preferences. This work demonstrates firstly that households composition and the care needs therein change over time. Secondly it shows that children, like the adults

in their extended families, are mobile migrants in seeking and giving care, and in seeking livelihoods. Caring by children was frequently found to be a temporary arrangement that was altered as resources and needs in the wider kin group changed.

Kin relationships that stretch across a rural/urban diaspora are commonplace in all the countries under review. However the influence of these on child caring has only been studied in Zimbabwe, where it was found that non-resident rural young relatives may become carers owing to urban family preferences to bolster the well-being of their own children (Robson 2000:65-66). Community nurses and social workers reported that families arrange for nieces who are leaving school in rural areas to help, so that their own children don't have to forfeit their education. Young relatives are also sometimes brought to the cities by urban relatives requiring a full-time 'minder' for a sick relative while they go out to work.

Poor employment prospects in rural areas underlie the growing numbers of children with rural origins arriving in towns to fulfil a caring role (ibid.). "For young people the social consequences in relocating as part of the migrations and geographies associated with caring responsibilities include dislocation of their social networks in their place of origin, which combined with the spatial restrictions of caregiving in their new homes mean they are often very isolated." (Robson et al, 2006:106). And, although Robson's research does not comment on the power dynamic between rural and urban kin, the fact that these arrangements arise from, and contribute to, status differences between urban and rural residents may place young carers from rural areas at greater risk of exploitation.

In its National Plan of Action for Orphans and Vulnerable Children, the government of Nigeria claims that "rural to urban migration has led to an increasingly weak family safety net and reduced communal sense of responsibility for children." This conclusion appears to arise from cumulative anecdotal evidence as no data are given to support it.

Trends in HIV infection within countries appear to vary: In Uganda, urban residents have a significantly higher infection rate than rural residents (UAC 2007:7). Epidemiological data able to capture these differences do not exist in Nigeria, but almost half the population is urban. If there are parallels in modes of transmission and risk factors related to urban living, Nigerian adults and their children could face a large increase in illness and death.

#### The impact of rapid socio-cultural and economic change

A study of the impacts of AIDS on the well-being of both AIDS-sick people and their carers in the Caprivi region of Namibia draws attention to the ways in which the parameters of care are affected by recent and rapid social change (Thomas 2006:3178). Residents of this region consistently referred to the degree of socio-cultural change since Independence in 1990, increasing economic heterogeneity, and an upsurge in witchcraft accusations. These changes were reported to have "resulted in a breakdown of familial support networks", meaning that "the welfare of the household was now considered a household responsibility, and that household members were expected to 'see for themselves' (be self-sufficient), before contemplating assistance from relatives or friends." (ibid.)

The ethnographic data showed that while social pressures to 'see for yourself' are paramount, transfers within and between households continue to form a vital support

network. Such transfers are however, rarely undertaken if they are not part of a reciprocal, although often unspoken arrangement. Thomas argues that “being cared for is not then an automatic right, but a status requiring considerable investment” (in networks of adult kin). She does not investigate or comment upon adults ‘rights’ to be cared for by their children, but her findings illuminate both the inter- and intra-household dynamics that can frame the setting in which children become carers. The repercussions of AIDS-related illness stand to affect children as both recipients and providers of care precisely because long-term illness “challenges the capability of the ill person both to reciprocate, and to actively contribute to the household, thus compromising their identity and role within the household and the level of care provided to them.” (ibid). In situations where sick adults feel socially isolated or of diminishing value within the home, we can expect their relationships with, and expectations of, their children to shift.

There are strong parallels in aspects of broad social and economic change across sub-Saharan Africa, frequent references are made within scholarly and policy documents to the increasing fragility of social networks between kin and neighbours. Thomas’ study highlights the importance of identifying the particular drivers to change in contexts where children are caring, investigating how these changes affect the social, economic and emotional resources of both adults and children, and interrogating the implications for inter-generational relationships and the well-being of child carers.

#### Synergistic relationships between chronic poverty and (AIDS-related) illness

The severe weaknesses in the support structures available to grandparents in Tanzania illustrate the particular ways in which AIDS and chronic poverty work synergistically, and indicate reasons why children are increasingly relied upon as carers.

Within the sample of 108 older people interviewed, approximately half of whom were caring for grandchildren, the average number of children born to them was six to seven, the average number of children still living was three to four, and the average number of living children able to help was one. The inability of the parent generation to support the grandparental generation on a large scale is a new phenomenon: Almost all grandparents said that they had been able to support their own parents, and less than one quarter said they received good support from their children (Hoffman et al: 5).

We can therefore expect that even when grandparents are notionally the carers of children, these grandchildren are likely to be called upon more readily and from a younger age to assist in the home or with income generation. The line between ‘carer’ and ‘recipient’ becomes blurred and if grandparents weaken or fall ill, children are likely to take on greater responsibilities within the roles they have begun assisting with.

#### The impact of ethnic and religious heterogeneity on attitudes towards children

The particular experiences of children who care, including the kinds of support they can expect from kin and neighbours, are shaped by culturally specific constructions of children and of parents. Anthropological work illustrates the way in which beliefs and values, often contained in particular idiom, guide relationships between the generations and the fulfilment of obligations to care. For example, Shona-speakers in Zimbabwe have the expression *mwana ndimambo* [‘the child is the king’] which implies that a child should follow no protocol when in need (Roalkvam 2005:214). He or she can demand and expect their demands to be met urgently, and the underlying meaning of the idiom is that “the parent or adult caretakers

should fulfil their obligation in protecting and providing for the child". Another expression, *mkuwa anufamba* ['walking or moving graves'] is used if adults do not do so, thereby conveying the presence of parents who are still living but who are as good as dead because of failing to care for their children. This and other anthropological work on Shona kinship reveal that "children can expect their kin to feel obliged by the very fact of being kin" (2005:214). For example, if a father dies, one of his brothers or a patrilineal cousin should take the father's place, so assuming legal and economic responsibility for the children. In the Shona worldview, the only orphans (*nherera*) that exist are children who are left on the streets or in child-headed households without adult care or support.

As Roalkvam points out, this image of provisory adult kin forms the normative backdrop against which high rates of adult AIDS-related illness and death have contributed to a situation where cultural ideals cannot be met. Her study and its findings regarding why certain children find themselves socially isolated highlights the importance of close understandings of culturally-specific concepts of childhood and adulthood, the workings of kinship, and of the manner in which socio-economic or health-related changes impact on these, prior to any effort towards supporting highly vulnerable children.

A recent study of knowledge and attitudes regarding HIV/AIDS and orphanhood in central Nigeria highlights the role of religious beliefs and their transmission through education, as well as gender, age and personal experience (Ohnishi et al 2008). These shapers of adult views are important because they are aspects of the socio-cultural framework surrounding children who care (about whose experiences and opinions there is no available evidence). In other words, we can realistically expect some similarities between attitudes towards orphans, particularly AIDS orphans, and those towards child carers, which will in turn affect the way they are treated in homes and neighbourhoods.

The study found that women and adults who believed that AIDS is a common disease scored higher in their knowledge of HIV transmission. But, interestingly, positive attitudes towards HIV/AIDS, orphans and AIDS orphans were associated with being male, of a younger age, Koranic schooling, practising polygamy, a belief that numbers of orphans in the community are increasing, and having close friends or relatives with AIDS. The authors point out that the positive male attitude towards orphans is consistent with cultural standards amongst Moslems in Nigeria (but give no details of these, making it difficult to infer whether men are likely to express benevolence and care towards children who care, or whether it is only the absence of living parents that triggers these attitudes).

Muslim adults who had been at Koranic schools knew less about the HIV/AIDS than their counterparts who did not attend such schools or local Christian adults, but they had more positive attitudes towards the disease, towards orphans and towards AIDS orphans. Thus, religion and ethnicity alone are not accurate predictors of how adults and families approach the experience of illness and its impact on children. Educational background and other social factors prompt variation even within Muslim communities.

The authors rightly alert us to the possibility that attitudes conveyed in a survey may be more reflective of the moral standards people would want to adhere to, rather than their behaviour towards children. This study alerts us to the variation in attitudes towards HIV/AIDS and orphaned children that occur within one town comprising two main ethnic

and religious groups. We can anticipate much a greater range of knowledge and attitudes across the whole of this vast country, especially given the presence of tribal groups with indigenous belief systems within the predominately Muslim north and Christian south. If we are to further our understanding of the experiences of being a child carer, research is required in all four countries around the manner in which socio-cultural and religious frameworks shape attitudes, beliefs and actual responses to sickness, and changes in children's roles in the home.

#### Socio-cultural change: Interaction with service providers and shifting familial practices

Ethnographic research over a 7 year period in south-eastern Uganda documents significant shifts away from familial practices influenced by long-standing cultural systems and towards models of care for children that are more in line with worldviews espoused by the state, churches and NGO services (Christiansen, 2005). Patterns of consanguinal relationships are shown to be changing, such that fewer widows are marrying their late husband's brother (in an area where leviratic practice was customary), and greater numbers of children are living with maternal kin despite the patriarchal inheritance system.

An increased demand for care in the context of AIDS-related sickness may be bolstering the trend to rely on, and often move in with, maternal kin, even in patriarchal societies as noted by Christiansen (2005) in Uganda, and Thomas (2006) in Namibia: "The gendered nature of caring in the Caprivi means that it is common for women to return to their own relatives for care, often their mothers who, if widowed, were likely to be disadvantaged in labour and resource assets and therefore, more reliant upon assistance provided by HBC workers." (ibid.:3176)

Christiansen (2005:174) argues that "in contemporary Uganda, raising children to become productive socialized adults is no longer entirely the domain of the extended family." On the one hand, rural Samia people (even from extended households) say firstly that childrearing is becoming more a duty of the single house and the biological parents. Such statements should be understood in an East African context, where childrearing has been conceptualised as a central dimension of community life (see Kilbride & Kilbride, 1990; Shorter & Onyancha, 1999; Swadener, Kabiru & Njega, 2000 cited in Christiansen, 2005). Secondly there is a realization that raising children can be expensive since they require school fees, clothes, medicine and food, and attending school keeps them from many hours of household chores.

And on the other hand, local caregivers who are not part of the extended family are primarily NGOs that run a range of programmes that primarily assist orphans living in households and their local community. This support is either given directly to children (as items such as school fees, clothes, medical care, and food) or indirectly through microcredit loans to 'orphan-households,' and some programmes give assistance to children who live in institutions like hostels and boarding schools. Thus, orphans and other deprived children may become part of institutionalised care that will provide them with the material resources and concern that are otherwise intrinsic to reciprocity among kin".

Studies like Christiansen's afford a fine-grained analysis of child-rearing ideals and practices, and shed light on the dynamic interaction between over-arching cultural or religious frameworks that might characterize an ethnic group or region, and what could be regarded as 'external' influences of state and civil society organizations operating in the area. They

serve to remind us that processes of change in the way children are viewed, and treated, are always underway and may occur very rapidly in certain areas and at certain times.

### Appendix 3: List of Acronyms

AIDS	Acquired Immuno-Deficiency Syndrome
ART	Anti-retroviral Treatment
COPE	Complimentary Opportunities for Primary Education
GCN	Zimbabwean Girl Child Network
HIV	Human Immuno-deficiency Virus
ILO	International Labour Organisation
INGO	International Non-governmental organisation
NGO	Non-governmental Organisation
NPA	National Plan of Action (for OVC)
NSP	National Strategic Plan
NSPPI	National Strategic Programme Plan for Implementation
OVC	Orphan and Vulnerable Child
PLWHA	Person living with HIV and AIDS
SSACC	Social Services Action Committee of the Cabinet
USAID	United States Agency for International Development
VSI	Vijana Simama Imara
WHO	World Health Organisation





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