## Ground Zero - The impact of AIDS on households

No matter the statistical abstractions, win or lose, the outcome of societies' encounters with AIDS will be decided by how communities and households are affected and are able to respond. And that depends on their room for manoeuvre, the options they have, and the choices they can and do make. These vary by place and shift through time. They're not all – and too often are not at all – of people's own making. Rather they're also the imprints of remote balances of forces, political judgements, strategic trade-offs, fiscal balancing acts, and sometimes plain ideological whimsy.

In South Africa's case, until a decade ago those options were single-mindedly designed and distributed to corral opportunity, privilege and power around a minority – at baneful, maiming expense to the majority of South Africans. Broadly, the effects persist, despite remedial efforts which, it must be said, often have lacked in confidence and resolve. They have been subordinated to other, hoisted goals: seducing 'the markets', shipping dead wood, reshaping a growth path, revising the guest list to the inner circles of privilege. Despite contrary hopes and intentions, privation has also acquired a new lease of life.

Such context, though, is often neglected when the impact of the AIDS pidemic is being considered. The emphasis in South

Africa – and elsewhere – rests instead on abstracted sectoral impact (on the economy, as measured by gross domestic product, on the business sector, and on the public health and education sectors), and on the ways in which 'affected' households 'cope'. The hobbling circumstances that typify their realities are acknowledged in cursory manner (they are 'poor'), and the systemic reproduction of those realities usually escapes mention. Households are described in sweeping, generalizing terms - ignoring the many inequalities and other dynamics, internal and external, that shape them and the communities they constitute. This allows a curious paradox to emerge. The pulverizing impact of AIDS is studied and documented, but it serves as a basis for a 'coping' fetish that exalts the presumed pluck and grit of the poor. All it takes to outsmart and outlast adversity, it seems, is some timely, targeted assistance. At work is a condescension that would make charities blush, and which hides, as condescension always does, a deeper disregard for its subjects.

This is possible because reality is caricatured, and in some respects even supplanted by assumptions and expectations. The interplay of impact and response becomes pictured in mechanistic and predictable sequences that scrub out the variety and contingency of reality. And these pictures, in turn,

give shape to the kinds of policies and interventions that are commonly touted and funded – to potentially unhappy and wasteful effect. The conceptualization of AIDS impact, and programming and institutional responses leaves much to be desired.

What's missing are more authentic (and therefore also panoramic) analyses – and responses – that balance agency against structure, and capabilities against constraints. The dominant model of AIDS impact enquiry shepherds households into one of two categories ('affected' or 'non-affected' by AIDS). Not only does this over-privilege AIDS, but it fictionalizes the realities households struggle with. Moreover, the household comes to be regarded as a discrete unit, with its strengths and weaknesses reified and quantified (incomes, labour power, agricultural production, dependency ratios etc.), an approach that stems from neoclassical economics (Beall & Kanji, 1999). The model skirts the various relations that constitute households, give shape to their livelihoods, and situate them within communities and society at large.<sup>1</sup> The distribution of power, authority, duty and entitlement within and beyond households, how they gain and retain access to opportunities and resources, the terms on which they achieve that, and the ways in which social networks

assumes that an inherent rationality guides all decision-making, for example.

<sup>1</sup> Following a path lit by World Bank AIDS impact research, the literature often places supply and demand dynamics as the core of analysis, and

are accessed and serviced – all this is of central importance to our understanding of how a scourge like AIDS ploughs through society. Yet it is routinely neglected in AIDS research.

#### Predictable consequences?

AIDS piles hardship upon adversity. There is ample evidence that households affected by chronic illness tend to be poorer than other households – and in some cases by a wide margin. Those battling serious illness in a rural part of Zambia's Kafue district were found to have annual incomes 46% lower than other households in the late 1990s," and a similar discrepancy was seen in a Cote D'Ivoire study around the same time (Bechu, 1998). This was partly due to the fact that the costs of health care are regressive – i.e. they impose a bigger burden on poor households, compared with their better-off counterparts. On average, poor households spend less on health-care, but those expenditures constitute a bigger share of their overall income than for wealthier households (Russel, 2003). It also expresses the fact that health outcomes tend to mirror other inequalities, and that health prospects are, to a significant extent, a function of the distribution of resources and power in society. AIDS and serious afflictions corrode household viability in many other ways, too. The reigning understanding is that AIDS robs households of income earners and carers, distorts consumption patterns, depletes savings and assets, and undermines livelihoods. In sum, it further impoverishes the poor and threatens to dump even the relatively secure into poverty. In severe epidemics, those effects acquire a critical

mass that buffets institutions and sectors, and mars public sector and civil society efficiency, even viability – all of which loops back and imperils households' abilities to recover or survive.

Generalized patterns of impact and response now form the bedrock of AIDS impact programming, which rests on the expectation that a doleful but standard sequence of events unfolds. AIDS threatens well-being primarily along two tracks: by sapping the productivity of (and eventually killing) house-hold members, and by imposing additional financial and labour needs. These effects and the responses they elicit usually are hitched into a standard sequence. Additional, sometimes extraordinary, care needs force trade-offs (for instance, withdrawing other household members from school or work in order to care for the ill). The ill person's income diminishes and his or her productive labour ebbs, and eventually disappears. Meanwhile, rising medical and related expenses (and, eventually, funeral and memorial costs) compel households to drain their savings, take on more debt and sell precious assets.

Indeed, AIDS literature has settled on a passage of decline that passes through relatively predictable stages. In the early 1990s already, Seeley (1993) had sketched a narrative in which households first deployed a range of standard responses, before resorting to the sale of key assets and finally imploding and collapsing. The scenario's schematic flow made allowance for the possibility that not all households were doomed to complete the entire sequence and that some managed to switch back and forth between the first two stages. Subsequently, Donahue

(1998) tried to refine this schema by laying more emphasis on the notion of reversibility. Households' financial safety nets were regarded as the biggest variable, and these depended on two factors: the initial financial status of the household, and the ability to (re)build financial security over time. Once households were forced to act in ways that compromised their longerterm viability (such as selling productive assets, sending relatives away or removing children from school) they tended to pass a point of no return. Destitution and dissolution awaited them.

'The stages of response,' according to Alex De Waal (2003b:21), can 'include relying on support from family networks, selling assets, and then the dissolution of the household altogether.' The fact that AIDS cases tend to cluster in households adds weight to such forecasts; once one partner is infected, the odds are high that the other will also become infected, and that an HIV-positive mother will transmit the virus to her newly born children. Such compressed effects are likely to have the harshest consequences for households that rely on their own agricultural production. Where one or two key crops must be planted and harvested at specific times of the year, for example, losing even a few workers at the crucial planting and harvesting periods could scuttle production (De Waal, 2003b:13):

The adaptive strategies followed by agrarian house-holds will mostly reduce productivity. A shift from more to less labour-intensive activities (and farming systems less reliant on periods of peak labour demand) entails a shift from plough agriculture to hoe agriculture, from

irrigation to rain-fed, from grain crops to root crops, and from cash crops to subsistence crops. Similarly, demand for fertilizers will decline. Some of these shifts will also be necessitated by distress sales of assets (e.g. plough oxen). Where land sales are possible, these will also become more common. The numbers of cattle (which need careful husbanding) will decline; the numbers of goats (which fend for themselves much more) are likely to increase [...] [T]he agrarian smallholder economy is likely to become unsustainable [...] it will have lost its resilience and will be stuck in a famine-like process of progressive destitution, marked by a steady a switch to less productive and less socially estimated modes of production [...] Ultimately, we can expect widespread entitlement collapse, either gradual or sudden, brought on by an external shock that suddenly lowers the returns to labour. In short, famine.

Influenced heavily by famine studies, such schema seem to have found broad support in anecdotal and research evidence, chiefly from sub-Saharan Africa and northern Thailand.vi Agricultural output in some communal areas of Zimbabwe reportedly shrank by almost 50%, according to a study conducted by the Zimbabwean Farmers' Union in 1997 (Kwaramaba, 1997).vii Almost half the respondents in a study in Uganda said they had reduced the variety of crops they farmed because of labour shortages caused by illness and death. Most households that had taken those steps were female-headed (Asingwire, 1996). Among urban Zambian households affected by AIDS a rapid transition has been noticed from relative wealth to

relative poverty, with disposable monthly income of more than two thirds of the families shrinking by more than 80%. (Namposyaya-Serpell, 2000). Another study, this time in Eastern Zimbabwe, reported a relatively standard chain of effects. The terminal illness and death of an adult was associated with high expenditures, income loss and sale of capital assets, the combination of which tended to undermine the viability of households, especially those engaged in subsistence farming. One in four households apparently relocated within a few months of an adult death (Mushati et al., 2003). Poor households in particular face the danger of losing their economic and social viability, and of eventually being forced to dissolve (Rugalema, 2000; Akintola & Quinlan, 2003). In severe epidemics, the now customary forecast is that inequalities and poverty worsen, social cohesion becomes more brittle, and domestic violence and crime are likely to increase (De Vylder, 2001; De Waal, 2003b & 2003c; UNAIDS, 2002 & 2004a).

#### Over-reaching

Although what has been described is a blend of intuitive reasoning and research evidence, such moulded expectations can mislead. The reasons are many and include the tendency to separate out the role of AIDS illness and death, hoisting it beyond the other factors that generate wretchedness. The complexity and messy contingency of real life is snipped and buffed until it tells a 'story' – in this case a story about AIDS – that easily translates into policy guidance. This is much less the fault of research than the doing of advocacy, fuelled as it is by

the perceived need to jolt political managers and policy-makers into action with easily-digestible, unequivocal stories of horror. This can tempt simplifications that stray toward travesty.

An example: more widespread planting of the starchy root crop cassava (also known as manioc) in the 1990s in some high-prevalence African countries has been attributed, in some guarters, to labour pressures caused by AIDS. Since cassava requires less labour and can be harvested piecemeal over a protracted period, it would seem to offer an ideal recourse for farming households battered by AIDS. viii It has also been suggested that shifting to the crop enables embattled farmers to reduce or withdraw from some reciprocal obligations; since cassava is easier to maintain and harvest, it requires less help from neighbours (who, typically, would be rewarded with a share of the crop). ix But the enterprising proposition that a move from the cultivation of nutritious cereals to low-nutrition cassava (thus also compromising food security) in some African countries is attributable to the pressures of the AIDS epidemic seems a leap too far – and an example of the single-mindedness that sometimes distorts perspectives regarding AIDS. In fact, cassava has been actively promoted as a central crop for food security programmes in several countries, especially because of its apparent resistance to drought. In Malawi and Zambia, as Jayne (2004) has shown, the shift toward cassava in some areas followed on far-reaching changes in agricultural policy. The withdrawal of state support for maize farming (fertilizer subsidies were slashed, marketing systems deregulated and credit access cramped, for instance) since the early 1990s as part of enveloping economic restructuring tilted farmers towards tuber crops.

With maize farming no longer financially profitable for many farmers, cassava became a cheaper, more viable alternative. In fact, some researchers have found that the shift to cassava seldom correlates with AIDS impact; a review of rural economies in five heavily-affected countries<sup>xi</sup> showed that households not directly affected by AIDS were equally or more likely to be growing tuber crops than AIDS-affected counterparts (Mather et al., 2004). Affected households tended not to have more land devoted to cultivating roots and tubers than did non-affected ones.

This is not to dismiss the possible effect of the epidemic on cropping patterns, but to caution against simple yet grand inferences. In parts of Rwanda, for example, a shift among AIDS-affected households away from cash crops such as coffee to less-remunerative crops such as sweet potatoes has been observed (with labour pressures and/or the loss of specific marketing and production possible causes). But this doesn't necessarily compromise the households' food security, though it could financially constrain their livelihood prospects and those of their kin. And even when crop-changing does appear to occur in response to an AIDS death, a number of factors converge to produce the shift; in Kenya, the gender and household position of the deceased was found to be a decisive variable when affected households changed crops (Mather et al., 2004).

A louder example of such AIDS exceptionalism was the widespread attribution of the food crisis in southern Africa in 2002/ 2003 to AIDS. Those claims drew partly on a clutch of bracing articles from Alex De Waal and others in which it was proposed that AIDS was priming a 'new variant famine' in high-prevalence settings.xii The epidemic's effects on household labour supply, skills and long-term viability were such, they argued, that traditional 'coping' strategies became much less effective and the prospects for a sharp decline into famine were increased. Importantly, the hypothesis located AIDS along-side other operating factors (De Waal & Whiteside, 2003: 1237):

The analysis does not neglect the role of factors such as drought and macro-economic disparities and mismanagement. Rather, it points to the way in which HIV/AIDS accentuates the existing difficulties, compelling us to confront many simultaneous problems, all of which require resolution.

Inspired by the thesis, some international agencies unfortunately chose to neglect the wider context and lay blame for the food crises primarily at the door of the epidemic – despite the paucity of evidence for the claim. Stephen Lewis, the UN Special Envoy for HIV/AIDS in Africa, for example, claimed that 'while there's no question that weather played a powerfully destructive role, there's equally no question that HIV/AIDS was the heart of the matter'. Earlier, he and James Morris, Executive Director of the World Food Program, had reported that the food shortages demonstrated 'the insidious potential of HIV/AIDS to undermine entire societies and nations ... HIV/AIDS is the most fundamental underlying cause of the Southern African crisis ...' AIDS was made to function much as the recidivist criminal

does in police work, as a 'usual suspect' – deflecting attention from the chief causes of food insecurity.

The reasoning hinged mainly on reduced labour inputs (due to widespread illness and death of working-age adults). But those inputs figure among a wide range of variables needed to achieve food security – including marketing systems, food reserve stores, rain patterns, soil quality, affordability of seeds, fertilizers and pesticides, security of tenure, food prices, income levels, access to and the terms of financing, etc. As a factor of production, labour would seldom contribute more than 50% of output (Wiggins, 2005). Where AIDS does affect food production, it does so in concert with other factors. But it is difficult, perhaps impossible, to unscramble the effects of AIDS on rural communities and food security from economic, climatic, environmental and governance developments. In the case of southern Africa's food crisis in 2002/2003, the epidemic's apparent effect on food production occurred in concert with a series of other factors, including aberrant weather patterns and an ongoing narrative of unbridled market liberalization, impoverishment, hobbled governance and wretched policy decisions. By any humane measure, the affected countries' development paths, not least their post-1970s adjusted variants, rank as failures. As a result, chronic poverty has left vast numbers of people constantly living on the edge of hunger. In several of the countries, agricultural policy decisions (often tailored to fit in with broader economic policy routes) badly compromised food production and availability. The AIDS epidemics added to the strain but almost certainly were not the dominant driving force. Calculating the epidemic's likely effect on agricultural production in Zimbabwe, an Overseas Development Institute study estimated that if it takes an average of eight years from initial HIV infection to AIDS death (with a person incapacitated during the final two years, and sporadically ill for a total of one year before that), about nine percent of the labour force would be out of action at any one time. Were one to assume 'this translates into the same loss of agricultural production, then the epidemic causes losses of less than 10 percent,' the study found, and 'at this rate, the epidemic cannot account for more than [a] minor proportion of the harvest losses seen' (Wiggins, 2005:10).

The upshot? For one thing, attention was deflected away from the main causes of food insecurity (which range from doltish policy decisions to the restructuring of the agricultural sector as an element of international loan conditionalities, and more). Singling AIDS out as a main or even salient culprit factor is a lot easier than fingering and tackling the other, more prickly factors – many of them tied to formidable interests and forces – that are (also) at play.<sup>2</sup> It can also be misleading, tempting short-sighted and inappropriate policy responses. When it comes to the epidemic's mangling consequences, policy responses are more likely to make a genuine difference if AIDS is made to take its place in the dock alongside the other culprits, which often include agricultural, trade and macroeconomic policies, land tenure and inheritance systems, marking and pricing systems, and the capacities of states to provide and maintain

vital support services in rural areas. The over-privileging of AIDS lets decision-makers off the hook by endorsing fashionable courses of action that can fail to go to the heart of the matter.

#### **Blind-spots**

The sequencing of effects in most AIDS impact writing is derived mainly from famine studies, a conceptual model that is not entirely appropriate for an epidemic such as AIDS (Rugalema, 2000). An impending famine, for example, typically provides ample signs of its approach – allowing households and communities to prepare themselves for the crisis. Within the limits of their resources and opportunities, they draw on the experiences and knowledge acquired from previous generations, and mount responses aimed at safeguarding the households' future viability. AIDS, on the other hand, arrives clandestinely and without telegraphing the severity of its consequences. Whereas famine and most other deadly illnesses tend to target the young and the frail, AIDS saps and then removes from households people in the prime of their working and nurturing lives. AIDS tends also to cluster in households, with partners and children often also becoming infected, triggering cumulative, trans-generational effects that can be unexpected, variable and complex. As a result, the sometimes mechanistic sequences of effects and responses developed to guide famine-relief programming can be inappropriate in the case of severe AIDS epidemics (Rugalema, 2000).

Several other blind-spots diminish our sense of how the epidemic affects households and communities. Relatively few studies have probed household impact in urban settings; a large part of our popularized knowledge is based on observations in rural locales (where HIV prevalence is typically lower than in urban settings). There is also a chronic temptation to distil ubiquitous 'truths' from very specific, localized research. Findings from a district in Burkina Faso, for example, might be invoked to predict what will unfold in guite different settings thousands of kilometres away. Or labour losses attributed to AIDS on a single farming estate in Zimbabwe, for example, end up being extrapolated to all of Zimbabwe (or even to 'Africa' as a whole). From this there might emerge a claim that, say, 'AIDS is cutting agricultural productivity by one third in Africa'. In advocacy terms, of course, this has great currency – it tempts jolting headlines and sound bytes. But it matters that the statement is inaccurate - and not just for didactic reasons.

The epidemic's impact at household level is complex and varying. Neither the effects nor the responses necessarily adhere to a predictable pattern, but are shaped by a range of other factors that can fluctuate over time and according to circumstances. This has an important bearing on the kinds of policies and

<sup>2</sup> For examples of attempts to take in the gamut of factors that caused the food crisis – some policy-driven, some structural – see Oxfam (2002). Death on the doorstep of the summit. Briefing paper 29. August. Oxford

<sup>(</sup>available at http://www.oxfam.org.uk/what\_we\_do/issues/debt\_aid/bp29\_death.htm), and Raj Patel and Alexa Delwiche (2002). The profits of famine: Southern Africa's long decade of hunger. Food First Backgrounder,

<sup>8(4).</sup> August (available at http://www.foodfirst.org/node/51/print).

interventions that are most likely to cushion the epidemic's impact. Many households, for example, regularly add and shed members – not only in response to their own predicaments and aspirations but also to those of others. But even the AIDS research that records such patterns seldom examine the social dynamics that underpin them, preferring to render them as disinterested adjustments or magnanimous gestures. Households are usually studied in isolation from another, and inequalities between (let alone within them) seldom enter the frame.<sup>3</sup> The pictures that emerge can be travesties.

## Beneath the surface of kin and community support

Kin and community support systems feature prominently as households struggle to overcome adversity. They include lending money, assisting with labour, providing food and fostering children. In times of food shortages in rural areas, for example, urban household members often help out by sending money or purchased food. For their part, rural household members provide food to urban counterparts who lose their jobs, or they allow them to rejoin the rural household.<sup>4</sup> Distressed house-

holds sometimes send children to live temporarily with relatives. In Rakai, Uganda, about 40% of affected households said they had received medical and burial cost support from extended family members, and studies in Tanzania have led to similar findings (Baylies, 2002). The impression created is of apparent altruism. The reality, though, is that the support is extended within networks of reciprocity, entitlement and responsibility; the support implies a new obligation or the settling of a previous one. And a person's ability to draw on that support depends whether s/he has the required time, energy and wherewithal to stay plugged into the social circuitry of reciprocity – which ultimately will also expresses disparities in the network of relations (Pieterse, 2003).5 The poorest households, especially those headed by women, find themselves pushed back in the gueue of entitlement (Lundberg et al., 2000; Baylies, 2002). This doesn't mean they are ignored entirely, but they may not receive the assistance they require. Even in generally poor communities, the unequal distribution of resources and opportunities alters the ways in which households – and their various members – experience and are able to respond to the epidemic. A Kagera (Tanzania) study, for example, found that poorer households had to rely more on loans than less-poor households, which had greater recourse to reciprocal arrangements (Lundberg et al., 2000). Buffeted and weakened by cumulative shocks, the poorest households face being forced into more constricted spirals of reciprocity and support, a process that also mirrors the introverting effects of AIDS stigma.

Even when these networks of reciprocity are functioning relatively well, they cannot address all the needs of distressed households. In many places, the cumulative stress of economic hardship, environmental degradation and disease has been taking its toll on these networks, with households reporting greater difficulty in drawing on assistance from families and friends (Mutangadura, 2000; Webb, 1997). In Zimbabwe's Manicaland, for example, needy households reported receiving some help with food, clothing and the ploughing of fields, but none with paying school and health care fees or rent. Most cited joblessness, high inflation and general economic malaise as the main reasons – highlighting the fact that community support networks cannot function effectively without consistent external assistance from the state and other institutional sources of support.

- 3 As a result, conventional narratives seldom capture the ways in which the travails of one household might affect the fortunes of others. While better-off households generally seem shielded against the more debilitating effects of an AIDS death, their misfortune can spill onto other households and with much more destructive consequences, especially in rural areas, where the destinies of the poor and the privileged often are intertwined. Severe illness and death in richer households can scupper the livelihoods of poorer households working for them if it forces them to
- cut back on expenses or economic activities (Food Economy Group, 2001).
- 4 Again, the elusive definition of the 'household' enters the picture. These kinds of transfers could be deemed *inter*-household (within an extended family network, of course), if the household is constituted by members living in and around the same dwelling. But apply a more flexible definition which includes, say, migrant workers in the household, and such transfers in fact could be *intra*-household. By the same token, a migrant worker would belong to two households at once.
- 5 In the phrasing of Francis (2002:549): 'Multiple livelihoods should not be uncritically celebrated. They are a response to a highly-risky environment, and their construction and maintenance often depend on a degree of flexibility and access to information that some people lack and on the negotiation of social relationships spread over space. They may not be sustainable in contexts where many in the younger generations are finding it difficult to form households in the first place.'

#### Juggling acts

Because AIDS mainly strikes adults in their productive years, it affects household labour supply. Illness decreases and, eventually, death removes the labour a person is able to contribute to the household. In the final stages of illness, care duties can become so time-consuming that other tasks have to be neglected or abandoned. In the standard scenario, these are some of the preludes to declining agricultural production and possible food insecurity.

Faced with lower household income and additional medical and related expenditures, how do affected households adapt their spending? One study conducted in the early 1990s in Kagera, Tanzania, found that most affected households freed up money for medical expenses by spending less on food, housing, clothing and toiletries (World Bank, 1999). Particularly in rural areas, household food security can be compromised. In the Kagera study, the poorest families reacted to an adult death by spending almost one third less on food.xiv After the death of a woman, some Zimbabwean households have been found to cut back on food purchases, especially protein-rich foods (such as meat, milk and eggs, which tend to be more expensive).xv

Most households, though, go to considerable lengths to avoid such crunches. Children are sometimes sent to live with relatives – one of the many ways in which the impact of the epidemic then becomes dispersed across communities (Bartnett & Whiteside, 2002). Additional members might be drafted in from the extended family, or un- or under-utilized labour is enlisted (including, sometimes, that of children). Another study in the Kagera region of Tanzania, for example, found that men and children contributed more labour after the death of an adult female, but at the expense of decreasing wage employment. Interestingly, no corresponding shift occurred after an adult male died, probably because additional labour was then drafted in (Beegle, 2003).<sup>6</sup>

Sometimes harsh and possibly self-defeating trade-offs occur. Researchers in Burkina Faso encountered instances where the ill would postpone treatment (and continue working), and suspend or reduce care-giving during labour-intensive farming periods such as planting and harvesting seasons – examples of morbid trade-offs, with short-term economic considerations eclipsing longer-term well-being (Sauerborn et al., 1996).

There is a general assumption that another common trade-off involves removing children (usually girls) from school to help

tend the ill and help with other chores. Likely though this seems, the evidence is mixed. Pisani (2003), for example, has noted a Botswana study that encountered scant school absenteeism attributable to household care duties. Just 2% of students (all of them boys – again, a counter-intuitive finding) were reported to have taken time off school because of illness in the family.xvi It is possible, for example, that affected households included other persons who were either unemployed or part-time employed and therefore could help with (additional) care and other household duties, perhaps also sharing chores with school-going kin who could reciprocate after returning from school. Other studies have found that school attendance can be lower in households affected by AIDS. The cause, though, is usually financial, with households unable to afford school and related fees due to a variety of factors that can include AIDS. Among 'AIDS-affected' households surveyed in Free State, Gauteng, KwaZulu-Natal and Mpumulanga provinces, about 5% of boys and 10% of girls were out of school. The main reason was lack of money for school fees, uniforms and books - as well as, in the case of girls, pregnancy (Steinberg et al., 2002).7

<sup>6</sup> For a critique of the typically 'gender-blind' interventions and policies that target distressed farming households, see 'Prime-age mortality and time allocation of labor'. *The Gender Newsletter*, 3(1). June 1997. Available at http://www.ifpri.org/themes/mp17/gender/news3-1/news3-1a.htm [Accessed 23 May 2005]. In areas badly hit by AIDS, it seems obvious that extension and other support services for farming communities need

to be adapted to the fact that an increasing number of households are now headed by (often elderly) women. This requires more than adjusting the gender bias of those services: female-headed households often also require additional types of support. A study in the Chokwe district of Mozambique's Gaza province, for instance, discovered that female-headed households planted fewer crops, worked smaller plots, and had

less access to family labour than male-headed households – all of which pointed to them being less 'seed secure' and probably less sustainable (ICRISAT, 2004).

<sup>7</sup> It's likely that once one controls for pregnancy, the gender discrepancy in school attendance found in this study would narrow considerably.

#### What is a household?

Defining a 'household' is a slippery undertaking. A single, universal definition is probably unfeasible (Beall & Kanji, 1999). Criteria for belonging to the household can include any combination of joint residence, joint consumption or joint production; depending on the criterion selected, the household's characteristics change. It might include or exclude live-in servants, absent migrant workers, boarders, part-time fostered children, etc. In line with the general trends, Statistics SA has settled for a fairly narrow definition that emphasizes joint residence; it deems a household to consist of 'a single person or a group of people who live together for at least four nights a week, who eat from the same pot and who share resources'.xvii

Many research studies approach the household as a discrete unit with relatively clear boundaries, employing an image of the domestic sphere that is better-suited to northern, industrialized societies. In fact, households' composition can be elastic, their membership fluid and their boundaries porous – and it follows that rights and obligations often extend between households, linking them into networks of support and reciprocity.xviii These networks might temper the effects of

shocks such as AIDS, but they also correspond to the patterns of inequality that pertain among the participants. In a society where circular migration and fostering is pervasive, a definition of the household that hinges on co-residency therefore seems especially inadequate (Murray, 1981). Absent members often play key roles in households. Migrant workers send back remittances and in-kind contributions. As Sigwana-Ndulo (1998) has shown, the affairs of households ostensibly headed by the wives of migrant-worker husbands often are being directed by those absent men.xix The rural household, meanwhile, might reciprocate by sending foodstuffs and traditional medicines to an absent worker, or by taking care of his or her children (Beall & Kanji, 1999). It would be more accurate – though also trickier – to acknowledge that the shape and form of households shifts, depending on the issue being investigated.8

The complications don't end there. When surveying household conduct there is a strong tendency to ignore power imbalances and other dynamics inside households: the household becomes an abstraction, smoothed of internal disparities, discrimination and exploitation. In contrast to the well-ensconced myth of the altruistic household, a good deal of research evidence shows

that resource allocations in male-headed households often are biased against women and children, for example, \*\* while gender and age often determines who does and receives what. Duties and entitlements are unequally distributed in most households, which has important policy implications; measures aimed, say, at boosting household incomes do not necessarily improve the welfare of all individuals in it (Beall & Kanji, 1999).

#### 'More equal' than others

The uniform category of 'affected households' not only papers over the variety and contingency of experiences and responses, but also veils the unequal distribution of authority, duties and resources within households. Nowhere is this more obvious than in the ways that gender relations distribute the effects of AIDS.

In all countries, women and girls perform the lion's share of social reproduction work – raising and nurturing children, schooling them in norms and values, managing their introduction into wider society, performing domestic labour and tending the ill, and much more. Most of this labour is not remunerated.

<sup>8</sup> Beall & Kanji (1999:3) argue that the contributions of absent members, while important, are 'qualitatively different from that of making day-to-

day resource distribution decisions, accessing services, negotiating social relationships or participating in community level activities'. This seems a

In societies defined by extensive labour migration systems – including those hardest hit by the AIDS epidemic in Southern Africa – women also head a large share of households. Almost three quarters of 'AIDS-affected' households in South Africa are female-headed, a significant proportion of whom are also battling AIDS-related illnesses themselves, according to one study (Steinberg et al., 2002).<sup>xxi</sup> The epidemic's impact therefore pivots especially on the ways in which women are being affected: '[Their] burdens are greater, their time limited, and their lives shortened. Can social reproduction be secured when half of all adult women die before they are forty?' (De Waal, 2003a:17).

What happens when women are debilitated by illness and die? Men, it seems, tend not to step into the breach; and those that do have to overcome or ignore seemingly intractable gendered expectations that are monitored and reinforced by peers. More often, the extra duties are divided among younger and older women. Some research suggests that households which lose adult women are more likely to dissolve – as seemed to be the case for two thirds of urban and rural households surveyed in Manicaland (Zimbabwe) (Mutangadura, 2000).

It seems logical to conclude, then, that the death of a adult woman tends to be more disruptive than the death of a man – 'logical' perhaps, but also simplistic. Gender relations add a few twists to the outcome. The point is less whether an adult

female death adds 'greater' stress to a household than an adult male death, but that each adds different kinds of burdens and prompts distinct reactions. Households compensate differently for the loss of male and female adults. As an example, consider the responses observed during a four-year study in Kagera (Tanzania). When an adult female died, men and children contributed more farm labour. But when an adult male died, women and children's share of farm labour stayed the same, which could imply that the male's contribution had counted for less. Not so. In fact, women and children devoted more time to wage labour and self-employment (Beegle, 1996). Each of the deaths had disrupted the gendered division of labour in specific ways, and the households responded accordingly.9 Gender inequalities register in other ways, too. Recent research in Kenya and Mozambique has shown that household crop production, income and (in Kenya's case) asset levels were worst affected by the death of the male head. This seems counter-intuitive, since women generally performed most of the agricultural work. One explanation might be that the women were prevented from taking control of the land and other assets after their husbands' deaths, and that household production therefore collapsed (Mather et al., 2004).

Indeed, discriminatory legal frameworks, institutional cultures and social regimes mean that the death of a husband sometimes plunges the surviving spouse into even more precarious circumstances. Access to productive resources like land, credit, knowledge and skills, training and technology is often decided along gender lines, with women typically discriminated against (UN Secretary General's Task Force, 2004). Deprived of access to the land, house, livestock and other assets a widow had helped develop and maintain, she now has to muster a new set of supportive arrangements. A study of farming households in rural Kenya, for example, found a significant drop in the acres of high-value crops (which are usually tended by men) farmed after the death of an adult male (Yamano & Jayne, 2002), mostly likely because the widows were unable to acquire title deeds to that land (Jayne, 2004). The agricultural output of family-based farmers – so vital to food security in many developing countries – and the supplementary incomes from wage labour are difficult to sustain in such circumstances. Often widows respond by resorting to marginal subsistence farming or by seeking piecemeal work – both precarious undertakings. As research in rural Malawi has shown, as more people end up relying on casual labour, low wages dip even lower. In such a pitiless labour market, women, children and the elderly are at especially great disadvantage: they can neither compete on an equal footing with stronger, younger men, nor can they undercut their wage demands by much.xxii Households turned to informal sources of support in their communities, but the effects of restrictive macro-economic policies has cramped neighbours' and other community members' abilities to provide

uses (wage employment, non-farm self-employment, and farming), and after the death of an adult male, households may be emphasizing the relative importance of those alternatives (for example, the need to sustain a source of cash income versus adjustments to the loss in farm labor) ...

We may not observe a response in farming among survivors after a male death but we can't infer what that means about the importance of primeage male labor on farms.' See 'Prime-age mortality and time allocation of labor', *The Gender Newsletter* Vol 3 No 1 (June 1997).

<sup>9</sup> Commenting on the research, The Gender Newsletter put it well: 'This result does emphasize the importance of women in agriculture but it does not necessarily indicate that male on-farm labor is not important. Male labor, as opposed to female labor in this particular setting, has alternative

such support – a reminder of how overarching economic policy decisions can throttle or expand capacities to respond to adversity (Mutangadura, 2000).

In sum, the notion that of the household as an undifferentiated unit does not hold up against reality, nor does the idea that households are governed by altruistic principle, as Folbre (1986: 263, cited in Beall & Kanji, 1999:4) has pointed out:

It is no longer acceptable to ignore inequalities of power and welfare among household members, or to assume that the household itself can be treated as an undifferentiated optimising unit. Though no paradigmatic shift can be settled once and for all by a barrage of evidence, the burden of proof has been shifted to those who stand by the conventional assumption of family altruism.

# Is the 'extended family' disappearing?

The phrase 'extended family' crops up repeatedly in AIDS impact literature, despite it being a tautology that implies the stereotypical nuclear family of the West as a universal default, a yardstick of 'normalcy'.xiii Usually,

the nuclear family comprises the husband and wife, their offspring (or adopted children), and (occasionally and temporarily) an ailing grandparent. Relatives beyond that circle are deemed to belong to their respective nuclear families. This, of course, is hardly the norm in most of Africa (and Asia), where the family spans a much larger array of relatives and generations (with their relationships marked out by kinship or marriage).

Anthropological literature since the 1930s has aired claims that black family structures in South Africa were being altered by urbanization and deeper integration into the wage economy, and gradually settling into the 'normal' Western forms better suited to the demands of industrial capitalism.xxv Such assumptions have gained currency since the late 1980s, with a presumed drift toward smaller, nuclear family type structures increasingly taken for granted. But whereas the process was long seen as a kind of involuntary drift towards a more 'rational' form of family structure, it now tends to invite a lament that not just the structure but also the ethos of the 'traditional' family was corroding.xxvi There is real concern that the social cohesion, mutual support and safety functions associated with those arrangements are disappearing at a time when they are especially

invaluable. As we discuss below, a routine romanticization of these family arrangements is on view.<sup>10</sup>

But is there proof of a shift towards smaller, nuclear family-type arrangements among black South Africans? Two decades ago, Simkins (1986) was still largely incredulous, saying that 'if there is a trend towards the nuclear household, it is a very weak one'. Russell (1994) has argued that such a drift, if it were occurring, would be most visible in urban areas, where deeper integration into the capitalist economy would lead to 'some convergence of black and white family distributions'. But evidence for this seemed scant. A later analysis of census data suggested black South African family structures were not shifting towards nuclear-type arrangements (Ziehl, 2001).11 Subsequent research has prompted Russell to assert that family arrangements were transforming, though not simply in line with the stereotypical nuclear system (2002). The pressures and values imposed by deeper integration into the capitalist economy meant that black South African domestic life was assuming 'a flexible array of householding arrangements' (2002:38), but with consanguinity still the fundamental ordering principle.12 Recent evidence suggests that city households have been splitting into smaller units over the

- 10 A further subtext sometimes lurks in this romanticization of the 'extended family'. It involves the assumption that the 'extended family' functions as an acceptable substitute for the failure of the state to ensure arrangements such as more and better employment opportunities, a living wage, social security provision and other entitlements, as Murray (1981) has
- note
- 11 However, Ziehl (2001) has warned that census data did not offer a clearenough lens for discerning, in a definitive way, family patterns in South Africa; Ziehl SC (2001). 'Documenting changing family patterns in South Africa: Are census data of any value?' African Sociological Review, 5(2).
- 12 Which seems to validate Siqwana-Ndulo's (1998) insistence that the ways in which black families restructure would be determined not simply by material forces but also by sociocultural values.

past decade. While the combined population of South Africa's nine largest cities swelled by just under 15% in 1996-2001, the number of households rose by almost 28% in the same period. In two of those cities, the number of households soared by 40% or more; for example, Ekurhuleni's population increased by just over 22% in 1996-2001, while the number of households rose by 43% (Parnell, 2004). So, households are shedding members and splintering across (and possibly also between) urban areas, and in some cities they might indeed be getting smaller. 13 But it is unclear whether and how the bonds of responsibilities and rights between these dispersed members may be changing, and whether the more self-centred and insular norms generally associated with the 'western' nuclear family may be gaining ground.

#### The fetish of 'coping'

AIDS impact writing betrays an almost fetishist faith in house-hold and community 'resilience', 'perseverance' and 'ingenuity'. Ritually talked up are interventions that can 'empower' house-

holds, strengthen kinship and community safety nets, and support the 'coping strategies' households deploy. Like mother-hood and *pap-en-vleis*, all this seems beyond reproach. In truth, though, it pivots on some unsightly, sometimes cynical, assumptions.

To 'cope' is to 'deal successfully' with hardship or misfortune; it's to see off adversity. Thus a 'coping strategy' is generally understood to be a coherent set of actions aimed at managing the costs of an event or a process that threatens the welfare of a household. At the very least it involves returning to the status quo ante, at the very best it enables one to achieve a better state of affairs than had pertained. To be sure, some studies have indicated that a partial recovery in consumption levels can eventually occur, suggesting that the households have overcome the shock and are again 'coping'. But to describe as 'coping' the activities of households sunk in impoverishment is to unmoor the discussion from ethics. By any humane definition of the word, such households are not 'coping'; a 'successful coping strategy' becomes an oxymoron. Regaining a precarious and chronically insecure form of household 'viability' cannot reasonably be declared a success. As Davies (1993) has pointed out in the context of famine studies, coping strategies actually are not about success – they're about failure. They can enable one to survive, but not to transcend the circumstances that

trapped one in the path of mishaps in the first place. Implicit in the discourse of 'coping' is an acceptance, an endorsement even, of the way things are, a patronizing gloss on a reality of privation and marginality.

#### Lineages

It's instructive to track the lineage of 'coping' strategy-speak, which acquired theoreticized footing during the African famines of the 1980s as part of efforts to explain – and anticipate - households' responses to disasters. Researchers sought to answer three important questions: what strategies did households use to survive, could coping strategies be used as a kind of 'early warning system' for impending famines, and what kinds of support could buttress those strategies? (Goudge & Govender, 2000). The research focused primarily on rural, agricultural communities (incidentally, a similar but less appropriate bias marks research on the household impact of AIDS nowadays).<sup>14</sup> From this emerged a relatively standard schema that described a sequence of responses that contained a 'tipping point' beyond which households would 'plunge' or 'tip over' into destitution and, quite possibly, dissolution.xxvii This notion of famine as a unique, singular shock would later be adopted in the AIDS impact literature, even after a more refined under-

AIDS impact literature tends to divide so-called coping strategies into three stages, famine studies often did likewise: first a shortage of food in a community or household, then a more generalized shortage that short-circuits the usual patterns of mutual support, and finally death, loss of productive assets, migration and the possible disintegration of

households (Goudge & Govender, 2000). In Bangladesh, for instance, there are three words for famine: *akal* (scarcity), *durvichkha* (famine), *mananthar* (an epoch-changing famine) (*ibid*.).

<sup>13</sup> This trend is generally attributed to two factors: increase in available housing stock, thanks largely to new housing programmes, and the residential 'decompression' that accompanied apartheid's demise and which has been spurred also by a growing African middle-class.

<sup>14</sup> There is another similarity worth pointing out. Just as contemporary

standing had found favour in famine studies. (By the early 1990s, studies were placing famine-related shocks in the wider context of long-term and structural vulnerability; the shocks, in other words, formed part of an agglomeration of chronic adversities.) The concept of 'coping strategies' entered AIDS discourse in the late 1990s amid a spate of research into the effects of the epidemic on households (and their likely capacities to mount and/or participate in home- and community-based care programmes) (Rugalema, 2000; Ogden & Esim, 2003).

But 'coping' strategy orthodoxy emerged also against the back-drop of ascendant neo-liberalism (Bailies, 2002). From the late 1970s onward, states were being shorn of their capacities to fulfill key societal duties and were recast as little more than interlocutors between the market and individuals – processes typically championed and coaxed by international financial institutions. In subsequent years, notions of community resilience and coping strategy gathered enthusiastic support among multilateral agencies, some of them active promoters of structural adjustment programmes in the South. After years of scorched-earth social policy directives, 'the community' found itself cast in an almost redemptive role as a repository of unfathomed vigour, invention and grit. And 'coping' strategy dogma schematized those qualities.

Analysis based on such models singles out specific shocks – a famine, an AIDS death, etc. – and then seeks to identify and track responses to those shocks. It's a triply-flawed perspective. The effects of 'shocks' tend not to register discretely but are

mixed in with other, often abiding difficulties – and responses tend to reflect this. As well, the nature of those effects and of households' responses are shaped by a widening spiral of factors (from local employment patterns to macroeconomic strategies, from management of district clinics and hospitals to national medicines procurement and distribution systems, from credit access to banking laws, etc.). Associating a particular activity or decision with an isolated shock is therefore seldom more than an illustrative fiction. Which is why coping strategy perspective tends to be foreshortened and unrefined - not so much 'short-hand' for complex dynamics and ambiguous activities as an errant simplification of reality. The approach blots out the potent ways in which households' predicaments can be relieved and their options boosted by decisions and actions elsewhere in the system. Micro-support is not enough, not when the mechanics of impoverishment continue to operate.

Nor does it seem accurate to describe as 'strategies' actions that seldom cohere as a plan or reinforce one another. As noted above, 'coping' strategies often involve trade-offs and gambles, some of them plainly improvident. The 'coping' lens tends not to capture adequately the potentially destructive long-term consequences of some short-term 'coping mechanisms' (such as curtailing children's schooling, selling key assets, taking on unsustainable debts that are then 'inherited' by surviving family members, allowing parcels of land to lie fallow, etc.).

'Coping' strategy models also overlook the non-material dimensions. Most research efforts leave unsighted the psychological

and ideological components of household responses – more frequent participation in religious services and rituals, enlisting the services of *sangomas* (which also carries financial costs), stress relief (which might take the form of binge-drinking, domestic abuse and violence), changes in the terms and manner in which discipline and control is exercised in the household, and possibly even shifts in power relations. These sorts of reactions tend not be easily quantifiable and thus do not feature in most research into the effects of AIDS and other serious illnesses on households.

#### Keeping perspective

Because of a tendency to grasp at sweeping truisms while relying on flimsy conceptual models, AIDS impact literature runs the risk of describing social caricatures. AIDS impact, for instance, is mistakenly portrayed as a discrete and singular catastrophe that unleashes exceptional consequences. In reality, it tends to arrive on the heels of other banes and is compounded by yet more travail – most of them the 'routinized' imprints of deprivation. What *is* exceptional is the buckling weight AIDS lends to these calamities.

Equally common – and erroneous – is the portrayal of 'affected households' as homogenous, and the notion that AIDS unleashes a predictable and uniform sequence of effects and responses in households, which risks misleading conclusions and inappropriate programming recommendations (Mather et al., 2004). Projected onto households and communities, and imbedded

in them are the contours of societal inequality and contestation. On one hand, they are the objects of systemic inequalities; on the other, they also embody and reproduce inequalities. They are not undifferentiated zones of harmony and pluck. Within them, prevailing hierarchies, priorities and inequalities help determine how the effects of shocks such as AIDS are distributed, what kinds of responses are mounted and the sequences in which these occur. Households are diversely constituted, maintained and managed. In a society as sundered, parcelled and tiered as South Africa, generalizations are likely to be especially inaccurate. To state the obvious, a middle-class Afrikaner household in Roodepoort looks and functions rather differently compared with a working-class Indian household in Chatsworth or a chieftain's household in Tabankulu or that of a domestic servant in Welkom ... or dozens of others.

Finally, AIDS is not an indiscriminate epidemic. Mature epidemics disproportionately target, and their harm is disproportionately concentrated among the poor and disadvantaged. While it is true that all 'races' are at risk of HIV infection, South Africa's demographic profile and its history also mean that the preponderance of HIV infections have been among black South Africans (HSRC, 2002), and especially those who are poor.

#### A bird's-eye view

The household-level impact studies that have been conducted in South Africa offer glimpses of what is already being experienced and what lies in store for millions of people. Wittingly or otherwise, they show AIDS intersecting with the hardships endured by millions of South Africans; it is not easily singled out from the other, up-to-now more commonplace adversities. We cannot fruitfully scan how AIDS affects households without also reviewing some of the key trends that shape those households' well-being and prospects.

Against a backdrop of modest but consistent economic growth, infrastructure development and service delivery has improved markedly on several fronts since 1994. Generally, though, these efforts have not matched mushrooming needs, and with provision increasingly occurring under aegis of the market, affordability has become a major concern. Meanwhile, the tandem trends of high unemployment and an ongoing shift toward poorly paid and insecure casual labour has continued to put a squeeze on the incomes of the poor. According to the latest Afrobarometer (2004) survey, 1 in 10 citizens (and 1 in 8 black South Africans) reports often going without food and fuel, while 1 in 7 lacks clean water. The 2004 survey also found a marked increase in the proportion of South Africans who

are often without cash income: 27%, compared with 16% in the 2000 and 2002 surveys. Periodic deprivation is much more widespread: 4 in 10 respondents said they went without food or were unable to buy medicine they needed, 3 in 10 couldn't afford to pay for water, and 6 in 10 went without an income at some stage in the past year (Afrobarometer, 2005b). In the 9 largest cities more residents had access to formal shelter, electricity, potable water and adequate refuse removal in 2001, compared with 1996. However, population increases have meant that the number of residents without such access also rose during the period (SA Cities Network, 2004). In Ekurhuleni, for instance, significantly more households were living in informal dwellings, lacked weekly refuse removal and on-site piped water and flush toilets, and went without electricity (Parnell, 2004).

The Taylor Committee of Inquiry into a Comprehensive System of Social Security (2002) reported that at least 45% of South Africans were surviving on less than R14 a day in 2000 – i.e. living in 'absolute poverty'. Later estimates indicate that between 45% and 55% of South Africans live in poverty, and that as many as 25% of households are trapped in chronic poverty (Aliber, 2003). Poverty trends and the definition of poverty itself<sup>17</sup> are controversial, partially due to disputes about the comparability of various data sets. But subjective experiences

estimate urban poverty since it does not take account of higher living expenses in urban areas. The yardstick of 'purchasing power' addresses that blind-spot to some extent. A better definition of poverty would reflect the fact that it expresses deprivation on several fronts: social, economic, environmental, infrastructural and spatial. See, for example, Parnell & Mosdell (2003).

<sup>15</sup> Note that such studies generally are conducted in a limited number of sites, often in the same region of the country. Their conclusions cannot summarily be generalized to the entire country or society. As well, the changes and responses detected in such studies are not of necessity (all) attributable strictly to AIDS. Filtering out 'non-AIDS' consequences would require also studying an appropriate control group over time, as the Free

State research project of Booysen et al. has set out to do. The data cited here from that research represents the early findings.

<sup>16</sup> The share of residents with water on site declined from 80% to 78%, while the share of residents with formal shelter was marginally smaller than in 1996, at just over 74%.

<sup>17</sup> Poverty is often still defined in terms of income, which tends to under-

surely count for something: according to the Afrobarometer survey, one quarter of respondents said that in the previous year they had regularly foregone a cash income – a response lent further credulity by the fact that 11% of respondents said they had gone hungry regularly in the previous year (Afrobarometer, 2005b). More than two thirds of households in Ceres, and more than four fifths in Mount Frere and Cape Town, reported having had too little food available in the previous year, according to an earlier survey (De Swardt, 2003).

Rural poverty is especially severe. Approximately 70% of poor households are in rural areas, and half of those are chronically poor (Aliber, 2003). Land-based livelihood strategies or agricultural subsistence generally appear not to provide viable escape routes from poverty, as both Sender (2000) and De Swardt (2003) have shown. In predominantly rural Mount Frere (Eastern Cape province), for example, food purchases comprised 44% of monthly household expenses (De Swardt, 2003). Other surveys and studies in KwaZulu-Natal and Mpumalanga have also found that crop and livestock production does not contribute significantly to African rural household's monthly incomes, and that the poorest rural households with relatively large numbers of females were least likely to earn any income by operating their own smallholdings (Sender, 2000). (As discussed below, this calls into question responses that hinge on the growth of smallholder agriculture and self-employment in

rural micro-enterprises.) While deprivation is usually associated with rural areas, South Africa's urban areas contain some of the greatest concentrations of poverty in the country – an observation that seems belied by the fact that average annual household income in the largest cities rose by almost 50% between 1996 and 2001.18 However, in a society fissured with inequalities, the devil lurks in the details, which is where one discovers that the proportion of households reporting annual incomes of less than R9 600 has grown dramatically. Income disparities have widened. Almost 20% of households reported no income in 2001, according to the SA Cities Network (2004), 5% said they earned less than R4 800 per annum, and about 12% said they earned less than R9 600 per annum. The volume of 'zero income' claims prompts disbelief and probably occurs because intermittent forms of income (earned in informal economic activities) are overlooked. 19 Even then, it appears that roughly 35% of urban households were living on less than R1 000 a month in 2001 in cities where life has grown costlier when gauged in monetary costs, transactions and opportunity costs (SA Cities Network, 2004).<sup>20</sup> This is partly because urban geographies in South Africa have become even more polarized and polarizing, with the jobless and the poorly skilled corralled in the under-serviced and grossly-underdeveloped perimeters of cities. Yet, poverty reduction programmes in South Africa are focused primarily on rural areas, and the linked character of rural and urban poverty is typically neglected.

The precariousness of income security is vivid in a rare income mobility study undertaken in KwaZulu-Natal in 1993-1998 (before a significant AIDS-related impact would have registered). During that period, just over 10% of the households slid into poverty (i.e. had a monthly income of less than R212 per adult in 1993 terms). As one might expect, job losses triggered the decline in about one third of the cases. But a significant number of households fell into poverty because of declining remittances, the loss of state pensions or grants, or falling income earned through small-scale agriculture. Almost all these points of vulnerability are potentially aggravated by AIDS-related illness and death - the exception being state grants and pensions\*xxii (Woolard et al., 2002). xxxiii (By virtue of their age, pension-earning persons are unlikely to be HIV-infected; AIDS therefore is a comparatively minor threat to their health and lives. Disability grants can, in theory, be accessed by HIVpositive persons with CD4 counts lower than 200. Paradoxically, the onset of AIDS can then increase gross household income, as we discuss below; though a good deal of it would be absorbed by medical and related expenses. We return to this matter below.) Conversely, one third of those households that moved out of poverty did so when a household member landed a job; no other single 'event' had such far-reaching consequences.

In urban areas, inequalities extend beyond income levels and are expressed both spatially and in terms of service access. Providing

<sup>18</sup> From R48 291 per annum in 1996 to R71 835 in 2001 (SA Cities Network, 2004:13).

<sup>19</sup> It may also be that pensions and state grants were missed and not counted

as 'income'

<sup>20</sup> The monetary costs are easy to calculate and include higher rents and transport expenses. It is estimated, for instance, that 48% of commuters

in the greater Johannesburg spend more 1/10 of their monthly income on transport (SA Cities Network, 2004).

care to an AIDS patient is arduous and time-consuming, especially if water has to be fetched from afar, and sanitation and washing chores cannot be carried out in or near the dwelling.xxxiii Yet, a 2002 survey (Steinberg et al.) of households affected by AIDS found, for example, that fewer than half had running water in the dwelling and almost a guarter of rural households had no toilet.<sup>21</sup> Almost a million urban households did not have water on-site in 2001<sup>22</sup> and three million urban residents were out of work (the urban unemployment rate was pegged at 38%, according to the South African Cities Network) (2004). Rising numbers of urban residents now live sequestered in informal settlements on the outer perimeters of South Africa's cities, which function as veritable holding tanks for the jobless and the under-skilled. Local work opportunities are scarce, transport costs are high, infrastructure is poor, access to basic services is uneven and services are generally unaffordable. It's also here, on the margins of urban South Africa, that HIV infection levels are highest (HSRC, 2003a), with many local antenatal clinic surveys indicating average HIV prevalence of roughly 30% among pregnant women (SA Cities Network, 2004). Burdens of illness in South Africa's largest cities are shockingly high – with TB incidence rates, for example, ranging from 251 per 100 000 population to

as high as 1 470 per 100 000 (SA Cities Network, 2004).<sup>23</sup> In short, the odds of escaping poverty are stacked against most poor urban residents; in the midst of the AIDS epidemic, the chances of keeping head above water are slim.<sup>xxxiv</sup>

Against this background, what patterns of impact and response are becoming apparent as the AIDS epidemic continues to gather momentum?

#### Juggling priorities

An ongoing longitudinal study in urban and rural parts of the Free State province has found that AIDS-affected households' income and expenditure were 10-20% lower than unaffected households and that they spent 20-30% less on food.\*\*

Income levels appeared to drop significantly after an AIDS death — due mainly, it seemed, to high funeral expenses (Booysen & Bachmann, 2002).\*\*

Bachmann, 2002).\*\*

Note, though, that affected households also tended to be poorer than unaffected ones; the discrepancy in food expenditure could therefore also have preceded illness or death. Overall, in fact, AIDS-affected households were found to be larger and poorer, and have lower employment rates than their unaffected counterparts (Bachmann

& Booysen, 2003). This could mean that members of households with limited (if any) access to wage employment are more vulnerable to HIV infection, and/or that many people living with AIDS join households with elderly care-givers (who probably also receive pensions) (Garbus, 2003). Because unemployment levels generally were extremely high, the study could not demonstrate a clear causal link between AIDS impact and joblessness (Bachmann & Booysen, 2003). However, a 2002 pilot study in Soweto did seem to detect such a link. Overall, 41% of the persons surveyed were unemployed (using the narrow definition of unemployment).<sup>24</sup> Of those who were HIV-positive and unemployed, more than two thirds said they had lost their jobs due to illness. And those who were infected but still employed said illness had forced them to miss work on an average of 30 days in the two months prior to the survey interview (Naidu, 2003). For low-skilled workers, the onset of AIDS (as with other debilitating) illness will probably loosen their toe-hold in the labour market even further.

How do households commonly respond once the costs of AIDS start racking up? What seems to happen is that affected households do their best to protect food provision by avoiding other expenditures (especially on clothing, education and

who did not work in the seven days prior to the interview, who wish to work and are available to start working within seven days of the interview, and who have taken steps to seek work or start some form of self-employment during the previous month. It is an obviously conservative yardstick. According to the 'expanded' definition (which ignores the third criterion), 53% of respondents in the survey were unemployed.

<sup>21</sup> The same survey found that more two thirds of the care-givers were female, and one quarter of them were older than 60 years.

<sup>22</sup> The number of urban households with running water on-site increased in 1996-2001, though the majority of water connections have been new so-called yard connections (the number of water connections into dwellings decreased during the same period). See SA Cities Network (2004-13)

<sup>23</sup> South Africa's burden of TB (which is also the most common AIDS-

related disease) is astonishingly severe. Compare the urban TB rates cited here with the 2002 notification rate of 93 per 100 000 in the Russian Federation, a country commonly associated with exceptionally high TB rates; see EuroTB (2005). Russian Federation country profile. Fact Sheet, available at http://www.eurotb.org/country\_profiles/russia.pdf [Accessed 22 May 2005].

<sup>24</sup> The narrow definition, as used by Statistics South Africa, regards as unemployed those persons within the economically active population

durables), all of which might entail an invidious postponement of costs. Similar responses have been observed elsewhere on the continent (see above). It doesn't always work, though. According to study conducted in four provinces, xxxviii about 5% of households were spending less on food due to the impact of the epidemic. AIDS care-related expenses on average absorbed one third of their monthly household income (Steinberg et al., 2002). Mills' (2004) research in KTC, Cape Town, had similar findings: AIDS-affected households were found to be rationing food and relying on donations of fruit and vegetables. Again, it's the underlying, pervasive poverty that catches the eye: almost 50% of the households surveyed in the four-province study were already experiencing food shortages before AIDS arrived in their midst (Steinberg et al., 2002). One analysis has calculated that, at the turn of the century, some 22% of households across South Africa contained members who went hungry because they could not afford to purchase enough food (Everatt, 2003). XXXVIII

#### Comings and goings

Under 'normal' circumstances, households are assumed to be stable and constant – hence the rather elementary arithmetic of income losses following the AIDS death of a member that some studies display. The reality is more fluid and indeterminate. In order to survive and reproduce themselves, households tend

to alter their composition regularly. Just 20% of the 1 000 KwaZulu-Natal households surveyed by Woolard et al. (2002), for example, stayed the same size during the five-year study period, while half of the households lost or gained at least two people. Such changes can be unexpected (deaths, births) or calculated (departures in search of work, marriages, births, fostering, etc.). The effects on household income depend on who is lost or gained. Very generally, households that lost members saw their incomes rise, except when economically active members were lost. And those that gained new members saw their incomes drop, mainly because the newcomers were either children or elderly dependants. It would seem to follow, then, that in a severe AIDS epidemic we can expect households to rearrange themselves along broadly predictable patterns:

- More households would lose at least one, relatively young adult member to illness and, quite likely, then death, and suffer a drop in disposable income as a result. Where possible, those households would try to compensate by dispatching more members into some form of income-earning activity, and/or by taking on additional members that can boost income and/or provide extra labour.
- More households would take in more children to foster, a
  move that would bring added financial strain unless offset
  by foster care and other grants. Many of these households
  would be elderly-headed with pensions, state grants and
  remittances serving as lifelines.

When Hosegood et al. (2003) examined data gathered from some 10 000 households in Umkhanyakude district in rural northern KwaZulu-Natal, they found that households with an adult death tended to dispatch one or more of the surviving members elsewhere – probably to supplement income and reduce the strain on the household. Some households, however, seemed to dissolve after an adult death; those which had lost an adult to AIDS were three times more than likely to dissolve than any other households. (Note that the rate of household dissolution might be overestimated in many studies, possibly because not enough effort is made to trace households that moved; see Mather et al., 2004.)<sup>25</sup> Similar patterns have been observed elsewhere in southern and in East Africa. But they by no means fully describe household shifts, the realities of which tend to be more obtuse.

Household adjustments are not discrete events that occur linearly in a simple, cause-effect-cause-effect chain. In the KwaZulu-Natal study, for example, about half the households that took in unemployed members fell deeper into poverty, which is to be expected – but a similar proportion saw their income *rise* after adding unemployed members. Why? It appears that households that increase their overall income often also attract new members who are unemployed (causing per capita income to fall again). Or, after welcoming a new member, they despatch someone into the job market (whose remittances can send per capita income higher again). Whereas impact

result of adult mortality, the rate of dissolution due to mortality is not as high as that found in some of the literature'.

<sup>25</sup> According to Mather et al. (2004:31), 'panel surveys in Kenya, Malawi, and Rwanda show that while household dissolution does occur as a

narratives tend to picture households reacting more or less mechanistically to misfortune, with AIDS the signal variable, these (re)configurations remind us that responses to AIDS illness or death are entangled with other, 'routine' adjustments. People try to remain agents of their destinies – but within limits that extinguish many, sometimes most options.

#### How much padding is there?

For most South Africans, the short answer is: not much. Savings tend to be low, debt high and access to medical aid and other forms of insurance a luxury comparatively few households enjoy.

Several accounts of AIDS impact assume that households first dig into their savings and assets before borrowing their way out of trouble – but the available evidence from South Africa suggests otherwise. Here, borrowing seems to be an early resort – not surprising when the juggling of multiple debts features so strongly in household survival strategies. Once borrowing options begin to thin, affected households tend to delve into their (usually meagre) savings and sell off assets. Once might expect this to mean that AIDS-affected households are more indebted than non-affected households. Not necessarily, as it turns out. In the Free State study, non-affected

households carried the most debt, especially in urban areas (where they held almost twice as much debt as affected households). This is probably because the *non-affected* households tended to have higher incomes to start with; the capacity to regularly service debts also enabled them to borrow more, hence their higher debt loads.

In many places, debt is ubiquitous, and an unnerving share of poor households are mired in it. A recent longitudinal study of savings behaviour among poor households in Langa (Western Cape), Diepsloot (Gauteng) and Lugangeni (Eastern Cape) found almost one quarter of households were highly indebted (and almost 30% in Langa and Lugangeni) (Saldru, 2005). Whether affected by AIDS or not, households in the Free State study were spending the largest share of borrowed money (more than one third) on food – a reminder of how close to the edge many are living. Most of the loans came from relatives and friends, but roughly one guarter of the borrowing involved micro-lenders and moneylenders. Those persons who were employed often also borrowed from employers (typically against future wages). When it came to paying back debts, scarcely a difference between affected and non-affected households was noticed, however: both tended to devote similar amounts to repaying their debts each month.<sup>26</sup> But the lower incomes of most affected households meant debt servicing weighed much more heavily on them than on their non-affected neighbours (Booysen & Bachmann, 2002).

Among very poor South Africans, most saving and borrowing occurs outside the circuits of formal finance services. Few financial institutions have widened their client base in the past 15 years to include the poorest 30-40% of South Africans. The 'financial diaries' project (which surveyed poor households in Langa, Diepsloot and rural Lugangeni), for example, has found that rural households rely heavily on loans from family and neighbours and on lines of credit from convenience stores (Saldru, 2005). That such exclusion from the formal financial circuits is commonplace in rural areas seems unsurprising; less so, the fact that 43% of urban residents do not use formal banking facilities (SA Cities Network, 2004). All in all, fully 95% of urban and rural poor households are paying off debt each month, according to one recent study, and one quarter of them are regarded to be 'highly indebted'.27 This raises questions about the appropriateness of wider credit access to relieve the impact of shocks like AIDS illness and death, and whether it's perhaps likely to increase indebtedness and compound penury (see Microfinance section below).

As for savings, only about 50% of the households in the Free State study said they were currently saving. That proportion seems high. De Swardt (2003) found that between 76% and 88% of households in Mount Frere, Ceres and Cape Town had

<sup>26</sup> Surprisingly large amounts were being repaid each month – on average, debt servicing came to almost twice as much as monthly per capita expenditure in both affected and non-affected households.

<sup>27 &#</sup>x27;Highly indebted' means that debt payments on average absorb at least 20% of total monthly income. In this particular study, 24% of households were using an average 31% of their monthly income to service

debts. See Ayanda Shezi, 'Under the mattress or into the stokvel, SA's poor puts money away for a rainy day'. *Business Day*. 24 May 2005.

no savings whatsoever. Affected and non-affected households in the Free State study drew on their savings for very different reasons, though, with the former using their savings predominantly to pay for medical expenses and funerals, virtually extinguishing their savings in the wake of a death. Funerals are a massive expense; households in which a person died in the six months prior to being surveyed used up to 38 months worth of savings.<sup>28</sup>

The sale of assets has been shown to be a commonplace reaction to AIDS illness and death, according to studies in East and southern Africa and in Thailand. This tactic, though, seemed to feature less prominently in the Free State study, where most households preferred to take on more debt or use savings before selling assets. This suggests an active sense that the future must be guarded. The few households that did part with assets sold household appliances<sup>29</sup> – and they did so primarily to service debts, buy food, pay for funerals or finance education.

According to Statistics SA, only 15% of South Africans have any form of medical aid (a drop from 1995, when 18% belonged to medical schemes).\*\*

Almost 68% of residents in South Africa's 9 largest cities are not covered for any sort of risk and barely one quarter of them belong to a medical

aid scheme (SA Cities Network, 2004). The racial disparities in medical insurance coverage are shocking. Some 70% of whites belong to such schemes, compared with slightly more than 7% of Africans (roughly 2.7 million out of 37 million), just more 18% of coloureds and 36% of Indians. The lowest coverage is in the Limpopo and Eastern Cape provinces (6.4% and 9.6%, respectively).xl Indeed, lack of access to medical aid appeared to be the single most important predictor of poverty status in the Free State study. Households with medical aid seldom delved into savings (Booysen & Bachmann, 2002). Bear in mind, though, that medical aid is probably a marker for unionized or professional employment in many places – which yields the unsurprising observation that households are less likely to be very poor if members are employed in the formal sector in circumstances where their rights as workers are respected.

The majority of South Africans rely on the public health system; Booysen & Bachmann's Free State study (2003), for example, found 74% of persons in AIDS-affected households used state-run clinics or hospitals. (Nationally, it is estimated that 40 million South Africans out of the total population of 47 million rely on the public health sector – ljumba & Barron, 2005.) Among households surveyed by Steinberg et al. (2002), utilization of public clinics was high, as was the general level

of satisfaction with their services. By contrast, both the use of and satisfaction with public hospitals was much lower. Traditional healers were also the subject of frequent complaints.

Few of the affected households surveyed in the Free State study benefited from life insurance when a member died; just 7% received a lump-sum payment after a death (Booysen & Bachmann, 2002). This reflects high unemployment and the poor employment conditions of those who do find jobs, and presents another example of how the costs of adversity and misfortune end up being deflected back onto the poor themselves. With scant access to institutionalized forms of (subsidized) security, the poor have to absorb the additional costs themselves.<sup>30</sup>

In the absence of medical and life insurance, burial insurance is widespread. The Financial Diaries project found that more than 80% of participating households belonged to burial societies. All Nevertheless, most of households still had to draw on contributions from relatives, loans, savings and (when available) insurance pay-outs to cover funeral costs (Saldru, 2005), which indicates insufficient coverage. This is underscored by another study finding that households on average spent four times their monthly incomes on funerals, and that only 14% could cover the entire cost via membership of a burial

<sup>28</sup> When households not affected by a death use their savings, they seem to do so in a strategic manner; in the Free State study, for example, they dipped into savings to pay for education, maintain assets and repay debts (Booysen & Bachmann, 2002).

<sup>29</sup> Mainly stoves, refrigerators and TV sets – non-productive assets. A tiny number of households parted with productive assets, such as cattle.

<sup>30</sup> In the study, inheritances were rare and meagre. Fewer than 20% of affected households received an inheritance after a member died, and in most cases it comprised clothing and a few other items (Booysen & Bachmann, 2002: 17).

<sup>31</sup> This kind of fragility is not restricted to low- and middle-income countries; in the United States of America, with its astonishingly low levels

of medical insurance coverage and high health-care costs, fully half of bankruptcies appear to follow ill health. See James Morone (2005). 'Good for nothing'. *London Review of Books*, 27(10). 19 May – a book review of Sandage S (2005). *Born losers: A history of failure in America*. Harvard.

society, stokvel or with a commercial insurance policy (De Swardt et al., 2003).<sup>32</sup> Other research (in Mount Frere, Ceres and Cape Town) found that between 54% and 73% of households had burial life insurance (De Swardt, 2003).<sup>33</sup>

It's unclear, though, to what extent the very *poorest* households are using 'informal' forms of savings and insurance, such as 'stokvels' and burial societies. According to Ardington et al. (2004), the *poorest* households tend to access 'stokvels' at low rates because they draw limited benefit from such schemes. 'Stokvels' also seem to complement – rather than replace – formal financial services. As a result, they're often used by households who also have access to the formal financial circuitry in South Africa; double-fold exclusion, in other words. 'Stokvels' also are not typically used as a form of financial insurance for the proverbial 'rainy day'. Rather, they're used as saving tools for specific purchases or occasions (Saldru, 2005).

Again, though, observing households in isolation provides only a partial picture of reality. The 'financial diaries' project found that the most frequent financial impositions took the shape of requests to help other households pay for funerals – expenses conventional insurance schemes don't cover. Almost half the households had to make two or more such contributions over a 28-month period (Saldru, 2005) – another example of how the effects of death ripple between households. Both 'stokvels'

and various forms of funeral insurance (including burial societies) doubtless will come under further strain as mortality rates increase.

In the context of high unemployment and low incomes, it's no surprise that debt is ubiquitous. Here it's important to differentiate among the poor: the *poorest* 20% of income-earners have only marginal access to insurance, for example, and most are able to borrow money mainly from relatives (Ardington et al., 2004). Relatively secure employment seems to constitute the threshold; persons able to demonstrate stable sources of waged income are, in theory at least, able to open bank accounts, take out loans and buy insurance. Those outside this comparatively 'charmed' circle have limited access to the kinds of financial services that could enable them to afford spending more on education and health services, for instance, and thus potentially improve the odds that their children would not have to endure (as much) adversity.

#### To and fro

The apartheid state's capacity to regulate the movements of black South Africans began to fray already in the late 1970s and had effectively dissolved by the late 1980s. More than ever before, South Africans became a people on the move. Migration

into urban areas is often seen as the dominant trend in the subsequent period, but the image is a bit simplistic. Permanent migration into cities does not yet appear to be predominate, partly because circular migration persists and partly because of significant migration away from urban areas to rural areas. In addition, there is also large-scale migration between rural areas (SA Cities Network, 2004).<sup>34</sup> Among the telling changes under way are the increasing migration of people in their late teens, the fact that women now comprise a larger proportion of migrants than they did two decades ago, and the rise in city-to-city migration (SA Cities Network, 2004). All these trends could weigh significantly in the epidemic's future growth patterns, and in the ways in which it affects households and communities.

It's not clear yet what impact AIDS will have on migration and, more specifically, on urbanization patterns in South Africa. Generally, migration is assumed to rank high among the stock of responses poor households use when in distress. One widespread assumption – based as much on intuition as on observations elsewhere in Africa – is that terminal illness prompts many people to return to rural villages where family care and support is more likely to be available. However, there is very little South African research available to validate this. Booysen (2003) found only 'relatively weak evidence' that HIV status featured in migration from urban to rural areas among

<sup>32</sup> The average cost of a funeral was R5 513. The study was conducted in Free State, Gauteng, KwaZulu-Natal and Mpumulanga provinces (Steinberg et al., 2002).

<sup>33</sup> In Mount Frere, 8% of households had life insurance, in Ceres 20% and

in Cape Town 9% (De Swardt, 2003).

<sup>34</sup> In 1996-2001, South Africa's overall population grew by about 10%, while the population of its 9 biggest cities grew by 15%. But three cities accounted for much of that surge: Johannesburg, Ekurhuleni and Tshwane.

Increasingly, though, the fastest growth is occurring in secondary cities, including uMhlathze (Richard's Bay and Empangeni), Rustenburg and Polokwane (SA Cities Network, 2004).

Free State communities. Aliii This might be because the adjustments are more complex than meets the eye, with other family members simultaneously dispatched to urban areas to assume the role of the ill or deceased person (as a source of remittances and more) (see above). Indeed, the Free State households were more likely to lose a member (to migration) after having suffered a death.

With those caveats in place, some likely trends can be anticipated, even if the precise manner in which they conspire remains a matter for speculation. The generally-higher HIV infection levels in urban areas imply that South Africa's cities could experience:

- lower birth rates (due to the loss of large numbers of women of child-bearing age) and an accelerated decline in fertility;<sup>35</sup>
- an abnormal shortage of young adults (25-45 years of age);
- an increase in circular migration, if significant numbers of seriously-ill people return to their families in rural areas, and are replaced by other household members.

Such changes could affect the availability of and need for health care services. The inverse applies, too: unevenly available antiretroviral treatment could affect migration decisions. (Already there are anecdotal reports from elsewhere on the continent that free antiretroviral programmes are attracting 'treatment migrants'.)

Given that HIV prevalence levels tend to be higher in urban than in rural areas, and the possibility that significant numbers of people may opt to join parents or other family in rural areas once chronic illness sets in, the pace of urbanisation looks set to slow in some cities. It is possible that departures, higher death rates and lower birth rates could eclipse the number of newcomers to some cities. Indeed, Dyson (2003) speculates that South Africa's urban areas could become demographic 'sinks' from 2010 already. On the other hand, further weakening of rural livelihoods could spur greater migration into towns and cities, with new entrants corralled into the poorest zones of urban society - where they, in turn, might be especially vulnerable to HIV infection, other diseases and poor health. At this stage, however, we just don't know. Entrenched circular migration could modulate such trends in ways that are difficult to forecast.

For its part, the South African Cities Network envisages three scenarios: a handful of cities (for instance, uMhlathze, Johannesburg and Ekurhuleni) could continue to experience fast population growth, while others lag, or growth could slow to a stable pace in all cities, or growth could fade under the impact of under-population and the AIDS epidemic (SA Cities Network, 2004). A combination of the first and third scenarios seems probable, with large-scale inward migration persisting especially in those urban zones with significant economic growth (and perceived job opportunities), while population growth in other cities slides back significantly.

So much for quantifying the effects of AIDS on South African households. Behind, or within, these statistical patterns lurks another dimension of the epidemic's impact – the unequal ways in which its crumpling weight is distributed across society, communities and households. Nowhere is this more manifest than in that zone of the epidemic where kin and friends try to provide for the millions of South Africans who succumb to deadly illness.

# Out of sight ... The underbelly of home- and community-based care

One of the central shifts in post-apartheid health policy was the decentralization of health service delivery, with a greater emphasis placed on supporting communities. The central aim was to replace the fragmented and highly discriminatory system of health care provision established during the apartheid era with one that would be more equitable, efficient, accountable and 'empowering'. A unitary health care system was assembled, comprising four tiers (national, provincial, district and community), with a 'continuum of care' ostensibly linking and making available, in a rationalized manner, the resources and services of each level. This was to be a 'win-win' arrangement: benefits would flow downward to households and communities which would be able to participate in a sustainable, efficient and

<sup>35</sup> Recall that South Africa's fertility rate has been slowing for some decades now. A recent comparative study in rural KwaZulu-Natal, for instance, found that fertility has declined rapidly for about two decades, and that

HIV seroprevalence seemed to account for a small part (about 12%) of that decline. See Camlin CS (2004). 'Fertility trend and pattern in a rural area of South Africa in the context of HIV/AIDS'. African Journal of Reproductive

Health, 49. Available at http://www.ajol.info/viewarticle.php?jid=49&id=19509&layout=abstract.

enabling system of health-care, and upward in the form of greater efficiency and more attractive cost-benefit ratios. Greater equity was to be the watchword and the outcome.

The adjustments were in line with the thinking behind the 1978 Alma-Ata Declarationxliv, which had called for a shift from the curative, hospital-centred model to a primary care model. Thus an important element of the post-1994 overhaul of South Africa's health-care system was the bid to ensure that 'care in the community' became 'care by the community'.xlv But the shift also dovetailed with two vigorously promoted global trends. One was the forced retreat, dating back to the mid-1970s, of the state from its erstwhile role as guarantor of the public good. The other was a corresponding zeal for civil society, which, counterposed with the belittled public sector, came to be hailed as a zone of neglected resourcefulness, ingenuity and power. Elsewhere in Africa, the AIDS epidemic seemed to validate such precepts – underscoring the fiscal frailty of the state and highlighting the public health system's apparent inability to meet care needs. Home- and community-based care came to be regarded with reverence since the sheer volume of care needs in high-prevalence countries would swamp hospital and clinic systems. Limited public resources required that community organizations, NGOs and households step into the breach.

In theory, such adjustments are intended to combine the respective strengths of households, of the communities they help constitute, of the organizations they spawn, and of course of the state. By slotting home- and community-based care into a 'continuum of care' which links together the various levels and zones of the public health-care system and other role-players, the aim is to boost the quality, scale and sustainability of the care effort. In such a context, home-based care in South Africa is seen as a more humane and dignified form of care, 36 while community-based care is seen as a way of drawing on and enhancing communal solidarity and mutual assistance.37 Supported in various ways by the public sector and NGOs, care-givers at the home and community levels would, to the extent possible, tend to the daily needs of patients, provide emotional support and help patients draw on 'formal' health-care and other services (for example, accessing grants, etc.). This would occur against a backdrop of 'integrated services' that addressed the basic needs of people infected with or affected by AIDS to food, shelter, education, health care and more.

The reality is rather more profane. Home- and community-based care might reduce the cost of care to the health system (and state), but it does so in the main by displacing costs onto caregivers, patients and the neighbourhoods they live and work in – with women bearing the brunt (Mill, 2004). This happens

primarily in two ways. Firstly, patients (and care-givers trying to tend to their health and other needs) bear the cost of not receiving the levels of care and support they require – the consequences of which spill across households and families. Secondly, patients and care-givers themselves often subsidize care provision (investing their time, borrowing and lending money, paying for transport, consultancy fees, food and more). Thus the poor subsidize the poor. These appear to be wide-spread features of home-based care, not just in South Africa but elsewhere in the sub-region too.

The ascendancy of home- and community-based care needs to be understood in a wider historical context. Generally, the ethic of care as a household and community responsibility – its veritable 'privatization', consigning it to the sphere of the home – has coincided with the increasingly implacable subordination of social life to the rules of the market. Many of the assumptions and injunctions surrounding home-based care (and by extension also coping) dogma fit snugly with neoliberal discourse. As more dimensions of life and work are ceded to the rule of the market, the responsibility for providence and calamity, for life and death is lodged with ever-smaller units of society (and is ultimately, in the neoliberal ideal, ceded to the individual). Hence the loud iteration of household and community 'resilience', and its centrality in policy and strategy (see 'The fetish of coping', above). In practice, in a society like South Africa, the

<sup>36</sup> The definition in the National Guideline on Home-based Care and Community-based Care makes that much clear. It defines home-based care as 'the provision of health services by formal and informal care-givers in the home in order to promote, restore and maintain a person's

maximum level of comfort, function and health including care towards a dignified death' (African National Congress, 2001, cited in Mills, 2004:3).

<sup>37</sup> Thus the National Guideline defines it as care which 'the consumer can access nearest to home, which encourages participation by people,

responds to the needs of people, encourages traditional community life and creates responsibilities' (African National Congress, 2001, cited in Mills, 2004:4).

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model rests on and underwrites a status quo of unconscionable inequality. Neoliberal discourse, of course, tries to skip around such contradictions. It proposes, for example, that households' and communities' close knowledge of their circumstances and environment enables them to act as rational agents within a market-governed context. In theory, the market, by rewarding and penalizing various courses of action over time, not only confers a good deal of this accumulated 'knowledge' but also imbues households' and communities' actions with rationality (Rugalema, 2000). When ambushed by adversity, households juggle alternatives and take decisions which, however apparently unpalatable, ultimately yield rational and provident outcomes. Such assumptions, although rendered in slightly more fragrant manner, circulate also in many multilateral agencies' thinking. Hence the widely-embraced tenet that what's required to make home- and community-based care 'work' is a secondary, reliable infusion of support from other sources, including the state. The fundamental narrative of amoutated options and foreclosed alternatives is backhandedly endorsed as 'the way things are'.38

Fee-based access to the public health system is another facet of this worldview. It expresses an ethos in which health is transformed into an individualized commodity and responsibility, not a common concern nor a society-wide onus. One of the

many unpleasant aspects of stigma is the way in which it mirrors such a disposition and expresses the ethical realignment it requires. By attaching guilt and moral opprobrium to HIV infection, stigma legitimizes the decision to withdraw sympathy and assistance. AIDS is transformed from social plight into private misfortune, with the task of 'coping' assigned to the afflicted. The latter – hailed for their toil, inventiveness and endurance – are thrust centre-stage, while society recedes into the background. Indeed, research outside Lusaka (Zambia) has noted that the notion of care as a duty lodged primarily with affected households seemed to harden in the context of liberalizing economic policies (Baylies, 2002). Thus the diffusion of market ethics through society (including the imposition of user fees for health-care services) accompanied a process of social fragmentation and introversion, a process that AIDS stigma also spurs.

#### **Paradoxes**

South African history applies a further twist. Amid the apparently steadfast sense of shared responsibilities crackles a tension between two powerful trends. On one hand, an ethos of communalism and mutual obligation survives and is encoded in social practices and arrangements. A mere generation ago,

for example, it also took the form of political solidarity that helped trap the apartheid regime in a cul-de-sac. Since the mid-1990s, that ethos has been enlisted also in an avowedly Africanist project of ideological recuperation and self-identification that taps into indigenous popular practices, 'the capacity for innovation, reinvention of traditions and resurgence of native skills'.xlvi As a result, it now also forms part of the 'language' or signifiers of identity and distinction that circulate in South Africa. In this sense, the ethos appears to be in fine fettle. On the other hand, the fracturing impact of colonial and apartheid social engineering – and, in its wake, the ascendancy of values appropriate to the hyper-animated consumerism that governs increasingly large parts of social life – should not be underestimated. All this while poverty, joblessness and disease saps the support that can be proffered. Powerful dynamics have been shrinking the boundaries in which obligations and entitlements circulate, and the extent of support that is on offer.<sup>39</sup> It is within this material and ideological environment that home- and community-based care practices operate. An odd confluence occurs between two apparently contrary ideologies: ubuntu and neoliberalism. The guiding principles of communitarianism, mutual assistance and the bonding sense of shared destinies that underpin ubuntu provide a bedrock for the anticipated community-level resilience and solidarity that is expected to animate and sustain home- and community-based care. Indeed,

in paying school or health-care fees or rent. This underscores the need to waive at least certain fees and to extend and deliver state grants more effectively.

<sup>38</sup> Functioning as an alibi is the patronizing insistence that communities and households 'know best' – rather like observing that the homeless know best how to erect temporary shelters and therefore require help in sourcing the plastic sheeting, two-by-fours and nails. The partial (and cynical) appropriation of development theory's post-1960s tilt towards

bottom-up, grassroots processes of change is obvious.

<sup>39</sup> Mutangadura's (2000) research findings in urban and rural Manicaland, Zimbabwe, are instructive. Fully 95% of respondents said it was difficult getting relatives and friends to help with loans or child fostering. Community support mainly involved food and clothing, and rarely extended to assistance

in some estimations such reciprocity and solidarity are deemed to constitute an alternative measure of value, as Jean-Marc Ela has summarized: 'In African societies, the truly poor person is the one who has no kindred: the family spirit and the principle of reciprocity underpin economic ties within the mesh of social relationships'. xlvii The strategy of home-based care in particular rests on such assumptions. This is surprisingly compatible with a central thrust of neoliberalism - which is to absolve or at least excuse the state from its encompassing responsibility for social reproduction. On one hand, then, there is the distended faith in 'coping' capacities at community and household levels; on the other, government strategies are marked with an overarching obeisance to the market and its organizing principles. Around AIDS, these two, apparently contradictory, value patterns converge. This is not to disparage the associational flowering that ubuntu is meant to evoke and which home- and community-based care, in theory at least, could entail, but to underline the wretched inequality and exploitation this cloaks as 'normalcy'. Claude Ake's cautioning rejoinder to the celebration of 'an explosion of associational life in rural Africa', seems better aligned with reality:

By all indications, this is a by-product of a general acceptance of the necessity of self-reliance ... Some have welcomed this development as a sign of a vibrant civil society in Africa. It may well be that. However,

before we begin to idealise this phenomenon, it is well to remind ourselves that whatever else it is, it is first and foremost a child of necessity, of desperation even.xiviii

To pretend that home- and community-based care express a reanimated social solidarity that can supplant the logic and the ethics of the market is to miss the plot entirely. While the well-being of the poor becomes ever more precarious, additional burdens are being shifted onto them. Celebrating this as an expression of hardiness and vim, an affirmation of *ubuntu*, seems morally base. In practice, home- and community-based care displaces much of the burden of care into the 'invisible' zones of the home and the neighbourhood – and specifically onto women, most of them poor, many of them desperately so.

The bulk of household labour and care duties are performed by women. And when a woman, saddled with those duties, can no longer perform them, it is typically another woman who steps into her shoes, seldom a man. Home- and community-based care are melded into the largely invisible and taken-forgranted labour women perform in the care economy. As such, the model also reinforces firmly-entrenched assumptions about women and domesticity, about their roles as bearers of children, nurses of the sick, nurturers of families. It rests on and further entrenches the assumption that 'care' is what 'comes naturally' to women, effectively locking women even more securely into

the domestic sphere. 40 The circumscribed esteem and sense of worth this grants women should not be ignored. The burdens and responsibilities borne by women often are extraordinary, but the expectation they live up to stays an utterly conventional iteration that women shall serve, literally, as 'mothers of a nation'. It ratchets up the exploitation of women's labour, financial and emotional reserves – a form of value extraction that subsidizes the economy at every level from the household outward; little wonder that such 'enforced', free caregiving has been likened to levying a tax on women.xix

In sum, home- and community-based care is not 'cheap'. It only appears that way because the true costs are hidden, deflected back into the communities and domestic zones of the poor. Not only is this unjust, it also undermines the sustainability of care provision in the drawn-out crisis that AIDS presents. Expecting the poor to provide the backbone and lifeblood of care – with a minimum of structured support – is unreasonable and unrealistic.

South Africa's dual health-care system, of course, mirrors such disparity. One part of it is a profit-making venture, run by the private sector and fed with contributions to medical and other insurance schemes. Its clientele represent not only the wealthier but the healthier in society. Hence a good deal of its services are highly-niched and arcane. The other part is an overburdened public health sector. The danger, of course, was that the restruc-

assessments of care-giving projects in Khayelitsha, Gugulethu and Delft (Cape Town), 2004; personal communication.

<sup>40</sup> When quizzed, care-givers complain, for example, that they are expected 'to be always around home' and have 'to do everything'; as reported in

turing of the public health system – noble intent notwithstanding – would serve as a footnote to these much more robust and polarizing trends that shape health care provision and the allocation of resources across society in general. As a percentage of gross domestic product, public health expenditure in 2000 was 3.7%, while private health expenditure was 5.1%, an exceptional ratio that is seen in fewer than two dozen countries around the world (UNDP, 2003b).<sup>41</sup> In South Africa's health-care system, the principle of universalism lacks even a toehold.¹ This duality is not of the government's making, but it does define the quality of health-care provision and the terms on which it is provided. And it is expressed – and reinforced – in home- and community-based care.

#### Spreading the burden

The public health services are poor at doing outreach work, while the palliative care provided at public health facilities is, to put it generously, variable. Limited or inconsistent opening hours of health facilities frustrate and discourage future use, especially when the possibility of encountering locked doors or stock-outs has to be weighed against the transport and other costs the visit entails. Communication between state clinics and hospitals is uneven, and clinics often lack sufficient supplies. Patients and care-givers often are sent shuttling between clinics and hospitals to access various services or to acquire different

medicines (treks that involve additional transport expenses, sacrificing other chores, taking time off work, etc.). User fees deter or postpone visits until health complaints deteriorate. Staff attitudes are a regular source of complaint, while counselling services leave much to be desired. On the other hand, interactions with health care workers who do provide information, encouragement and emotional support typically has a morale-boosting and energizing effect on patients and care-givers. There are ample reports, too, of doctors and health-workers who venture far beyond the call of duty by personally financing step-down facilities, creating projects to provide orphans with food, subsidizing school fees, and more. Sadly, these appear to be the exceptions that underscore a dispiriting rule.

In such an erratic context, the 'continuum of care' relies heavily on the services of non-governmental organizations (NGOs) and community-based organizations (CBOs), and on the toil and resources of individuals. Most of the care projects in South Africa rely on neighbourhood volunteers who perform basic nursing and other care-giving tasks in patients' homes. They tend to emerge haphazardly, separately struggling along similar learning curves. By no means do they constitute a cogent response yet. Rather, the overall tenor is one of crisis management (Akintola, 2004).

The distinction is not watertight, but the support provided by NGOs and CBOs tends to divide into two categories: the provi-

sion of some form of health care and emotional support to the sick in their homes (effectively a kind of health outreach service), or motley assistance with food, school fees, day care services, grant applications and income-generation (Giese et al., 2003).

Assessments of self-initiated care projects report that care-givers often lack the basic resources they need to safely and efficiently perform their tasks. Home-based care kits are essential, and increasingly are being made available by government departments or funded by donors. In addition, better training and equipment is needed for performing care tasks, as well as psychological support and counselling. And sometimes the kind of knowledge that is lacking is about AIDS itself, and even about the fact that the person being cared for is HIV positive (Campbell et al., 2005). In such cases, basic precautions don't feature, and the care-giver risks becoming infected herself. When surveyed, care-givers routinely cite as major problems the mental and emotional strain their work entails. They are thrust into the roles of mediators, counselors, saviours. Yet they may not even be able to provide something as basic as a painkiller. Most rely on support from friends, colleagues and/or family but, when guizzed, they typically admit to feeling overwhelmed and alone (Giese et al., 2003; Ogden et al., 2004). The stereotypical image of the stoic, strong and silent 'woman of the house' is a blinding caricature. Although pummeled with emotional stress and physical fatigue, few, it seems, are able to benefit from mental health services.

<sup>41</sup> Only one of those countries (the United States of America) ranks in the top 60 of the UNDP's Human Development Index. Countries with similar

ratios include Brazil, Cambodia, Cameroon, Dominican Republic, El Salvador, Georgia, India, Kenya, Lebanon, Morocco, the USA, Vietnam and Yemen.

Stigma warps the process further. It affects whether and how people engage with the formal health-care system and with home- and community-based care initiatives. Care-givers have discovered, for example, that wearing uniforms of distinctive clothing when making home visits is guickly interpreted by neighbours as a tell-tale sign that someone in the house has AIDS. People are discouraged from participating in the initiatives. Often care-givers introduce themselves to neighbours and even other family members as 'a friend' of the patient. These forms of subterfuge do not always successfully shield them or their patients from stigma and abuse, which some caregivers say can be as debilitating and draining as the care-giving process itself. iii The stigma has an imprisoning effect, locking caregivers (who have often already reduced their social contact by relinquishing income-earning jobs) and patients even more firmly into a sphere of intensive domesticity and secretiveness. It's no surprise then that home- and community-based care projects that rely on volunteers report high attrition rates (Akintola, 2004).

The context in which care-givers work compounds the stress and includes difficulties in accessing formal health care services (even when they're free), lack of affordable transport, and generalized impoverishment.<sup>42</sup> Indeed, they are quickly confronted with the multifaceted problems and needs that patients and their families bear. In Akintola's (2004) summary:

A home-based care project may start with caring for sick individual adults, but over time, has to confront needs such as child care services for sick parents, provision of material support for the affected families and, ultimately, orphan care services ... The evidence from South Africa is that most care organizations do not have the resources to take on these services, such that the burden of trying to provide such assistance is carried in practice by the care-givers. Grandmothers, mothers, sisters, women friends and neighbours of the sick thus bear the actual burden of trying to meet the changing needs and demands of sick people and their families.

Essential needs – such as food and money for other basic necessities – often go unmet (Mills, 2004; Campbell et al., 2005). As a result, many home-based care projects are having to incorporate food relief into their work, sometimes at the expense of other tasks if staff and resources are limited. When a need as elemental as a square meal goes unmet, the 'continuum of care' is effectively robbed of meaning.

Home- and community-based programmes in Uganda acquired a character different from those being seen in South Africa. There, attempts were made to professionalize care provision, and greater effort went into trying to co-ordinate and network the various types and levels of care-giving activities. Volunteers played a pivotal role in identifying and supporting

ill persons and providing them with basic care, but they in turn were supported by mobile teams of professionals. As a result, according to Akintola (2004), the programmes in Uganda were 'community-oriented', whereas those in South Africa tend to be 'community-based'. Is such an experiment feasible in South Africa? One is tempted to answer 'Why not?'. By some accounts, many communities already boast cadres of grassroots health workers; what's lacking is the will and the way to tap into this resource (Campbell et al., 2005). These workers need training, support and stipends to cover basic expenses – all eminently reasonable and, judging by many care-givers' accounts, necessary steps. Unfortunately, it's doubtful whether many health facilities currently are able to perform consistent outreach work; staff shortages and the lack of transport are among the many shortcomings cited.

The paucity and inconsistency of institutional support is the single biggest weakness in home- and community-based care currently. Against a backdrop of rampant impoverishment, the skewed distribution of care duties (mainly among women, most of them poor), and burgeoning need for care, it is vital that the state identify and, drawing also on the assets of other sectors of society, implement mechanisms for providing better and more reliable support to poor households and communities that are engaged in community-level responses (Giese et al., 2003).

munication. Among the surveyed care-givers, 95% were women who ranged in age from 18 years to 69 years.

<sup>42</sup> Assessments of care-giving projects in Khayelitsha, Gugulethu and Delft (Cape Town), for example, exemplify these experiences; personal com-

Projects should, for example, be able to provide volunteers with stipends or honoraria in order to lower drop-out rates and reduce the financial strain on care-givers. This could be done in tandem with some form of monitoring their care-giving work. The experience with government grants suggests that the benefits of such stipends would stretch beyond the recipients themselves and reach relatives, as well – investing them with a redistributive quality (see below).

Better co-ordination and stronger collaboration between different government departments is needed at the local level. In some respects, the rudiments are in place; in education, for example, school feeding schemes, the national life-skills programme and the formal guarantee of free basic education for children entail collaboration between various departments (health, education and social development). But the coverage of those initiatives is patchy; greater effort must go into ensuring the commitments are met.

#### Adjusting perspectives

In a sense, such adjustments would still leave one aiming far too low, so low that efforts almost surely will be swamped by routine privation and strain. A much wider-angled perspective is required, one that recognizes and establishes as a starting point the fact that the social template on which home- and community-based care has to operate not only harbours the potentialities of communal solidarity and support, but is also defined by recurring and multifaceted distress, needs and ine-

qualities. Valuable as technical adjustments are, their scope ultimately is decided elsewhere in the system – by the over-arching dynamics that determine the distribution of privilege and deprivation. The sights of change have to be set higher. This is *not* to flippantly contrast 'tinkering' with 'structural change'. Ensuring that support programmes (existing and new) evolve fully from plan to reality, that care-giver stipends are financed, that funding, procurement and distribution systems reduce clinic stock-outs – all this is vitally important. But alone, it's not nearly enough.

The 'continuum of care' has to be conceived of as an aspect of a more encompassing 'continuum of well-being'. One elemental feature would be the phased decommodification of essential services (including free basic health-care with a particular emphasis on palliative care), as well as stronger measures to combat hunger and malnutrition, and ensure food security among the poor. This implies investing South Africa's development path with a much stronger redistributive character. Few dilemmas exemplify this as clearly as the pitiless absurdity that leaves people unable to adhere to a life-prolonging drug regimen because they cannot afford food to eat. The AIDS epidemic reminds us that what passes for the commonplace, what constitutes routine for millions of South Africans is extraordinary but, tragically and unconscionably, not unusual. If nothing else, this epidemic highlights the central challenge we face - which is to make what is today the harrowing routine of millions, the extraordinary ordeal of a few. AIDS present us with the opportunity to right our perspectives, realign our priorities, repair our strategies.

# Home alone – orphans in the age of AIDS

'A country like ours has to deal with that. That mother is going to die, and that HIV-negative child will be an orphan. That child must be brought up. Who's going to bring the child up? It's the state, the state. That's resources, you see.' – Parks Mankahlana, President Thabo Mbeki's spokesperson at the time, in *Science* interview, 2000

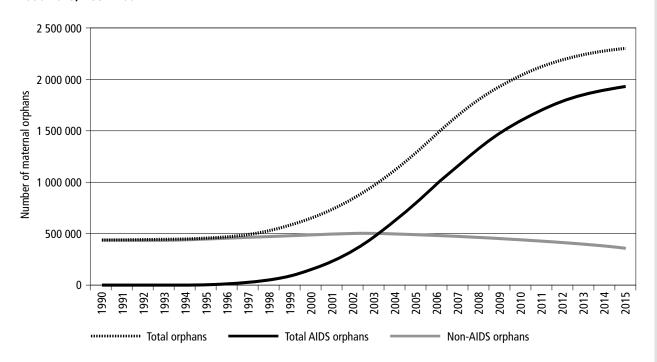
An outcome of the AIDS epidemic's still-rising death toll in South Africa, the number of children orphaned by AIDS is expected to peak around 2015 (Dorrington et al., 2004). These orphans constitute the 'fourth wave' of the epidemic – the first being a rising number of new infections (HIV incidence, which appears to have peaked in the late 1990s in South Africa), followed by rising HIV prevalence (estimated to have reached its zenith in the early 2000s) and rising numbers of AIDS-related deaths (which are expected to peak around 2010).\(^{\text{IV}}\)

How many children are being orphaned by AIDS? The estimates vary, partly due to changing definitions of orphans (see box). UNAIDS in 2004 estimated that there were between 710 000 and 1.5 million children younger than 18 years who had lost one or both parents to AIDS in South Africa (UNAIDS, 2004a). The number probably errs on the high side, possibly because it is derived from assumptions that overestimate the maturity of South Africa's AIDS epidemic. A more reliable guide is the estimate arrived at by the ASSA 2002 AIDS model.

It indicates there were over 1.1 million orphans in 2004, more than half of whom (626 000) had been orphaned as a result of AIDS. The model forecasts a steady increase in the number of children orphaned by AIDS, which could exceed 1.9 million and push the total number of orphans in the country to over 2.3 million by 2015 – more than twice the number in 2005 (Dorrington et al., 2004).

This poses two, tandem challenges: limiting the rise in orphan numbers by radically expanding antiretroviral (ARV) treatment programmes, and dramatically strengthening efforts to realize children's (including orphans') rights to a stable and secure upbringing. The ASSA model suggests that a significantly scaled-up ARV treatment programme could, by 2015, reduce by half the number of children who have lost a mother to AIDS (Bradshaw et al., 2002).

## Projected number of maternal orphans under the age of 18 years due to AIDS and other causes of death for 1990-2015, ASSA 2002<sup>Ivii</sup>



Source: ASSA 2002

#### What's in a word?

The age limit used in some orphan calculations is 15 years, despite the fact that children generally (and certainly in the South African Constitution) are defined as persons younger than 18 years. In addition, orphans have been variously defined as children who have lost their mother ('maternal orphans') or both parents ('dual orphans') or either of their parents. Each definition, of course, yields different orphan estimates. The UN system now defines as children orphaned by AIDS those children under the age of 18 who have lost one or both parents to HIV. Mili The ASSA model's definition of orphans (children under the age of 18 years who have lost a mother or both parents) is narrower than that used by UNAIDS. Were the ASSA 2002 model to apply the UNAIDS definition, the difference between the two projections would likely narrow.

There is a tendency to automatically equate orphanhood with vulnerability, but in the southern African context, a more elastic definition of 'orphan' probably needs to be used. This is because the model in which the child-bearer is necessarily and constantly also the child-carer does not apply universally. Significant proportions of children who are not orphaned live mainly with only one of their parents, and both orphans and non-orphans are often placed in the care of relatives, where they experience a variety of living circumstances, propitious

and otherwise. A study by the government of Botswana, for example, has found that just 40% of primary school children with both parents alive were living with both parents most of the time (Botswana, 2000). In South Africa, too, such fostering is commonplace. One study found that almost 30% of orphans in rural KwaZulu-Natal were not resident with either surviving parent (Hosegood et al., 2002). Because so many children live with relatives for varying durations, the illness or death of such a foster parent can have as great an impact on a child as the death of a natural parent. On the other hand, not all orphans are necessarily 'vulnerable children' (Meintjies et al. 2003b).<sup>43</sup> And those who are, do not necessarily become vulnerable only when orphaned; with terminal conditions such as AIDS, that process often starts long before a parent or care-giver dies (Giese et al., 2003). All this, as we shall see, has vital bearing on the appropriateness and viability of responses to South Africa's emerging orphan crisis.

#### **Expecting the worst**

The death of a parent or primary care-giver is one of the biggest traumas a child can experience. Anguish and bewilderment are common reactions to seeing someone you love wither, but the death of a parent tends also to rupture a child's sense of

security. A fairly consistent roster of reactions is associated with children who have lost a parent: low self-esteem, depression, anxiety and occasionally aggression. When AIDS or another debilitating disease is the cause, the ordeal will have started earlier, as the parent or care-giver succumbs to illness and loses the ability to support his or her children. It's at this stage, too, that a reversal of parent-child roles sometimes ensues, with the child having to assume 'adult' duties (Smart, 2000). If AIDS is the culprit, the odds are high that the child's other parent will also succumb. In high-prevalence countries, the orphan's caregiver may also fall prey to the epidemic (though this is less likely to happen when the care-givers are elderly). The child's suffering could be aggravated further by being separated from his or her siblings. Compounding this is the stigma that still clings to AIDS, and the social abandonment it can cause – all of accumulating into what Stein (2003) describes as a kind of 'social death'.

Who takes care of a child who has lost a parent? The answer highlights one of the recurring disparities in the epidemic: the inordinate responsibilities women bear. It's not always the surviving parent who raises orphaned child(ren); they are much more likely to remain with a surviving mother than with a surviving father. Overall, it is mainly women – either the surviving mother, a grandmother or other female relative – who take care of children who have lost a parent, as several surveys have shown (Monasch & Snoad, 2003). Often, they are assisted by the eldest of the children who assume some adult roles (with girls taking on additional roles) (Mutangadura, 2000). According

to a review of data from 40 sub-Saharan African countries, one in three orphans was living apart from his or her surviving parent (Monasch & Snoad, 2003). According to Ainsworth and Filmer (2002), maternal orphans in East and southern Africa were much *less* likely to be living with their fathers than their counterparts in other regions of the world. In Zambia, for example, just 40% of maternal orphans were living with their fathers, compared with 74% of non-orphans (Case et al., 2003).

Another disparity reveals itself in the fact that households with orphans tend to be poorer than households without orphans – at least in the 10 African countries<sup>lx</sup> surveyed by Case et al. (2003) Households with orphans also tended to contain more elderly persons, and were usually headed by a woman.

Much of the literature emphasizes the heightened risk of malnutrition, interrupted or stunted schooling, vulnerability to exploitation and abuse, and social maladjustment orphans face. It's generally believed that orphans are at greater risk of malnutrition, illness, early school termination, physical and sexual abuse, and sexual exploitation. Many also have to contend with the stigma and discrimination associated with HIV/AIDS, which may also deprive them of basic social and education services. These expectations tend to be stitched together from various study findings (mainly from East and southern Africa, and Thailand), some of them interpreted with a degree of licence. The composite image arrived at is one of children 'cast to the fringes of society' and 'left to fend for themselves in a world

where life is often "short, nasty and cheap" (Pharaoh, 2004). Tragically, this does describe the lives of some children and their numbers will probably grow as the AIDS epidemic worsens.

#### Cue: Panic

An even darker current of received wisdom has acquired prominence in recent years. It forecasts that the blighting experiences awaiting many orphans will spawn large numbers of maladapted, traumatized and aberrant children, many of them doomed to become fodder for criminal gangs, vigilante groups, paramilitary adventures and worse. The anticipated chain of effects runs roughly as follows. High AIDS mortality will lead to a massive increase in orphans, large numbers of whom will grow up with untended traumas, stunted schooling lxii, inadequate nourishment and poor health, and abnormal socialization – all of which will sabotage their prospects of participating productively in social and economic life. Lacking appropriate family environments and role models, many of them will be poorly schooled in responsible social citizenship and will fall prone to antisocial behaviour and delinquency, possibly in large enough numbers to threaten social stability and even trigger social breakdown (Bray, 2003). Featuring even in otherwise

well-reasoned documents, bill such soothsaying is in wide-enough circulation to have acquired the status of self-evident 'truth'.

The heritage of these panicked scenarios to some extent also betrays their weaknesses. Although the AIDS epidemic had, by the mid-1990s, acquired a ferocious grip in some of the poorest countries in the world, the response from most Western governments ranged from maudlin concern to aloof indifference. In order to spark greater commitment, advocacy efforts of multilateral agencies increasingly sought to couch AIDS in geopolitical terms, one of the tactics being to present it as a potential threat to political stability and security:

A State less able to provide social services (be they education, health or justice) may unwittingly foster political alienation and weaken its own political legitimacy. Through its impact on both State and community capacity, AIDS can thus contribute to social disruption and perhaps even civil unrest (UNAIDS, 2002:58).

Orphans have been made to occupy a central part in such narratives of insecurity, breakdown and collapse, with the conjecture often tracing a 'diseased-like' sequence of atrophy:

In countries where institutions and social capital are already weak, HIV/AIDS may lead to a virtual social collapse, with problems related to crime, vast numbers of orphaned street children growing up in anxiety and without adult role models, drugs, prostitution, violence and social strife reaching levels which directly affect the economy in a disastrous way through mechanisms such as capital flight, accelerated brain drain, collapse of domestic and foreign investment, etc. (de Vylder, 2001:18).<sup>44</sup>

Orphans have been cast in the role of alienated, antisocial and enraged outcasts, prone to crime, violence and worse. The imagery is that of swarming gangs of delinquent youth. Occasionally, the speculation has degenerated further into grasping attempts to yoke AIDS, orphans and an increased threat of terrorism into a chain of causation, spawning claims that 'it is undeniable that AIDS, and the deadly conflicts that have ravaged Africa, have created a steady stream of orphans that can be exploited and used for terrorist activities' (Neilson, 2005).<sup>45</sup> One hitch in this apocalyptic outlook is so obvious that, like the proverbial elephant in the room, it escapes notice: the forecasts busy themself mainly with male orphans, since delinquency, violence and crime are preponderantly male phe-

- 44 To be fair, De Vylder goes on to sketch a picture in the 'very long term' which is characterized by the stigmatization of extra-marital sex and prostitution, challenged and changed gender norms, a more open attitude to sex and reproductive health and strengthened civil society. But, like the cataclysmic variant, this is little more than speculative whimsy. Any number of other variants can be imagined. Garrett (2005:11), in a Council on Foreign Relations publication, has linked the orphan-security fears to 'youth-bulge' demographics, whereby the premature deaths of large numbers of adults distort demographic structures and inflate the proportion of young people in society: 'There is strong evidence that societies with such dramatic youth-bulge demographics are at greater risk of civil disturbance,
- conflict and disorder. While the predicted tends of millions of children who will be orphaned by HIV/AIDS do not individually constitute threats to the state, failure to provide these children with services and education that can foster productive contribution to the labour force and social order may well exacerbate the youth-bulge effect.'
- 45 This particular 'discussion paper' ranks among the more noxious examples of this line of advocacy. It was released during the annual meeting of the World Economic Forum in Davos, Switzerland, by the Global Business Coalition on HIV/AIDS in January 2005. Its press release claimed that the paper 'analyzes the link between the 12 million AIDS orphans that now live in Africa, and the long tradition of using child soldiers for non-traditional

warfare and terrorism on the continent' and urges that 'the AIDS orphan issue should not just be seen as another "humanitarian" issue, but rather as a legitimate security concern'. AIDS, the paper warns, represents a potential 'national security crisis for the US and other western states'. See 'Global Business Coalition on HIV/AIDS releases new paper on link between AIDS and terrorism'. Press Release. 26 January 2005. Global Business Council on HIV/AIDS; and Neilson, T (2005). AIDS, economics and terrorism in Africa. Discussion paper (January). New York. Global Business Coalition on HIV/AIDS.

### TRUE GREATNESS

nomena everywhere in the world. So, whether valid or not, the scenario speaks to only 'one half' of orphans. In keeping with predominant stereotypes, girls and young women are presumed to bear their plight in stoic, unseen solitude. More generally, though, the reasoning behind such scenarios is slipshod, the evidence feeble and the ethics grimy.

#### The colour of fear

At face value Hobbesian, the doomsday-orphans scenario and its imagery of feral youth belongs in a long and execrable tradition of racially-tinged contempt for the underclasses. Wittingly or not, it is anchored in the assumption that the default state for the Other, once abandoned to the fringes of 'civilized' society, is that of barbarism. The notion has retained strong appeal down the years, and erupted garishly again in the media reports when Hurricane Katrina crashed through New Orleans, in the U.S.A., in August 2005. Sometimes varnished with concern but always laden with contempt and terror, it has been used to frame everything from 'law and order' campaigns to imperial crusades. It enjoyed pride of place in apartheid discourse, and was deployed widely during the demise of that

system, when the spectre of an uneducated, undisciplined and unrealistically-expectant 'lost generation' of youth caused consternation at all ends of the political spectrum. A decade ago, even liberal South African journalists were agonizing over 'marauding cohorts of youngsters – depraved, as the song puts it, because they are deprived – whose behaviour is so savage as to arouse the impulse towards counter-violence'. but Thus, the underlying assumptions of the feral 'AIDS orphans' branding ring oddly familiar in South African ears, as Nattrass (2002) has noted. The demonization of male youth that has seeped into AIDS discourse drifts along a similar route: 'Crime will increase because of the disintegration of our society ... Children orphaned by AIDS will have no role models in the future and they will resort to crime to survive.'

Three discursive currents converge here – one a 'language' that has been used to describe and 'apprehend' Africa since the advent of colonialism, one a 'language' used to legitimize an idealized state of normalcy and to demonize 'deviance' (and for the past several decades customarily directed at young black men), and one a 'language' of inclusion/exclusion that typifies AIDS discourse. <sup>47</sup> These trains of thought tend to regard the deprivation, hurt (and, for many also, abuse) that frame child-

hood for so many young South Africans not as an indictment of state and society but as preludes to law-breaking, delinquency and crime, and which call for special disciplinary measures:

[M]any such orphaned children will grow up under impoverished conditions which will increase their temptation to engage in criminal activity at an early age [...] Traditional methods of fighting crime, such as tougher laws, more policy officers and more prisons will do little to counter this [...] Adequate staffed and resourced juvenile detention centres, rehabilitation and diversion programmes for young offenders, and an effective children's court system should also feature prominently on the government's list of priorities (Schonteich, 1999).

Like the coping pieties (see above), this implies that the baseline state of affairs – the-way-we-are – represents normality<sup>48</sup>, which is now destined to be wrenched apart by a surge of deprived, maladjusted discontented orphans. It positions orphans as the problem, allowing social and other dynamics to recede into a distant, foggy 'context'. What's more, it is based on feeble evidence.

David Philip, Cape Town. The Spanish, meanwhile, pontificated with assurance about subhuman 'wild men' that inhabited the fringes of the known world. See Friedman JB (1981) *The monstrous races in medieval art and thought*. Cambridge, Mass., cited in Frederickson GM (2002). *Racism: A short history*. Princeton University Press. Princeton. But more endemic and enduring is the imagery that pictures young male Africans as tenuous members of civilised society, always at risk of straying across the threshold of depravity and irrationality.

<sup>46</sup> These sorts of portrayals gained loud currency in the heydays of European colonialism. At one extreme lay the comical fantasies of figures such as the 17th century historian and 'travel writer', Olfert Dapper, whose Description of Africa included a catalogue of African 'tribes', among them the Cynocephales (said to resemble dogs and capable of barking) and the Blemmyes (who lacked heads and whose eyes and mouths were mounted on their torsos). Dapper, by the way, is said never to have ventured outside Amsterdam; see Breyten Breytenbach's Return to Paradise (1993),

<sup>47</sup> AIDS discourse is replete with such binary logic. In this case, one pertinent example is the inclination to distinguish 'AIDS orphans' (or 'children orphaned by AIDS') from other orphans.

<sup>48</sup> That assumption can also be found in some of the writing that takes a more sanguine line, such as Foster (2004), who claims that less than 2-3% of orphans live without support or are being exploited. Given the endemic impoverishment in the societies he reviews, one shudders to imagine what these '2-3% of orphans' are enduring.

#### Intolerably ordinary

Reviewing the literature, Bray (2003) has found mixed evidence regarding the effects of AIDS orphanhood on child well-being, but encountered no empirical evidence demonstrating a link between AIDS orphanhood and rising rates of juvenile delinquency, or encroaching social breakdown. Stein (2003), too, has found that the general research evidence on orphanhood does not point to so-called 'conduct disorders' and delinquent behaviour. Much of the writing, Bray concludes, is misleading and diverts attention away from 'the multiple layers of social, economic and psychological disadvantage that affect individual children, families and communities' (Bray, 2003:7).

The AIDS epidemic almost certainly will transform childhood into an ordeal for many more children in poor communities. But no simple, linear link can be drawn between such hardship and a putative psychosocial explosion, as both Richter (2004) and Killian (2004) have argued. That process of 'collapse' or 'disintegration' tends to occur if a series of filtering or braking factors fail or are absent. Are children surrounded by caring adults and social support, and do they have genuine prospects of recovery, changing their circumstances, striking up new relationships? If the answers tend to be 'no', the odds of maladjustment shorten (Pharoah, 2004). It's not so much about the 'condition' of orphanhood per se, therefore, but about how children – including orphans – are treated, the conditions they live in,

the affection and support they receive, the opportunities they can grasp.

The evidence points to outcomes which, perhaps, are even more disheartening than the jittery scenarios of breakdown and implosion. Often children respond to systematic deprivation, mistreatment, trauma and stigmatization not by 'expressing' their pain and insecurity but by inverting it. Depression, low self-esteem, passivity, withdrawal and social isolation, lack of motivation (along with somatic complaints, and the physical symptoms of poor growth and health) become common (Richter, 2004; Stein, 2003). Ixvii It's a kind of disappearing that occurs; these are children who are imploded, who are collapsed into themselves, banished into a kind of invisibility. Again we encounter this, by-now familiar, theme of 'disappearance', of a retreat into twilight zones, into a kind of imprisonment. kviii It is a powerful but overlooked thrust of the epidemic, the way it sequesters and desocializes, polarizes and divides – while, at the same time, providing a 'language' and experience of distinction, enabling people to define themselves by way of exclusion and elimination (not HIV positive, not an orphan, not promiscuous, not at risk).

As Bray (2003) has argued, it's the routine experience of impersonal care and/or abuse that can prime more overt and possibly 'antisocial' reactions over time – such as difficulty demonstrating compassion, and a tendency toward aggression or even violence

– not the sheer absence of 'role models' or 'father figures'. What matter are the kinds of care, the sorts of role models, the types of parental guidance a child experiences. In this view, the chain linking mass orphanhood with delinquency, crime and social instability is flimsy. The issue is not so much orphanhood per se but the punishing realities in which many orphans and other children (are likely to) grow up. The danger is less the fact of orphanhood than the social arrangements that permit the exclusion, abandonment and abuse of children, orphaned or not. More than the loss of one or both parents, it's these experiences – along with the stigma associated with AIDS – that do the most damage. <sup>49</sup> Indeed, Stein (2003) is correct in criticizing the ways in which the labelling of AIDS orphans as delinquents and criminals entrenches the stigma the children experience at all levels of society.

None of this warrants a sanguine outlook. Whether or not all this is likely to precipitate collapse and carnage is not really the issue. What matters is the failure of society to protect the weak and the largely defenceless against harm and suffering. Demonstrably, South Africa fails on this front; and as AIDS scythes along it will probably fail on an even larger and more horrific scale. Many children, far too many, are already falling through the cracks, suffering abuse and neglect at the hands of parents and care-givers who, very likely, endured similar childhoods. Decades of apartheid corroded the capacity of family and other social networks to shield children against

<sup>49</sup> Stein also makes the important observation that the research foundations for our current understandings of how children in Africa deal with

neglect and abuse. Whether they can absorb the additional strain of the AIDS epidemic is moot. These mechanisms have to be repaired, adjusted and fortified.

#### **Unbreakable?**

Fostering is a common form of support in South Africa (and the rest of the sub-region) and is often used to enable households and individuals to weather distress or establish new forms of livelihood. But as the demand for fostering grows, how strong and adaptable will this capacity prove to be?

One study in a rural region of Uganda found almost no evidence of child-headed households (Floyd, 2002), while a Zambian study concluded that almost all the orphans surveyed were being cared for within their extended families (Nampanya-Serpell, 2001). In the late 1990s and early 2000s, much of the fostering demands in Zimbabwe were still being absorbed by 'extended' families, but some studies (for example, Mutangadura, 2000; Nyamukapa et al., 2003) were encountering signs that this system of child-care was beginning to crumble as the number of orphans rose and socio-economic hardships worsened. A 1999 UNICEF study in two Zimbabwean districts found that 11 000 of 11 500 orphans and vulnerable children were being cared for by relatives in the community – though

mostly by older women, many of them widowed (UNAIDS, 1999). bxix

The still-largely anecdotal evidence from South Africa suggests that the safety net might prove to be more threadbare than assumed. For at least the next decade. the total number of orphans in South Africa will keep growing and is expected to peak at roughly 2.3 million – almost four times greater than it was at the turn of the century (Dorrington et al., 2004). Set this outlook on a social landscape in which many millions of households experience chronic impoverishment and it seems foolhardy to stake unmitigated faith in the 'resilience' and grit of extended family networks. A 2002 South African survey of AIDS-affected households concluded that the extended family safety net was still holding, though beginning to fray (Steinberg, 2002:23). Indeed, not all orphans are being absorbed into fostering arrangements. Some 3% of households were found to be 'child-headed', according to the Nelson Mandela/ HSRC (2002) study. Subsequent anecdotal reports speak of a steadily worsening situation.

Foster (2000) has argued that safety net mechanisms for the care of orphans were weakening in many African countries even before the arrival of AIDS, which has aggravated that process and prompted new responses. One is the increasing number of grandparents saddled with fostering roles. Another is the emergence of childheaded households, often as a consequence of a grandparent's illness or death (Foster, 2004).

An epidemic that causes high mortality rates in the 25-45-year age bracket to soar alters erstwhile fostering arrangements, with the burden shifting preponderantly onto the elderly, particularly women. Current research is not yet adequately capturing this important aspect of the epidemic's impact: the added burdens that now characterize fostering arrangements, and the various ways in which foster parents (especially the elderly) are having to respond to those ballooning demands. A review of demographic and health surveys (Bicego et al., 2003) found that in Zimbabwe 50-55% of orphans lived in households headed by grandparents. In general, in the 17 sub-Saharan Africa countries studied, orphans were more likely than non-orphans to be living in female-headed households. Findings from South Africa conform with those patterns. In Welkom and QwaQwa (Free State province), one in five households not yet directly affected by AIDS were sheltering orphans in 2001, as were one in three affected households. More than 80% of households sheltering orphans were women-headed, and more than 60% of those women were widows (Booysen et al., 2002).

When elderly care-givers of foster parents die or when illness forces them to seek refuge with other relatives, the children arrive at yet another crossroad. The young among them might be taken in by other relatives, but their older siblings are sometimes left living together (though often supported by relatives and neighbours). The reasoning varies and might reflect a reluctance to split up brothers and sisters from one another, or it might be an attempt to avoid losing the deceased parent's homestead.

Child-headed households endure enormous difficulties. Their abilities to meet basic needs, achieve a semblance of good health, attend school and acquire life skills and knowledge are deeply compromised. Nevertheless, Foster (2004) has contested the image of child-headed households as being entirely abandoned and bereft. Such households tend to be temporary arrangements, he argues, with the children eventually taken in by relatives who earlier had shunned that responsibility. And they often receive some form of basic support (such as food and clothing) from relatives and neighbours. Provocatively, Giese et al. (2003:xiv) have gone further to claim that 'if adequately supported (a crucial caveat), children living alone can find themselves safer than if living with adults'. In Foster's (2004) view, it is mistaken to picture child-headed households as uniformly vulnerable and precarious, though he acknowledges that many are just that. His suggestion that 'some cases can be viewed as a new mechanism to cope with the impact of AIDS' (2004:73), however, seems unduly optimistic. 1xx Rather than describing an expedient

way forward, the idea that child-headed households constitute a potential 'coping mechanism' stands as an indictment of society.

#### Degrees of deprivation

Are children orphaned by AIDS worse off than other orphans? We cannot say, for there is a dearth of studies that enable a clear comparison of that sort to be drawn. Intuitively, the endemic presence of AIDS-related stigma – and the confusion, anxiety and social isolation it spawns – would seem to have a poisoning effect. Even here, though, the available evidence is less clear-cut than one might expect. As Stein (2003) reports, one attempt to compare peer problems experienced by children orphaned by AIDS with those of non-orphans seemed to find no significant discrepancies, except for this harrowing one: 97% of the orphans said they had no close friends.

Beyond that, it gets murkier. One the whole, available evidence seems not to merit many unequivocal assertions about the comparative experiences of non-orphans and fostered orphans. (There is one exception, though: as Pisani (2003) has pointed out, there is no proof that orphaned girls are more likely to drop out of school than are orphaned *boys*.) Orphans who are not in foster care are almost certainly worse off than other children, and, according to some studies, even those in foster care tend to live in poorer households than non-orphans. But

the assumption that children, by virtue of their orphan status, are consistently worse off than other children - or, to invert the notion, that children who have not lost a parent are consistently better off than those who suffered such a loss – seems open to questioning. South Africa's socio-economic conditions, the persistently high prevalence of chronic diseases, and the swath cut by the AIDS epidemics virtually guarantee that much larger numbers of children will lack having needs as basic as regular meals and elementary health-care met, will have their schooling retarded or halted, will shoulder responsibilities typically associated with adulthood, and will do this while dazed by trauma and grief. Many of these children will be orphans, most of whom will have been orphaned by AIDS. However, many others will not be orphans, yet will be living in equally strenuous circumstances. As Pharaoh (2004) reminds us, 'the conditions in many poor communities mean that few, if any, of these effects are specific to children affected by HIV/AIDS' (2004). When privation is this common, reductionist distinctions between orphans and non-orphans can serve poorly as a programming compass.

Interpretations of the evidence can be grouped into two, broad camps. One supports the view that there generally are few significant and consistent differences between the experiences of orphans and those of other vulnerable children. And it associates those differences that do occur mainly with overarching dynamics such as impoverishment and inequality. The other suggests that the different experiences are acute and are symptoms of systematic discrimination against orphans.

Many of the studies gathered in Pharaoh (2004) suggest that the experiences of orphans and other children affected by AIDS do not qualitatively and consistently differ from those of other poor children. Earlier, Foster and Shakespeare (1995) arrived at similar conclusions. The underlying assumption is that orphans are routinely cared for as part of the ongoing allocation of resources and responsibilities that occurs in networks of families and friends – and that financial hardship is spread more or less equally across the entire household. Orphanhood, in these settings, is not regarded as an exceptional status, and orphans do not face particular socio-economic disadvantages compared with equally poor non-orphans. Dociii

In Botswana, for instance, a report by the Ministry of Education concluded that school drop-out rates among orphans were not significantly different from drop-out rates among other children. (Botswana, 2000) This may be in part because food rations and other material support for uniforms, transport and accommodation might have functioned as a positive incentive to enrol all children (Pisani, 2003). Yet, in western Kenya, where school drop-out rates generally were high (partly because of user fees), orphans were no more likely to drop out of school permanently than non-orphans, according to another study (Ferguson & Johnston, 1999). However, one of the biggest differences between children orphaned by AIDS and other orphans is that the former are more likely to lose both parents, often

within a relatively short space of time. Double orphanhood tends to increase where adult HIV prevalence is especially high (around 20% and above). The loss of both parents is typically more prejudicial to the welfare of a child than the death of a one parent. In a study in Botswana, orphans who had lost both their parents were significantly more likely to stop attending primary and junior secondary school on a temporary basis than children who had lost neither parent.

Neither is it clear whether orphans are more prone to nutritional disadvantage than non-orphans (once other factors, such as household poverty, are considered). At least one comparative study has found that orphans are not more likely to go hungry regularly than are other children living in the same kinds of circumstances (Cluver, 2003, cited in Stein). A Lusaka, Zambia, study has found that orphans were not being fed less than other children in the same household (Poulter, 2001, cited by Nattrass, 2002).

Findings of this sort remind us that although the vulnerability of children (including, of course, orphans) is many-sided, impoverishment very often is the common, overriding factor. Doziv And they suggest that AIDS worsens children's circumstances mainly by aggravating impoverishment. Ainsworth and Filmer (2002), in their review of Demographic and Health Surveys and Living Standard Surveys in 28 countries around the world

(including South Africa, Malawi, Mozambique, Zambia and Zimbabwe), at first seemed to point in a different direction when the noted large discrepancies in school enrolment by orphan status. In 22 of the countries, orphans aged 7-14 years were less likely to be in school than were non-orphans. However, a closer look revealed other, telling patterns. When the authors correlated the findings against other variables – such as household income levels - they discovered that in most cases the discrepancy narrowed or disappeared once households of similar income status were compared. The biggest school enrolment gaps were often between poor and non-poor children, whether or not they were orphaned. In other words, orphans in poorer households were as likely to be in school as non-orphans in equally poor households (but they were less likely to be in school when compared with non-orphans in better-off households).<sup>50</sup> It got even more intriguing. In the Sahelian (specifically Chad, Mali and Niger) and southern African countries studied, enrolment rates were generally similar for orphans and non-orphans, although in some countries (such as Zimbabwe), lower enrolment rates for orphans did appear to be associated specifically with orphanhood. In Nigeria and Tanzania, meanwhile, orphans were more likely than non-orphans to be in school. A more in-depth study has found that in Botswana, orphans had better primary school attendance than non-orphans, while in Malawi and Uganda their attendance was worse (though not by a large margin) (Bennell et al., 2002). On such evidence, conventional

<sup>50</sup> Note that the Case et al. (2003) study concluded that poverty did not explain the lower school enrolment among orphans; even within specific households, orphans were less likely to be in school than non-orphans. The conclusion seems a little overwrought. Poverty is probably a powerful,

underlying factor in this intra-household discrimination against orphans – since, faced with limited resources, households might discriminate in favour of the children to whom they are most closely related, as the Case et al. study indeed suggests. Orphans who lived with non-relatives

or with distant relatives, it found, were less likely to be in school than non-orphans.

wisdom that orphans are more likely to drop out of school by virtue of being orphans seems open to question. The biggest barrier in many places appears to be the inability to afford school fees and related expenses.

However, other research has exposed discrepancies that seem not to stem strictly from income differences. Some care-givers, it seems, do treat orphaned children differently from their own. Some comparative studies have indicated that children orphaned by AIDS are more prone to suffer hunger than nonorphans, for example (Makame et al., 2002; Manual, 2002, cited in Stein, 2003). Orphans living with foster families appeared to be more malnourished, underweight or stunted for their age when compared with non-orphans, according to research in Tanzania, western Kenya and Zimbabwe (Ainsworth, 2000; Monasch & Snoad, 2003). LXXV According to Monasch and Snoad (2003), orphans in sub-Saharan Africa generally are less likely to attend school than non-orphans, especially in countries where overall school attendance is low. Some country-specific studies have come to similar conclusions (Rossi & Reijer, 1995; Suliman, 2003). In Uganda, for example, when compared with non-orphans, orphans in primary school were twice as likely and those in secondary school were almost three times as likely to miss an entire school term (Hyde et al., 2002). Bicego, Rutstein and Johnson's (2003) review of demographic and health surveys in 17 sub-Saharan African countries also found that orphans were less likely than non-orphans to be in the appropriate grade for their age.

Do those patterns remain once data are controlled for income status and other socio-economic variables? Case et al. (2003) pointedly did so in their review of demographic and health surveys in 10 countries between 1992 and 2000, and concluded that orphans indeed were less likely to be enrolled in school than were non-orphans. Poverty, they agreed, was a factor (orphans, for example, tended to live in poorer households than non-orphans), but it did not account alone for all of the enrolment gaps. They found that within specific households, orphans were less likely to go to school than were nonorphaned children - i.e. orphans were being discriminated against, especially in households that were already struggling to make ends meet.<sup>51</sup> The most decisive variable turned out to be the relationship between the orphan and the decisionmaking adult in the household. Children living in households headed by distant relatives were less likely to be in school than were children under the care of, say, grandparents. The conclusion of Case et al. is that household decision-makers seem to 'allocate resources towards children with whom they have closer relationships, and discriminate against children whose ties are more distant' (2003).

We don't know which of these trends are occurring in South Africa. The Free State research of Booysen et al. (2002) found that only one orphaned child in an AIDS-affected household was not attending school at the time of the survey. Recently, though, an extensive study undertaken in the uMkhanyakude district of KwaZulu-Natal suggested that orphans are less likely

to be in school than non-orphans, regardless of whether they're in poor or fairly well-off households. And when orphans are in school, less is spent on their education than on that of nonorphans in the same household (Case et al., 2005). What's particularly striking – and fits findings from elsewhere on the continent – is that these discrepancies tend to occur mostly when the child has lost his or her mother (Case et al., 2005). In 2000, the demographic household survey in Ethiopia found that 22% of maternal orphans were severely malnourished, compared with 15% of non-orphans. In eastern Zimbabwe, too, the gender of the deceased parent is decisive in orphans' schooling prospects: children who lost a mother were less likely to be in school than those who had lost a father, which suggests that surviving mothers paid greater heed to children's education than did widowed fathers (Nyamukapa et al., 2003). In other words, it's children who have lost their mothers, and not so much paternal orphans, that seem to be most disadvantaged.

Intriguingly, Pisani (2003) has suggested that another factor prejudicing prospects for orphans may also be at play. It's households in rural areas, where access to schooling is at a premium, which tend to take in most orphans, especially 'double orphans'. Households in rural Zimbabwe have taken in an estimated 53 000 children who have lost both parents ('double orphans') since 1995, twice as many as were absorbed into urban households. In Kenya the effect is even more dramatic. While rural households have somehow found a way to cope with an additional 75 000 'double orphans', the

<sup>51</sup> Dual orphans were the most disadvantaged – even in relatively wealthy households.

number of 'double orphans' in urban households decreased by about 4 000 children (Bicego 2000). Since children in rural areas generally have less access to schooling, health services or the media, this has implications for both the development of orphaned children and for their access to information and services that could help them avoid becoming HIV positive.

Other dimensions of orphanhood are even more opaque. The experience of losing a parent or care-giver imprints on children an experience that distinguishes them from their peers – although exactly how is not clear. The mental health and psychological effects of illness and death on children is poorly researched and understood, and not easily remedied. This is perhaps one of the reasons why these aspects of 'orphanhood' and of AIDS usually feature as rhetorical afterthoughts in policies and are largely absent in programmes. The trauma these children have to contend with weighs also on care-givers who, increasingly, are elderly. Even in the most advantageous circumstances, deciphering the effects of emotional turbulence and communicating across such wide generation gaps is a frustrating and bewildering experience.

#### Making sense

Scientists have long understood that outcomes seldom betray their causes. Yet, when considering the effects of orphanhood on children's well-being, it's the outcomes themselves that are in dispute. The contradictory evidence should bridle the tendency to broadcast generalizing truisms – for it seems not to

favour the unequivocal statement that, in Africa, orphans invariably are worse off or are not worse off than non-orphans. Arrived at in different social arrangements, amid distinct dynamics, such varied findings should come as no surprise. Societies are not cut off a standard-issue cloth, yet so much of the AIDS impact literature implies otherwise.

What is clear is that orphanhood is by no means a prerequisite for privation and misery. Giese et al.'s (2003) research among poor households found that distressingly consistent and widespread deprivation affected the children, irrespective of whether or not their parents were alive. Frequent hunger and food insecurity was reported, as was the inability to afford school fees and related expenses, and difficulties in gaining access to suitable housing and water. The rates at which children presented with kwashiorkor and marasmus, diarrhoea and chest infections, and the frequency of child sexual abuse were especially shocking.

This is no esoteric dispute: the policy implications are huge. If orphans generally are no worse or better off than non-orphans of similar socio-economic status, singling them out for support is inappropriate. Relief and support to poor children, irrespective of whether or not they are living with their biological parents, are then called for. And constantly reducing the number of children who are in need has to be the long-term goal, which, in a society warped by such withering impoverishment and inequality, implies radical, redistributive change.

#### Making a difference

The starting point, clearly, is to avoid children being orphaned by AIDS. This entails ensuring universal access to antiretroviral programmes that can keep parents with HIV alive and healthy as long as possible. Looking ahead at the next 10-20 years, the most effective way to reduce the numbers of orphans will be a sustained and effective roll-out of antiretroviral treatment. This will enable HIV-infected parents and care-givers to raise, nurture and love their children much longer than is currently possible.

Beyond this, the generally-favoured interventions tend to be home-based, child-centred, and focused on health, nutrition, psychosocial care and support, and income generation. The dominant position is that institutional care – i.e. 'orphanages' - are neither ideal nor long-term solutions, cannot be sustained and are known to have detrimental effects on children. Removing children from their communities and kin is seen as unjustifiable. Instead, the consensus is that help should be available to support families and improve their capacity to take care of children who otherwise might be dispatched into institutional care. It is a position shared by the South African government, which has sought to focus on 'empowering the community to take care of orphans' (Desmond & Gow, 2002:41). Nevertheless, some religious groups and NGOs have continued to set up and run places for orphan care, many of them serving as 'half-way houses' for very young, often abandoned children.

Indeed, an orphan crisis of the scale looming in South Africa would seem to force the option of institutional care back

into the frame. An effective institutional response is necessary to deal with the large – and, very likely, growing – numbers of neglected and abused children, orphans and non-orphans alike. There are and will be instances where children desperately require institutional, residential care, temporary or otherwise; well-managed and monitored facilities must be available for them (Giese et al., 2003). As well, the current labour-intensive, process-heavy and manifestly under-resourced foster care system has to be refurbished and restructured as part of such a response (see Conclusion below).

For those children who are fostered, enabling them to complete their schooling should be a society-wide priority; the same, of course, holds for all children. Staying in school offers children, especially females, a possible exit from extreme poverty and its associated risks. Everything possible needs to be done to enable children to complete their schooling. Even when orphans' schooling prospects are worse than those of non-orphans, targeted relief could be a misguided response, and for two reasons. If orphans are being discriminated against inside their households, cash relief might end up being channeled disproportionately to the other children in the household (Case et al., 2005). Other forms of transfers – such as subsidies for school fees, transport, uniforms and textbooks - could avoid that pitfall. But they pose a larger question: Why subsidize only orphans' schooling and not that of all poor children? And why, for that matter, not provide free universal education?

Targeting can be successful – up to a point, and at a price. A 'technocratic approach to a highly complex social problem',

it often carries the cost of isolating and stigmatizing beneficiaries (UNRISD, 2000:14). Singling out children orphaned by AIDS for material support can invite other undesired responses, too. Daniel (2003) reports that in Botswana, for example, families chose to avoid food and other relief services because of the stigma attached to the aid. To the extent that is possible, material support needs to be generalized and where possible it has to be incorporated into the 'logic' of the system. The basic needs of the poor must be met as a matter-of-course – not as an exceptional act of relief or charity – with social security provision serving as one of the instruments for achieving this (see below), along with resolute steps to decommodify access to essential services and to boost income-earning.

Officially, South Africa does provide school fee relief to poor children. But one is hard-pressed to find evidence of this in areas such as the uMkhanyakude district surveyed by Case et al. (2005). In this very impoverished poor area, just 1% of schoolgoing children aged 6-16 years were not paying school fees. Why so few exemptions? Because it's up to the local schools to waive fees – and, in doing so, also reduce the discretionary income they need to maintain and run the schools. That powerful disincentive therefore neutralizes the official guarantee of fee waivers. Instead, as new research in KwaZulu-Natal confirms, some schools are levying extra fees to help finance themselves, a situation that occurs across the country. Ixxvii The funding mechanisms for schools therefore discourage school fee exemptions, despite the manifestly huge need. | Some NGOs intervene by helping pay some children's schools. More often, households devote part of the social security benefits

they receive to financing children's education – which in effect amounts to a circuitous transfer of funds from the Department of Social Development to the Department of Education via poor households (Giese et al., 2003).

School feeding schemes should form another core of a wider package of support provided to all poor children, including orphans. The school feeding programme was one of the first major initiatives introduced after the democratic elections of 1994 to address the plight of poor children, and by 2004 the Department of Health claimed that 85% of the 15 000 targeted schools were being serviced. More than a decade later, though, the programme appears to be faltering in some areas. Two thirds of the schools in KwaZulu-Natal's Newcastle area were recently found to lack an active feeding programme, for example. Details of the research has encountered widespread unhappiness with feeding schemes, ranging from poor quality or inadequate amounts of food to frequent interruptions in the supply of the meals and non-payment of suppliers (Giese et al., 2003).

The stigma associated with HIV poses one of the biggest obstacles to recuperating or improving an AIDS-orphaned child's well-being. It has been suggested that special counselling efforts tailored for children are needed when a parent tests HIV positive (Stein, 2003). At the very least, this underlines the need for counseling to be an integral part of testing, which is scarcely the case at the moment. That said, as ARV therapy coverage increases, it's more likely that in instances where a parent tests positive s/he would then enlist for antiretroviral treatment, thus diminishing the prospect of orphanhood. The children that then

fall through the cracks are those whose HIV-infected parents or main care-givers never discover their serostatus. In an epidemic as severe as South Africa's, they will be numerous in number. The only feasible way of reaching them is at school – all the more reason to broaden HIV/AIDS curricula components far beyond prevention sermonizing to include some forms of consciousness-raising around stigma, orphanhood, death and AIDS.

Tackling the emotional trauma children experience remains one of the more neglected areas of support. Schools offer perhaps the best launch-pad for providing psychosocial support to children. Teachers' training in bereavement counseling is vital, so too their ability to spot symptoms of trauma and to refer children for trauma counselling elsewhere. This is not easily achieved, as Daniels (2003) has reminded, especially when even the 'standard' elements of schooling often go wanting. Even piecemeal progress on this front would depend on the support and involvement of other service providers, governmental and non-governmental (Giese et al., 2003).

Counselling is possibly the most neglected dimension in the entire HIV/AIDS response cycle. Many commendable initiatives have been created to provide emotional and psychological support, but in a society awash with trauma, their overall effect is rather like trying to bat away a rainstorm. Ours is a conflicted, damaged and, in some respects, necrotizing society. The hurt, anxiety and confusion that churns along with AIDS is keeping it that way. On this front, there's no quick fix – just the self-evident need to reduce as much of the damage and soothe as much of the pain as possible.

#### The 'reverse orphans'

When an adult woman dies, her nurturing duties usually are transferred to other, often older, women who step in to foster the children (Urassa et al., 1997). Dox But this pattern of burdensharing will prove difficult to sustain in South Africa where, according to one study, at least one in five AIDS-affected households is headed by a woman older than 60 years (Steinberg et al., 2002). This increasing reliance on grandparents in fostering and raising children is a strong hint that family safety-nets of old are wearing thin. While most of the attention is directed at the prospects of those in their care, little of note is being done to meet the material, emotional and social needs of elderly care-givers and fosterers – the 'reverse orphans' who, in the twilight of their lives and in grossly disadvantageous circumstances, are transforming themselves again into mothers and fathers.

This pattern of burden-shifting onto the elderly is clearly visible in most high-prevalence countries. In the late 1990s already, a study in six provinces of Zimbabwe found that in more than 80% of households containing older people it was the elderly who were the main care-givers of the ill and of orphans; fully 70% of them were already in their 60s or older (WHO, 1999). More than half the foster parents surveyed in Mutangadura's (2000) study in Manicaland (Zimbabwe) were grandparents, most of them the parents of deceased mothers. In Namibia, in 1992, about 44% of orphans were being fostered in households headed by their grandparents; by 2000, that proportion had swelled to 61%. Dozi Usually these fostering households are headed by women.

The extraordinary roles assumed by the elderly stem not only from the AIDS epidemic. Across South Africa, economic hardship and the struggle to achieve viable livelihoods spur more young women to migrate in search of employment. When possible, they relegate their childrearing and other household duties to the older women who remain behind, in return for providing financial and other forms of support. Indeed, most female-headed households in South Africa are headed by grandmothers, and financial pressures weigh especially heavily on them (May, 2003). Dociii In rural Eastern Cape, for instance, it has been relatively common for households to be headed by widowed, and sometimes, very elderly women (Siqwana-Ndulo, 1998). Dociii

AIDS now threatens such reciprocal arrangements. Migrating young parents who fall ill and die can no longer provide financial and other support to the grandparents and other relatives who foster their children. As the epidemic's effects accumulate, the numbers of other adults able to step into that breach dwindle as well. Instead of being cared for as their lives draw to a close, the older poor are increasingly compelled to assume productive and reproductive duties (May, 2003). They're expected to care for the sick, nurture and raise children, and financially sustain or at least support their households.

A gauntlet of recurring difficulties awaits these 'reverse orphans': loss of remittances and other forms of financial support if their adult children become ill or die, shortages of food and clothing, problems affording health care expenses or paying school fees, emotional stress and, especially in rural areas, tough physical toil. A recent in-depth study in Mpumalanga found that 1 in

10 elderly poor were tending ill young adults, for example, often with skeletal amenities and services at their disposal. Most used wood or coal for cooking, piped water was a privilege restricted to those in formal urban areas, and a small minority had access to a flush toilet. The elderly were the main breadwinners in 3 out of 4 of the surveyed households. By far their most important source of income was the government old age pension, followed by contributions from other family members. A tiny proportion of older persons managed to supplement their incomes with piecemeal work. When it came to expenditure, there was scarcely margin for manoeuvre: 97% of their money went toward basic household necessities, and the remainder was spent on water, electricity and education (Makiwane et al., 2004).

The vital importance of *pensions* and other state transfers is obvious. South Africa's non-contributory old-age pension system was originally aimed at reducing poverty among the elderly. But the scale and depth of impoverishment has transformed it into a lifeline for younger household members also, to the extent where it now ranks among the few redistributive channels reaching large numbers of the poor (see below). Pensions go more to women than to men, they reach people in rural areas and they often sustain entire households, serve as a basis for credit access in local markets, help finance the education of grandchildren, and safeguard the right of older persons to remain in the home (May, 2003; Ardington & Lund, 1995). As the Committee to the Minister of Social Development put it, 'communities, not just pensioners, now wait for pension day' (2001). Poor As the AIDS epidemic siphons off other

sources of household income, pensions become even more vital (Legido-Quigley, 2003).

The travails of the elderly are not limited to material needs. The Committee to the Minister of Social Development's countrywide research found that for many old people life is a lot tougher than that clumsy word 'overburdened' can convey. When the elderly fall ill, the care they receive is 'often abysmal', the Committee (2001) reported. For women especially, old age brings 'fear, depression and anxiety' (Committee to the Minister of Social Development, 2001). Abuse, including sexual assault, has increased (HelpAge International, 1999). Social services intended for the elderly in many cases remain ramshackle, badly managed and poorly resourced. In Mpumalanga, only 10% of the pensioners have their money paid into bank accounts; the rest have to endure the gueues and the crush of 'pension day' (Makiwane, 2004). Reviewing the pension payout system, the Committee to the Minister of Social Development concluded that outsourcing had brought no improvements to the service.

Many sensible and potentially valuable measures have been recommended over the past several years. They include expanding targeted subsidies and discounts for essential foodstuffs and services (including water, electricity, transport and healthcare services). Such support will in all likelihood also be shared by other household members – much as the old age pension currently is – but channelling it via the elderly can have the added advantage of bolstering their sometimes tenuous status in households. Collecting pensions needs to be made

easier and quicker. One of way of doing so is to shift away from the single-payment-point method and pay more pensions via the post office and/or banks. Given the redistributive value of the old age pension, increasing the amount or at least indexlinking it to inflation (measured against a basket of essential purchases and services) would seem prudent; so, too, publicizing the care-giver allowance more widely in a bid to increase take-up by pensioners and their families.

Much more difficult, though, is the task of finding ways to provide the elderly with the kind of psychosocial support and counselling they often need (Daniel, 2003). Many will have repeatedly endured hurt, despondency and a sense of helplessness in watching loved ones die in their care. Those fostering orphans will probably be contending with children who themselves are traumatized and resistant or unable to adapt to their new circumstances. The sheer difficulty of achieving dialogues built on mutual understanding and respect across generations and in the midst of grinding deprivation cannot be underestimated. If there are heroes in this epidemic, the elderly surely rank high among them. The social and economic importance of the roles they adopt in old age cannot be underestimated and yet most policies, including those focusing on AIDS impact, seem to regard them as little more than an afterthought.

#### **Chapter endnotes**

- i See, for example, Beall J & Kani N (1999). Households, livelihoods and urban poverty. Urban Governance, Partnership and Poverty Theme Paper No 3. August. London School of Economics.
- ii Topouzis (2000), citing Mutangadura and Webb (1999).
- iii UNDP, 2001, HIV/AIDS: Implications for poverty reduction, position paper, p 10
- iv Seeley J (1993). 'Searching for indicators of vulnerability: A study of household coping strategies in rural, south west Uganda'. Background report, cited in Baylies (2002:620).
- v De Waal cites Rugalema (2002) and Baylies (2002) in support.
- vi See, for example, Adams A, Hien M & Sauerborn R (1996). 'Household strategies to cope with the economic costs of illness'. Social Science and Medicine, 43(3): 291-301; Pitayanon S, Kongsin S & Janjareon WS (1997). Economic impact of HIV/AIDS mortality on households in Thailand. In Bloom D & Godwin P (eds). The economics of HIV/AIDS: The case of South and South East Asia. Delhi: Oxford University Press.
- vii Bear in mind, though, that by the late 1990s, it was also clearly in the interests of agribusiness in Zimbabwe, predominantly white and fearful of land expropriation, to show that the country 'could not cope' without their dominance of the agricultural sector.
- viii Introducing cassava requires considerable labour because of the need to fence areas and establish rides; however, once the crop is established, labour needs diminish.
- ix See De Waal and Whiteside (2003). Some observers have dubbed cassava a 'selfish crop' for these reasons.
- FAO (2001). FAO/GIEWS Food Outlook No.4 October 2001. Available at http://www.fao.org/documents/show\_cdr.asp?url\_file=/docrep/005/y6027e/y6027e03.htm. Cassava was originally introduced into Africa by Portuguese colonialists. Early in the 20th century, its cultivation was also encouraged as part of attempts to control deforestation and erosion. Despite initial resistance from many farmers, the crop eventually became an important staple in some places, producing good yields even in poor soils where most other crops failed. Household models suggest that cassava can boost the number of people supported on a piece of land by two to six times, and that households can meet their food requirements with 40% less labour input, yielding larger surpluses for sale. See Ecoagriculture Partners (2004). Reduce (or reverse) conversion of wild habitat to agriculture by increasing farm productivity. Review case studies. Available at http://www.ecoagriculturepartners.org/CSIII.htm#1.
- xi The countries were Kenya, Malawi, Mozambique, Rwanda and Zambia.
  De Waal and Whiteside had cited Malawi, Zambia and Zimbabwe as

- examples where staple-food cereal production shifted to cassava production to compensate for the labour losses caused by AIDS in the 1990s. The production of cassava in Malawi, Zambia and Zimbabwe increased from 880 000 metric tonnes in 1990 to 2 036 000 metric tonnes in 1999, for example (De Waal & Whiteside, 2003).
- For a crisp summary, see De Waal A & Whiteside A (2003). 'New variant famine: AIDS and food crisis in Southern Africa'. *The Lancet*, 362, pp. 1,234-37. Available at http://www.earth.columbia.edu/cgsd/documents/de\_waal\_lancetarticle.pdf. See also De Waal A & Tumushabe (2003). 'HIV/AIDS and food security in Africa'. Report for DfID. February. Available at http://www.sarpn.org.za/documents/d0000235/P227\_AIDS Food Security.pdf.
- See 'Speech by Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa, to the Global Health Council's Annual Conference', 28 May 2003, Washington. Available at http://www.sarpn.org.za/documents/d0000357/index.php. A study by the South African Development Community hedged its findings, describing the impact of AIDS on food security as 'strong and negative'; see SADC FANR Vulnerability Assessment Committee (2003). Towards identifying impacts of HIV/AIDS on food insecurity in southern Africa and implications for response: Findings from Malawi, Zambia and Zimbabwe. Harare.
- Booysen & Bachmann (2002), citing Lundberg M & Over M (2000).
   Transfers and household welfare in Kagera. World Bank. Washington.
   Booysen & Bachmann (2002), citing Lundberg et al. (2000). 'Sources of financial assistance for households suffering and adult death in Kagera, Tanzania'. South African Journal of Economics, 68(5): 947-984.
- Pisani (2003) went on to note that, at junior levels, boys were twice as likely as girls to be absent from school due to sickness or duties at home, though at low rates still (roughly 4%).
- xvii See Statistics SA, 'Census in brief: Introduction', available at http:// www.statssa.gov.za/census01/census96/HTML/CIB/Introduction. htm [accessed 24 May 2005]
- viii For more, see MacAllister PA (1985). Agricultural 'betterment', conservatism and resistance in poverty in Willowvale District'. Rural poverty and development strategies in Transkei proceedings of a workshop held at the University of Transkei (26-28 April 1989). University of Transkei. Umtata, cited by Siqwana-Ndulo (1998); Beall J & Kani N (1999). 'Households, livelihoods and urban poverty'. Urban Governance, Partnership and Poverty Theme Paper No 3. August. London School of economics; Guyer J & Peters P (1987). Conceptualising the household: Issues of theory and Policy in Africa. Development and Change, 18; Murray C (1981). Families divided: The impact of migrant labour in Lesotho. Ravan Press. Johannesburg.
- ix Conducted in the Idutywa district of the former Transkei, the research suggested that such women generally commanded minor decision-

- making power on day-to-day issues but that significant decisions required consulting their husbands. According to Siqwana-Ndulo, 'the household is viewed as home to a collective, members of which may or may not be present at the time' (1998:415).
- See, for example, Heinonen, TI (1994). Gender differences in house-hold approaches to adult illness in rural Philippines. PhD thesis, Institute of Development Studies, University of Sussex; Hunte PA & Sultana F (1992). 'Health-seeking behaviour and the meaning of medications in Balochistan, Pakistan'. Social Science and Medicine, 34(12): 1385-97; Stock R (1983). Distance and the utilization of facilities in rural Nigeria. Social Science and Medicine, 17(9): 563-570.
- In 17% of the cases, households heads were suffering from AIDS-related illnesses, and in a further 14% of cases, household heads were described as chronically ill (a possible indicator of unrecognized HIV infection). See Steinberg et al. (2002:12).
- xxii For a sobering account of the livelihood strategies pursued by poor rural women in Mpumalanga province, see Sender J (2000). The struggle to escape poverty in South Africa: Results from a purposive rural survey. June. Department of Economics, School of Oriental and African Studies.
  London
- xxiii For an edifying corrective to notions that the nuclear family represents a singular, ideal type of arrangement, see Russell (2002:31-33).
- xxiv The 1995 October Household Survey showed that more than half the households contained at least three generations (Moller, 1998).
- As examples, Siqwana-Ndulo cites Krige EJ (1936). 'Changing conditions in marital relations and parental duties among urbanized natives'. 
  Africa: Journal of the International Institute of African Languages and Cultures, 9(1). London; Hunter M (1936). Reaction to conquest. Oxford University Press. London; Schapera I (1940). Married life in an African tribe. Pelican. London; Phillips A (ed.) (1953). Survey of African marriage and family life. Oxford University Press. London. For a handy roster of scholarly work on these matters, see Russell (2002:1-2,11).
- This shift mirrors the way in which the earlier portrayals of African-American families in the U.S.A. as 'irrational', 'self-destructive' and 'pathological' have yielded, in the dominant literature, to an admiration for their adaptive strengths and resilience. See, for instance, Farley R & Walter RA (1987). The color line and the quality of life in America. Russell Sage Foundation. New York, cited in (Siqwana-Ndulo, 1998).
- xxvii See, for example, Walker P (1989). Famine early warning systems: Victims and destitution. Earthscan Publication. London.
- Kviii See, for example, De Waal A (1989). Famine that kills: Darfur, Sudan, 1984-1985. Clarendon Press; Keen D (1994). The benefits of famine: A political economy of famine and relief in southwestern Sudan, 1983-1989. Princeton University Press.
- xxix See, for example, UNAIDS (1999). A review of household and commu-

- nity responses to the HIVIAIDS epidemic in the rural areas of sub-Saharan Africa. UNAIDS Best Practice Collection. Geneva.
- xxx For a detailed review of service delivery see Hemson D & Owusu-Ampomah (2004). 'A better life for all? Service delivery and poverty alleviation' in Daniel, Southall & Lutchman (eds.). State of the nation: South Africa 2004-2005. HSRC Press. Cape Town, pp 511-537.
- xxxi A significant proportion of households escaped poverty, if only temporarily, due to an increase in income from pensions, state grants or remittances.
- xxxii In high unemployment settings, though, it cannot be assumed that the loss of a household member automatically translates into long-term income losses. The KwaZulu-Natal study, for example, found that 1 in 5 households that moved out of poverty did so by losing a household member (Woolard et al., 2002).
- xxxiii The same survey found that, on average, a person sick with AIDS was chronically ill for a year before dying (Steinberg, 2002:ii).
- xxxiv And yet, when asked whether they thought their children's lives would be better than theirs, 73% of city residents said they believed their children would be better off (SA Cities Network, 2004).
- xxxv These findings were based on observations six months into the study. xxxvi According to a study in four South African provinces (Steinberg et al,
- 2002), households experiencing a death spent an average of one third of their annual incomes on funerals.
- xxxvii A total of 771 households were surveyed in parts of Free State, Gauteng, KwaZulu-Natal and Mpumalanga.
- xxxviii Based on statistics drawn from the 1996 and 1999 October Household Surveys, as well as the Committee of Inquiry into a Comprehensive System of Social Security for South Africa (2002).
- xxxix The figures were drawn from the 2004 General Household Survey; see 'Fewer people on medical aid'. *Health-e*. 16 July 2005.
- xl Ibia
- xli Households participating in the Financial Diaries project were in Langa, Diepsloot and Lugangeni.
- xlii See, for example, Girdler-Brown B (1998). Migration and AIDS: Eastern and Southern Africa. *International Migration*, 36(4): 513-549, cited in Booysen (2003).
- xliii Booysen highlights the tentative nature of the analysis, since the health status of the person before and after leaving the household was not known.
- Issued at the International Conference on Primary Health Care, held in early September 1978 at Alma-Ata in the USSR. The Declaration is available at: http://www.who.dk/AboutWHO/Policy/20010827\_1
- xlv Mills (2004) citing African National Congress (1994). A national health plan for South Africa. African National Congress. Johannesburg; and African National Congress (2001). A national guideline on home-

- based care and community-based care. African National Congress. Johannesburg. Like most public health strategies of this era, the shift also consummated the centuries-long transformation of hospitals away from their previous functions as poor houses, orphanages and refuges for the mentally ill, and into secularized, medicalized and exclusive institutions.
- xlvi Jean-Marc Ela (1998). 'Looking to a new Africa'. Le Monde Diplomatique. October. Paris, cited in Marais H (2001b). 'Principle and expediency: South Africa and the African Renaissance'. Conference paper. April. Dakar.
- xlvii Jean-Marc Ela (1998). 'Looking to a new Africa'. Le Monde Diplomatique (October). Paris.
- xlviii Quoted by Patrick Bond (2001). 'The African grassroots and the global movement'. January. Znet. Available at http://www.zmag.org/CrisesCurEvts/Globalism/african\_grassroots.htm. The quote is drawn from Ake C (2000). The feasibility of democracy in Africa. Codesria. Dakar.
- xlix Glendinning C & Millar J (eds.). 1987. Women and poverty in Britain. Harvester Press, cited in Mills (2004).
- Although a new charter of the public and private health sectors, aimed at improving access, equity and quality, was being drafted in mid-2005, amid reports that private medical aid schemes were also becoming unaffordable to erstwhile users and that access to such schemes was diminishing. See 'Manto concerned about high cost of health care'. Mail & Guardian Online. 11 July 2005. Available at http://www.mg.co.za/articlepage.aspx?area=/breaking\_news/breaking\_news\_national/&articleid=245083
- li See Giese et al. (2003:xxii).
- lii As reported in assessments of care-giving projects in Khayelitsha, Gugulethu and Delft (Cape Town), 2004; personal communication; see also Akintola (2004).
- liii Interestingly, some care-givers instinctively grasp the need for a more holistic 'continuum of care', arguing that the formal health services (which they probably see as a proxy for the state overall) should provide material support that includes 'groceries, clothes and money'. Assessments of care-giving projects in Khayelitsha, Gugulethu and Delft (Cape Town), 2004; personal communication.
- liv Recall that some antiretroviral drugs, like many medicines, should not be taken on an empty stomach.
- Iv See Bradshaw et al. (2002). 'Orphans of the HIV/AIDS epidemic: The time to act is now'. MRC Policy Brief, 2. May. MRC. Cape Town.
- Ivi Population-based surveys in sub-Saharan Africa have also tended to indicate lower numbers of orphans than demographic models used by the US Census Bureau, according to Bennell (2003).
- Ivii Precise data are available at http://www.commerce.uct.ac.za/care/Research/ Papers/IndicatorsASSA2002.pdf

- Until 2003, the age limit was set at 15 years in UNAIDS calculations.
- Botswana, Ministry of Education and United Kingdom Department for International Development, 2000. The impact of HIV/AIDS on primary and secondary education in Botswana: developing a comprehensive strategic response. Gabarone, December 2000, cited in Pisani (2003).
- Ix The 10 countries were Ghana, Kenya, Malawi, Mozambique, Namibia, Niger, Tanzania, Uganda, Zambia and Zimbabwe. Together they accounted for approximately 27% of the children living in sub-Saharan Africa, and 50% of the AIDS orphans.
- lxi See Stein (2003:3) for some illustrative references.
- Ixii It is widely assumed that orphans are less likely to be enrolled in school than are non-orphans, and there is some evidence to that effect. According to one Tanzanian study, orphans (particularly those who have lost both parents) are more likely to enter the labour market as children than are non-orphans (Suliman, 2003). See below for a more detailed discussion of the evidence.
- Ixiii One surprising example was a Medical Research Council (MRC) Policy Brief which concluded with the claim that 'South Africa's capacity to provide care for these orphaned children will determine the long-term social stability of the country' (Bradshaw et al., 2002).
- Ixiv The UN Security Council in January 2000 for the first time in its history debated a health issue: AIDS. Its Resolution 1308 (2000) pointed to the potential threat the epidemic posed to international peace and security.
- Ixv Ken Owen, writing in the Sunday Times, cited by Hein Marais. 'The new barbarians'. Work in Progress, 90. July/August 1993, p 10.
- Ixvi Ashraf Grimwood, then of the National AIDS Coalition in South Africa, quoted in MM Mackay. 'AIDS will spur crime, say experts'. Saturday Argus. 9 January 1999, cited in Schonteich (1999).
- xvii As confirmed also by the nine studies reviewed by Stein (2003:14-15).
- lxviii Please see 'Out of sight ...', above.
- Ixix UNAIDS. 1999. Children orphaned by AIDS: Frontline responses from eastern and southern Africa. UNAIDS. Geneva.
- Ixx Foster is not alone in entertaining such notions; Johnson and Dorrington (2001:29), for example, mention that 'it has been suggested' that a second possible model of community-based care 'may be to allow the formation of child-headed households'.
- Ixxi Cluver L (2003). The psychological well-being of AIDS orphans in Cape Town, South Africa. Masters Thesis. Oxford: Applied Social Studies, Oxford University.
- lxxii For example, neither the multi-country reviews of Ainsworth and Filmer (2002) and Case et al. (2003), nor Nyamukapa et al.'s study in Eastern Zimbabwe (2003) provide proof for this commonplace assertion.
- İxxiii Foster G & Shakespeare R (1995). 'Orphan prevalence and extended family care in a peri-urban community in Zimbabwe', 7(1): 3-17; Kamali

- A et al., (1996). 'The orphan problem: experience of a sub-Saharan Africa rural population in the AIDS epidemic'. AIDS Care, 8(5): 509-515; The World Bank Group (2002). *Education and HIVIAIDS, A window of hope*. World Bank. Washington, DC, all cited in Case, Paxson, Ableindinger (2003).
- Ixxiv Stein (2003:7) cites Brooks-Gunn et al. (1997), Fitzgerald, Lester & Zuckerman (1995), and Rogers & Ginsberg (cited in Dawes & Donald, 1994).
- Ixxv See Ainsworth M (2000). The impact of adult deaths on children's health in northwestern Tanzania. Policy Research Working Paper 2266. World Bank. Washington D.C.
- lxxvi According to UN Pop Div (2003:4) also confirmed by Bicego et al (2003), Case et al (2003), Suliman (2003).
- Ixxvii Jacqui Pile. 'Orphans' trials mount'. Financial Mail. 20 May 2005. As described by another overview, 'unscrupulous and not-so-unscrupulous principals who require income additional to that provided by the Department (of Education), often fail to inform or are unable to implement fee-exemption policies'; see Chisholm L (2005). 'The state of South Africa's schools'. In Daniel, Southall & Lutchman (eds.) State of the nation: South Africa 2004-2005. Human Sciences Research Council Press. Cape Town, p 211.
- Ixxviii For a thorough discussion, see Fiske & Ladd (2004).
- lxxix Jacqui Pile. 'Orphans' trials mount'. Financial Mail. 20 May 2005.
- Ixxx Note that it's not necessarily the deceased's 'own' children they, too, may have been fostered.
- Ixxxi UNICEF-MICS, Measure DHS 1992 and 2000, cited in UNAIDS (2004a).
- lxxxii According to May (2003), some 42% of black South African households are headed by women.
- Ixxxiii More than a third of the households were headed by widows, an unsurprising pattern given that husbands were often 10-15 years and sometimes more than 20 years older than their wives (Siqwana-Ndulo, 1998).
- lxxxiv By some calculations, South Africa's poverty head-count would be 2% higher if the non-contributory pension were removed, and the average poverty gap would be 10% wider; see Barrientos (2005).
- Ixxxv Many instances of pension and other grant 'fraud', the Committee reported, were poverty-related and were desperate bids for an income (2001); see Chapter Four.

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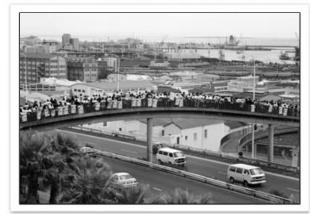


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