The Living Openly Project is about the experiences of HIV positive South Africans who have gone public about their HIV status.

We cannot ignore the fact that millions of South Africans are infected with HIV, and that most are unaware of their infection. For many of those who know their status, living openly is difficult. It requires a safe environment and the support of family, friends and the community.

The more we are open about HIV/AIDS, the better equipped we are to tackle the disease and its consequences. Through this project we aim to change the stigma and turn the voices of those who have lived with HIV/AIDS into what they have always been — a voice.

The Living Openly Project was developed as part of Beyond Awareness — A National Awareness Campaign for HIV/AIDS in 2004. The campaign is also a part of the national government’s strategy to reduce the number of people who test HIV positive and to increase the number of people living with HIV/AIDS who are on antiretroviral treatment. The project is supported by the Department of Health and the Department of Social Development.

The photographs and interviews are the work of photographer Christian Few. This exhibition is dedicated to all those living with HIV/AIDS.

Buckling
The impact of AIDS in South Africa
2005
Hein Marais
The impact of AIDS in South Africa
2005

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At the launch of the book *Nobody ever said AIDS*¹ Eddie Maluleke recited her poem from which the title of the book came. The final verse reads:

... We all died  
Coughed and died  
We died of TB  
That was us  
Whispering it at funerals  
Because nobody ever said AIDS

The vibrancy of her performance lay in sharp contrast to the muted response to the HIV and AIDS epidemic by the state – muted in all aspects except for denial, prevarications, neglect, stigma and discrimination. It was also in contrast to the muted response from industry, civil society, the medical profession and most citizens. It was a performance that showed how a state and the society should be responding to the epidemic and was a performance of passion, commitment and energy that shamed all but a few people.

This epidemic calls for a robust and vibrant response. It calls for commitment, energy and passion. Over the past five years, the Centre for the Study of AIDS, based at the University of Pretoria has published an annual *AIDS Review*. Each of these Reviews has taken a seemingly intractable issue and tried to develop a critical and robust engagement with it and give a critique of the issue and its ramifications. Starting in 2000, with *To the edge* which asked how it was possible that with the vibrant and committed NGO sector, the energy of the NACOSA process, the flawed but the starting point of the ATICs and media campaigns prior to 1994 and the development of the National AIDS Plan in 1994, South Africa by 2000 appeared to have got it so wrong in terms of the AIDS response. This was followed in 2001 with the analysis *Who cares?* – asking who really cares about the African epidemic, who will care for the people who are living with HIV and AIDS, who cares about how the state responds and in the end, who cares about how a society will be affected by this lack of compassion, humanity and urgency.

In 1844 Hegel compellingly wrote:

> when one individual inflicts bodily injury upon another, such injury that death results we call the deed manslaughter; when the assailant knew in advance that the injury would be fatal, we call his deed murder. But when society places hundreds of proletarians in such a position that they inevitably too meet a too early and an unnatural death, one which is quite as much a death by violence as that of the sword or bullet; when it deprives thousands of the necessaries of life, places them under conditions in which they cannot live ... knows that these thousands ... must perish, and yet permits these conditions to remain, its deed is murder just as surely as the deed of the single individual ... we read these things every day in the newspapers and take no further trouble in the matter. But society cannot complain if after the official and non-official testimony here cited must be known to it – the offence may be more one of omission than of commission. But murder it remains.²

A commentary, as fitting in 2001, about the failure to care about the AIDS epidemic as the failure to care about health and livelihoods in 1844.

The 2002 *Review* followed on this lack of caring by examining the relationship between AIDS and human rights – *Whose right?* – does the lack of understanding of this epidemic and its wide ramifications lead to a lack of understanding about how this failure to care allows for a failure to protect and ensure human rights? How do we measure the theory against the reality? Good legislation and good policies exist in most of the countries reviewed, but this does not translate into programmes that allow people with HIV and AIDS and their families and

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communities to access their rights. In 2003 the examination moved to the level of the family – *Over extended* – asking how families, the bedrock of society, cope with such an epidemic and the demands it makes on individuals, their families and that communities in which they are located. Far from finding the we have families and communities that generate safety, compassion and comfort we observe that families are over-extended, unable to cope, and struggling to come to terms with the reality of stigma and discrimination and with the demands of care for people with HIV and AIDS, orphans and other affected family members. There were stories of families and communities that did cope. They were in a twilight world and living precariously on the edge.

In 2004 the lens shifted to the individual and in *(Un)*ereal we challenged the stereotypes that have developed around men in the epidemic. We challenged the notion of men as isolated and uncaring and looked at how they have been positioned by the discourse of the epidemic. The *Review* considered the social construction of masculinity and sexuality and how men’s role in society has been and will be fundamentally challenged by HIV and AIDS.

*Buckling* starts to pull all these themes together and takes a critical look at how we should be measuring the impact of HIV and AIDS on South Africa. What have we learned from our past, from the ways in which we have described and understood the epidemic and from the ways in which we have chosen to analyze and interpret its impact? Can a society such as South Africa come to terms with the impact of AIDS and generate a brave, vibrant and robust response? Can we understand the lessons of the past and create a future that protects and supports us all as we negotiate our way through this most fascinating of all epidemics and the many social, political, economic and personal ramifications it will produce? For in the end

This disease not seldom attacks the rich, but it thrives among the poor. But by reason of our common humanity we are all, whether rich or poor, more nearly related here than we are apt to think. The members of the great human family are, in fact, bound by a thousand secret ties, of whose existence the world in general little dreams. And he that was never yet connected with his poorer neighbour, by deeds of charity or love, may one day find, when it is too late, that he is connected with him by a bond which may bring them both, at once to a common grave.³

These are the words of William Budd writing about typhoid fever in 1874, and as with Hegel, providing as perceptive a social commentary for AIDS in 2005.

*Buckling* tells us how and why *Nobody ever said AIDS* and why it is imperative that we do.

The University of Pretoria is committed to a comprehensive HIV and AIDS programme and institutional response that includes all aspects of the University – the Rector, Vice Rectors, Deans, staff, students, community and government. The Centre for the Study of AIDS has international collaboration with key HIV and AIDS research units, and with UN agencies, and is working with regional and national tertiary institutions to increase our knowledge and develop effective responses.

The Centre for the Study of AIDS acknowledges the sustained support and commitment of the International Development Research Centre (IDRC), Canada.

The views expressed in this *Review* are solely those of the author and the Centre for the Study of AIDS.

Mary Crewe
Director, Centre for the Study of AIDS

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BUCKLING – Introduction

An AIDS epidemic as severe as the one plowing through South Africa will change society. AIDS impact literature indeed predicts catastrophic outcomes, but the scenarios tend to be roughly hewn and formulaic, and fixate on the epidemic’s likely impact on productive and governance capacities. Thus they foresee a chain of effects in hard-hit settings that culminate in stunted economic growth, dysfunctional state institutions, possibly even ‘derailed development’ and state failure.

This approach expresses dominant ideological trends of our time, not least the overriding obsession with productive processes and growth potential, governance and security. The well-being of humans is refracted through these cognitive screens. What emerges is a fuzzy picture of a calamity that flattens everything in its path with a sort of ‘democratic’ disregard. Narratives about the impact of AIDS therefore tend to ignore the distribution of risk and responsibility in society, the evasive agility that privilege and power affords, and the sheer fact that adversity often is also the mother of short-sighted invention. In this fanciful world, we’re somehow all bobbing in the ‘same boat’, if not exactly equal then all equally-at-peril. Scrubbed clean of its gnarly injustices and inequalities, society is reduced to a fiction in which a special place is reserved for a heartwarming but vapid faith in the abilities of ‘the poor’ to weather adversity, with a little help from their friends.

In all this, AIDS is seen to feature as an exceptional and distinct factor of destruction, its interplay with the broader dynamics that determine the distribution of power, resources and entitlements seldom earning close examination. A misshapen picture of how AIDS alters our worlds is one result. A short-sighted guide to strategies for containing the epidemic, and preventing or repairing the damage, is another outcome.

This publication’s starting point is the need for a more and rigorous picture of the AIDS epidemic’s impact, an analysis that takes proper account of how the epidemic meshes with the specificities of society. ‘Buckling’ is intended as a modest step toward such an understanding. The method chosen is transparently simple: a critical review of a large volume of AIDS impact research evidence focused around a specific sociological and political-economic reality – in this case, South Africa. ‘Buckling’ widens the perspective and tilts it in ways which, hopefully, reveal more clearly the contingency and complexity of the epidemic’s impact, and which bring its interplay with other dynamics into clearer view, particularly those involved in the reproduction of deprivation and inequality.

First, the introduction positions the epidemic within a wider historical and ideological context. Chapter Two (‘Gauging the epidemic’) then surveys the epidemiological evidence and some of the controversies surrounding it. Chapter Three (‘Ground Zero’) examines and critiques the conventional narratives of AIDS impact on households, of orphanhood and of home-based care, and shows how the epidemic is accentuating and hardening some of the most grievous features of our society. Chapter Four (‘Fall-out’) pans wider to critique the popularized images of societal impact, and offers an alternative analysis of what AIDS is wreaking in South Africa.

What emerges is a nuanced but horrifying picture of a society that is being ruptured and buckled into an antithesis of the humane, just and dignifying society millions struggled for and continue to strive toward. It need not be this way: history does not run on rails. But this epidemic is reiterating and intensifying already-powerful features of society with such ferocity that it will require extraordinary boldness and invention to reclaim the future. We have not yet been where we are likely headed.

Rooted

South Africa is experiencing one of the most intense, and probably the largest HIV/AIDS epidemic in the world. The epidemics in South Africa and several of its neighbours are unique in at least two respects. National adult HIV prevalence levels in southern Africa have soared to heights not seen anywhere else in the
Nowhere else has national adult HIV prevalence reached or exceeded 20%, or more in six southern African countries, including South Africa. This apparent ‘stabilisation’ probably reflects a terrible equilibrium – with the numbers of people newly infected with HIV roughly equaling the numbers dying of AIDS.¹

These epidemics are changing these societies, but in ways that are not yet fully understood. These epidemics cannot be understood or effectively confronted – nor, as we shall see, can their impact be appreciated or cushioned – without taking account of the ways in which power is amassed, exercised and distributed across and between societies. The origins and driving factors of South Africa’s AIDS epidemic are entangled in the distribution across and between societies. The origins and driving factors of a national AIDS epidemic were essentially social. The resultant patterns of circular migration are largely on mining, as well as agri-business, before later also extending to urban manufacturing and service economies. Transport networks were assembled to service these economies, with major rail and road systems linking harbours, mining hubs and agricultural basins. The resultant patterns of circular mobility associated since the late 19th century with labour conscripts was approximately 12% in 1991-1993; among pregnant women prevalence reached 15% in the early 1990s, after which it declined steadily – most probably due to a combination of increased AIDS mortality and changes in sexual behaviour. It is sometimes pointed out that HIV infection levels reached double figures in parts of Thailand in the early 1990s. This is partly true. In the Upper North, HIV prevalence among new army conscripts was approximately 12% in 1991-1993; among pregnant women prevalence reached almost 8% in the Upper North of Thailand in 1995. National HIV prevalence never reached such levels. See UNDP (2004), Thailand’s response to HIV/AIDS: Progress and challenges. Bangkok. UNDP, p 21. Nine countries in southern Africa had adult HIV prevalence levels of 10% and more at the end of 2003 (UNAIDS, 2004a). Together, those nine countries accounted for 2% of the world’s population – but almost 30% of the global total of people living with HIV (between 10.5 and 12.6 million people, according to UNAIDS estimates).

In South Africa, for example, HIV prevalence has been found to be twice as high among migrant workers (26%) compared with non-migrant workers. However, the high prevalence of HIV in southern Africa currently means that it is considerably more difficult to map the prevalence and spread of disease onto spatial patterns of migration than it was in the past (Crush, 2001).

Buckling – 2005

1 National adult HIV prevalence reached or exceeded 20%, as it has in Botswana, Lesotho, Namibia, South Africa, Swaziland and Zimbabwe. National prevalence in Uganda, according to some estimates, reached 15% in the early 1990s, after which it declined steadily – most probably due to a combination of increased AIDS mortality and changes in sexual behaviour. It is sometimes pointed out that HIV infection levels reached double figures in parts of Thailand in the early 1990s. This is partly true. In the Upper North, HIV prevalence among new army conscripts was approximately 12% in 1991-1993; among pregnant women prevalence reached almost 8% in the Upper North of Thailand in 1995. National HIV prevalence never reached such levels. See UNDP (2004), Thailand’s response to HIV/AIDS: Progress and challenges. Bangkok. UNDP, p 21. Nine countries in southern Africa had adult HIV prevalence levels of 10% and more at the end of 2003 (UNAIDS, 2004a). Together, those nine countries accounted for 2% of the world’s population – but almost 30% of the global total of people living with HIV (between 10.5 and 12.6 million people, according to UNAIDS estimates).

2 In South Africa, for example, HIV prevalence has been found to be twice as high among migrant workers (26%) compared with non-migrant workers. However, the high prevalence of HIV in southern Africa currently means that it is considerably more difficult to map the prevalence and spread of disease onto spatial patterns of migration than it was in the past (Crush, 2001).
past two decades amid the introduction of neoliberal economic adjustments – overlaying gender and other inequalities that provide the relational dynamics which enable a mainly heterosexual AIDS epidemic to flourish. The labour market has been radically restructured, with vast numbers of workers shifted from a ‘rationalized’ formal sector into insecure contract and casual labour roles, the ‘informal’ sector or unemployment. The past two decades have seen massive job losses in most sectors of the economy, including industries in which female workers predominated, such as textiles and clothing. Unemployment, the shift from permanent to casual employment, and stagnant pay have hit African women hardest, most of whom are trapped in poverty with sporadic access to poorly paid and insecure jobs. The overlap of gender and socio-economic inequalities is especially harsh in South Africa, where many women depend on social grants, remittances from male partners and other kin, and other, inconsistent and informal sources of income. All this has further weakened women’s economic status, aggravating gender inequalities and exacerbating their exposure to HIV risk. Research in Mamdeni, for example, has shown a close correlation there between exceptionally high HIV infection levels, widespread transactional sex, and job losses in the female-intensive textile and garment industry (Hunter, 2002). Driven by relative poverty, many women and girls find themselves using sex as a commodity in exchange for goods, services, money, accommodation, and other basic necessities; transactional sex reflects the superior economic position and access to resources men generally enjoy. However, it is not always and simply a matter of victimhood. The many computations of sexuality and desire feature, too, as Jonathan Berger (2004) has reminded us. Many young women look to older men as potential marriage partners, or as sources of assistance in obtaining access to education and jobs, and addressing other aspirations or desires. Research in several African countries indicates that some young women ‘trade’ sex and companionship for gifts that have connotations of ostentation and luxury (clothes, jewelry, cellular phones, perfumes, etc.) and which boost their self-esteem and status among peers (Luke & Kurz, 2002; Longfield et al., 2004). In urban areas especially, these relationships are formed amid aggressively propagated cultures of consumerism, and in the midst of vivid juxtapositions of deprivation and abundance, covetousness and fulfilment. Sexuality, status and consumption become closely intertwined. Besides the obvious importance of procreation and the overlooked roles of hormones and libido, sex is entangled also in people’s need to have fun, to seek and express trust, to build status and self-esteem, to escape loneliness, even to relieve boredom. Research in South Africa, for example, indicates that in the context of deep impoverishment and high unemployment (and in the absence of affordable recreation), sexual relationships often feature in bids to boost self-esteem and peer status, or simply to relieve an important factor in southern and East Africa’s epidemics, where a young woman’s chances of becoming infected tend to increase with the age gap between her and her partner (Kelly et al., 2003). This is partly because older men are more likely to have been exposed to HIV, and because girls and young women are physiologically more susceptible to infection (UNAIDS, 2004b). In rural Zimbabwe, for example, HIV prevalence was approximately 16% among teenage girls (15-19 years) whose last partner was less than five years older than themselves, but among girls with partners 10 or more years older, HIV prevalence was twice as high (Gregson et al., 2002). In Kisumu, Kenya, among women three years or less than the junior of their husbands, none was found to infected with HIV, but half the women with husbands 10 years or more their senior were HIV positive.

4 This is not to suggest that such epidemics explode wherever there are severe inequalities. But severe inequalities appear to be a precondition for epidemics as exacerbating and apparently unmitigating as those experienced in southern Africa, where intersecting forms of inequalities define social relations.

5 The lifting of tariffs in the textiles and clothing industry, along with other moves to harden its ‘competitive edge’ have depressed wages and spurred the conversion of secure jobs into ‘casual’ labour. According to the South African Clothing and Textile Workers’ Union (Sactwu), some 88 000 jobs were lost in this sector in 1989-2003, with half the factories shutting their gates for the last time between 1990 and 2001. The process continues throughout the region; in late May, 1 600 Namibian textile workers lost their jobs in one week, for example; see IRIN, ‘Textile sector stumbles as foreign owners pull out’, 19 May 2005.

6 Men in their late twenties and thirties, however, are more likely to be HIV-infected, and the dependencies built into such relationships can severely limit women’s abilities to protect themselves against HIV infection. Most explanations of transactional sex with older men attribute it to material desperation. In many instances, this is indeed the case. But often other factors are at play, as one recent multi-country survey in sub-Saharan Africa has shown; see Luke N, Kurz KM (2002). Cross-generational and transactional sexual relations in sub-Saharan Africa: Prevalence of behaviour and implications for negotiating safer sex practices. September. Washington, AIDSmark. Available at www.icrw.org/docs/crossgensex_Report_902pdf.pdf.

Prevention strategies aimed at reducing unsafe sex have to be built on recognition of the fact that, for some women, sex can be one of the few valued forms of capital at their disposal.

7 Transactional sex appears often to involve younger women and older men. Such ‘age mixing’ (whether inside marriage or outside it), appears to be
boredom and torpor (Jewkes et al., 2001). What makes these quests dangerous for so many is that they are played out not only in areas where HIV has firm footholds but also in circumstances marked by glaring gender and other inequalities.

Research is also confirming a strong association between sexual and other forms of abuse against women, which increases the odds of becoming HIV-infected. The links between intimate partner violence and an increased likelihood of HIV infection, for example, appear solid. At antenatal clinics in Soweto, HIV infection was found to be significantly more common in women who had been physically abused by their partners than in those who had not been abused (Dunkle et al., 2004).

The HIV/AIDS epidemic is intertwined, in other words, with the circuits and terms on which power, authority, value and opportunity are distributed — highly unequally, in the case of South Africa. Many of these inequalities are still being reproduced along an economic growth path that favours high-end, skilled labour and requires the increased informalization of other tiers of workers (especially women) — all of this occurring within systems of social relations that saddle women with most of the responsibility for social reproduction (bearing, raising and socializing children; managing the domestic realm; and providing care and other forms of support).

**Points of reference**

AIDS discourse tends to not shy away from hyperbole. The epidemic is typically portrayed as an exceptional, even unique, phenomenon. An unprecedented impact is anticipated, of an order comparable to or exceeding the upheavals of the 14th century or the famines and other disasters that beset parts of Asia and Africa in the 19th century. De Waal (2003:7), for example, has claimed that ‘none of the existing models for disaster, whether they are based on plagues, famines, environmental disasters, or wars, match the specific character of the HIV/AIDS pandemic’. Whether or not that is correct, the spectre of disorder and collapse hovers about AIDS impact literature, much of it forecasting eventual disintegration in ‘vulnerable countries’ that are unable to cope with the epidemic’s effects.

The distinctive features of AIDS are the concentrated toll it takes among young adults in the prime of their productive and reproductive lives, the fact that this toll tends to cluster within households (with partners infecting each other and the virus also being transmitted to newborns), and the long-term momentum a serious epidemic can acquire. Famines and infectious diseases usually claim the lives of the weak and frail — the very young, the already sick, and the elderly. Natural disasters tend to be less discriminate, although they are usually geographically concentrated (the December 2004 Asian tsunami having been an exception). Wars, too, are indiscriminate, although significant proportions of casualties are concentrated among males in their late teens to late thirties. Memorials in French villages, for example, still bear witness to the fact that in many thousands of small communities a significant proportion of their young men (mostly in their late teens and twenties) died during World War I. During the Rwandan genocide of 1994, almost one million Tutsis and Hutus (as much as one eighth of the population) were slaughtered in three months. During the four-year period that Cambodia’s Khmer Rouge regime was in power (1975–1979), an estimated 1.5 million of the country’s 7.9 million people perished amid the wholesale destruction of agricultural, transport, commercial and health infrastructure (Kiernan, 1996). Along with the American bombing of Cambodia, these are not entirely ‘indiscriminate’ disasters; poor communities usually bear their brunt.

8 HIV-positive women were more likely to have experienced a history of physical and sexual violence at the hands of male partners than were women without HIV, according to studies in Kigali, Rwanda, and in Tanzania (van der Straten et al., 1998; Maman et al., 2002).

9 These are not the only factors that decide the pace and severity of a mainly heterosexual epidemic such as South Africa’s. Other possibly definitive factors include which HIV subtypes are dominant, the prevalence of other sexually transmitted infections which can aid HIV transmission, whether or not circumcision is commonly practised, the physiological vulnerability of women (especially girls and young women), and more. The relative weight of these respective biological, physiological and sociological factors in specific settings remains a matter of supposition.

10 For a relatively restrained example, see Stabinski L et al. (2003) for an attempt to frame the AIDS epidemic in high-prevalence countries as a ‘disaster’, defined as a ‘serious disruption of the functioning of a society, causing widespread human, material or environmental losses which exceed the ability of a society to cope using only its own resources’ (p 1101). A more lurid example is a discussion paper ‘AIDS, economics and terrorism in Africa’, which was issued to coincide with the 2005 gathering of the World Economic Forum in Davos, Switzerland (see below).

11 These are not entirely ‘indiscriminate’ disasters; poor communities usually bear their brunt.

12 There has been considerable controversy about the Cambodian death toll. Kiernan’s (1996) estimate of 1.5 million tallies with that extrapolated from several other surveys. Research suggests that several provinces lost 20% or more of their inhabitants.
(which is estimated to have killed at least 150,000 Cambodians, although possibly many more, in 1969-1973), this constituted the most systematic and concentrated obliteration of lives, institutions, infrastructure and developmental capacities perpetrated anywhere since World War II. The effects have been grievous and have seeped deep into Cambodian society, possibly eclipsing the aftermath of any pestilence anywhere in recent times.

**The ‘Spanish Lady’**

The 1918-19 influenza epidemic killed more than 20 million people globally in just over six months (though some estimates put the toll at least twice as high). In India, the ‘flu claimed an estimated 17 million lives, in France at least 400,000, while in the USA it killed at least 500,000 and possibly as many as 675,000 people, more than the combined number of American deaths in World Wars I and II, the Korean War and the Vietnam War (Kolata, 2000). In South Africa, it is estimated to have killed 140,000 people in late 1918, roughly 2% of the entire population (Simkins, 2001). In Alaska and parts of southern Africa, entire villages are said to have been wiped out. The epidemic struck with extraordinary speed and hit three distinct age groups hardest: infants and babies under five years, the elderly (especially those older than 60 years), and people between 20 and 40 years of age (Kolata, 2000). Mortality rates were high enough to cause shortages of coffins in Cape Town, where some of the deceased had to be buried in mass graves (Kilbourne, 1987). In hard-hit cities, illness and death cut into business operations. The demographic shock was severe, but short-lived. Life expectancy in the United States of America, for instance, recovered to pre-epidemic levels within a year; in South Africa it took longer, although the impact appears not to have extended much beyond the early 1920s.

**Middle passage**

The search for reference points is perhaps better directed at the Atlantic slave trade, ramifications of which probably dwarfed the damage wrought by any famine or scourge in Africa. In 400 years (from the late 15th century to the late 19th century) some 18 million African slaves were exported from tropical Africa – most from West Africa and destined for the Americas and the Caribbean, but a significant number also transported via the Sahara Desert or Red Sea and from East Africa. Of this number, at least 9 million slaves were shipped across the Atlantic Ocean; at least one million more did not survive the ‘middle passage’, and an unknown number died before ever reaching the coast of Africa and before being herded onto ships. The effects of the Atlantic slave trade have proved hard to assess, although there can be little doubt that they were massive and prolonged. In Basil Davidson’s view, ‘the Atlantic trade had grown to such size by 1650 that for at least two centuries it did unquestionably bring a major influence to bear on many coastal and near-coastal peoples from the mouth of the Senegal to the southern borders of Angola’ (2003:219).

Long-term depopulation and demographic skewing were two of the effects noted. By the early 20th century African populations appear to have grown at a considerably slower pace than European, American or Asian populations. Those changes, however, cannot safely be attributed solely to the slave trade, as Davidson has pointed out. Colonial population estimates tended to undercount (as shown in Nigeria and Ghana, for instance), while the upheavals and invasions of the 19th century also took a horrible toll on many populations. Joseph Miller’s study of the Angolan slave trade suggests that an average of 6 people per 1,000 were captured each year, compared to an estimated 50 people per 1,000 who died from disease and other natural causes. Still, it meant that most sizeable communities could expect to lose at least one young man in each agricultural cycle or two – and the probability of kidnapping, capturing and enslavement lasted for centuries (Reader, 1998). Numerous African societies lost their best producers, the youngest and strongest of their men and women – not once or twice, but in successive generations over several centuries. The worst damage was inflicted on communities that were relatively small and economically weak, many of which disintegrated. In heavily raided areas, settlement patterns changed. The psychosocial effects of

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13 The outbreak was known in Britain, Canada, France and the United States as the ‘Spanish flu’ – possibly because the epidemic received more press coverage there, since Spain was not subject to wartime censorship – though in Spain it was known as ‘the French flu’, another example of the tendency to lay calamities at the doors of others.
repeated, periodic raids, the violent separation of kin, and the disruption of authority systems are not known in detail, but must have been deeply traumatizing.

But the slave trade’s most lasting and profound consequences did not stem directly from its demographic impact: they were more obtuse. Slavery transformed local economies and had a profound effect on the exercise – and usurpation – of political power. Able-bodied young men and women were removed from local economies and sold abroad for goods, creating a cycle of transactions and dependency that would change Africa’s history. The trade commercialized local economies, even those that were not directly involved in the slave trade, creating a demand and eventually a reliance on imported goods. Local political economies warped, as warlords and merchants acquired the leverage to compel indebted chief and elites to capture slaves as payment for loans. The long-term consequences were severe:

Essentially, the Atlantic trade was a large and long-enduring exchange of cheap industrial goods, mainly cottons and metalware and firearms, for the ‘raw material’ of African labour [...] By providing Africa with cheap substitutes, the Atlantic slave trade under-mined the local production of cotton goods and metalware; against the partial benefit of cheaper imports, it discouraged expansion from the handicraft stage [...] Above all, the overseas slave trade introduced and confirmed an underlying dependency that the colonial period was going to complete (Davidson, 2003:221).

The terms of Africa’s dependence on European industrial economies and the basis for its chronic ‘underdevelopment’ were thus laid. The slave trade had shackled Africa to the economic imperatives and political ambitions of Europe (Reader, 1998). Comparatively little is known or understood, though, about the long-term social and sociocultural imprints the slave trade left.

If the literature on the long-term effects in Africa of the Atlantic slave trade remains thin on sociological detail, a cataclysm that occurred several centuries earlier in Europe has yielded, by contrast, a treasure trove of studies that hint at the kinds of ramifications AIDS might unleash.

**‘King Death’**

The plague (or Black Death, as it later became known)\(^\text{14}\) which swept through western Europe between 1347 and 1351 was a singular, highly compressed shock – albeit on an unmatched scale. In four years, ‘King Death’ claimed an estimated 25 million lives, killing at least one third of Europe’s population, and possibly halving England’s population (Kolkata, 2000; Kelly, 2005).\(^\text{15}\) In some cities, such as Florence, between one half and three quarters of the population was wiped out. Although often seen as an indiscriminate epidemic, the plague – like almost all epidemics – was nothing of the sort, at least not in places like Oxford, where carefully maintained records showed a much higher mortality rate among the rural poor compared with the elites.\(^\text{3}\)

The plague shifted Europe on its foundations, with consequences that would alter the course of European history (Herlihy, 1997). Average life expectancy in western Europe prior to the Black Death was believed to have been around 35-40 years; in the second half of the 14th century, it fell below 20 years. It took some 100 years before Europe’s population again began to grow, and more than 200 years before it reached its pre-plague levels.\(^\text{16}\)

\[\text{14}\] The phrase ‘Black Death’ was not used in the Middle Ages. Coined by Scandinavian writers in the 16th century, it entered into wide use only in the early 18th century, with the publication of a book titled The black death and written by a German physician; see Herlihy (1997).

\[\text{15}\] The death toll remains difficult to peg with precision, and for obvious reasons. According to Herlihy (1997), local records suggest the populations of some cities and villages in England and Italy shrank by 70-80%. According to him, ‘Europe about 1420 could have counted barely more than a third of the people it contained one hundred years before’ (1997:17).

\[\text{16}\] Just as with AIDS, a minority position does question the primacy of the plague in the demographic and other disruptions witnessed in western Europe during that period. Focusing on an area of Normandy, France, Guy Bois developed a tantalizing Marxist analysis of the crisis, attributing it largely to a wider crisis in the social order (of feudalism, specifically), with the plague a subordinate factor. See Bois G (1984). The crisis of feudalism: Economy and society in Eastern Normandy c. 1300-1550. Cambridge University Press. Cambridge; for a brief discussion, see Herlihy (1997:35-38). Parts of the ‘denialist’ camp in South Africa seem similarly inclined, although their contributions have not yet ventured beyond the declamatory phase. Lacking a conceptual framework, analytical rigour and an informed engagement with the various types of data such an undertaking would require, the ‘denialist’ output – for all its pretences of excavating the social and political-economic undercurrents of the AIDS crisis – remains largely intellectually barren (see below).
Demographic ruptures of such intensity conceivably would have badly damaged institutions, particularly those reliant on highly skilled persons. Yet the picture seems mixed. At the height of the plague, universities were still being founded (in Florence, for example) or expanded (Cambridge established Trinity Hall and Corpus Christi College in 1350 and 1352 respectively). In the decades immediately after the plague, universities continued to be set up, including in Cracow (Poland), Orange (France) and Vienna (Austria) (Pennington, 2005).

More generally, as David Herlihy (1997) has shown, the routines of work and service were upended, as the high death rates left posts vacant and services unfulfilled. The volumes of land under cultivation shrank due to labour shortages which, with dramatic effect, also forced landowners to revise the terms of their relations with labour tenants and other workers. Agricultural rents collapsed and the wage demands of workers (especially those of artisans and other skilled workers) soared (Herlihy, 1997; Cantor, 2001). Not only did the labour market change, but the status and power of its various strata radically altered as greater possibilities for social and economic mobility opened up in rigidly stratified societies. Some forms of discrimination were temporarily abandoned due to the need to maintain essential services. Growing demand for the services of priests and physicians opened the way for new entrants into those ranks, some of them brazen charlatans and others (like women physicians) path-breakers. Grudgingly, the Church acceded to women performing pastoral functions or administering sacraments, while in the courts, women were for the first time allowed to serve as witnesses.\textsuperscript{16}

The ranks of craftsmen and other professionals were drastically thinned, and the professions responded by vigorously recruiting new members. That meant relaxing rules of admission, with guilds spreading the ‘net broadly and bring[ing] in new apprentices with no previous family connection with the trade’ (Herlihy, 1997:45). Incrementally, in such ways, the wedge of social transformation worked its way through society. In the longer term, the ructions were much more dramatic, for the Black Death ‘let loose hectically intense social pressures which the old-order conservatism could not contain’ (Rissik, 2005).

The fuse of the English Peasants’ Revolt of 1381, for instance, was lit when landowners convinced Parliament to impose controls they hoped would reinforce their control over peasants.\textsuperscript{17}

More generally, the plague divided, separated and polarized. In Herlihy’s summary:

The plague caused divisions between the healthy and the sick; between those in the cultural mainstream and those at its margins ... and between the mass of society and its cultural leaders, its governors, priests, and physicians. These fissures cut across society in complex and at times pernicious ways ... (1997:59)

Herlihy, rather grandly, maintains also that the labour short-ages caused by the plague accelerated the quest for and the introduction of new, labour-saving technologies, especially in agriculture. This is moot. In silk and wood manufacture, the big technological advances preceded the Black Death, as did the development of new types of scythes and more complex field systems.\textsuperscript{18} Nonetheless, the changes that can plausibly be traced to the plague’s decimating passage were clearly momentous and echoed down the centuries.

Seldom considered in the context of AIDS is how the epidemic might play itself out in non-material – or ideological – realms. Shocks this extreme enflame doubt, invite ‘heresy’ and provoke rebelliousness. The dialogues that ensue are personal and intimate but also lewdly public – and they tend to drift in two directions: secular skepticism and rebellion in thought (if not deed), and millenarian or ‘apocalyptic’ faith. Common to both is a suspicion and possibly even a rejection of orthodoxy and of hegemonic ideology. Like AIDS currently, the Black Death in western Europe encouraged ‘popular distrust of expert opinion, particularly of the medical profession, and ... led more forcefully to suspicions, fears and hatreds of the alien’, as Samuel Cohn has observed.\textsuperscript{19} As to the actual cause of the cataclysm, exotic accounts did the rounds. Academics at the medical faculty of the University of Paris, under orders from the monarchy, contrived a meticulous astrological explanation for the plague: ‘With a careful thesis, antithesis, and proofs,’ Barbara

\textsuperscript{17} The immediate trigger was the levying of a third poll tax, but the revolt was long in the making, with the 1351 Statute of Labourers having caused lasting resentment. Designed to curb workers’ demands for better pay and working conditions, the Statute was used to fix wages and limit the mobility of labour, and was viciously enforced.
The impulse is especially prominent in philosophical traditions in which Mary Lindemann has issued the same caution, pointing out that it was very even trace some of the early stirrings of the Enlightenment, puritan sects in England, for example (Kelly, 2005). Others Death’ and the rise of anti-clericism and the emergence of peddled. Some historians have drawn links between ‘King indictment of the Church, its mandarins and the worldview they with beneficence and goodwill. For many, the plague further authority of organized religion was not everywhere associated for by the early 14th century already, the all-encompassing on their treks before they were disbanded by the military arm of the Church. Other cultural and ideological shifts ensued, for by the early 14th century already, the all-encompassing authority of organized religion was not everywhere associated with beneficence and goodwill. For many, the plague further indicted the Church, its mandarins and the worldview they peddled. Some historians have drawn links between ‘King Death’ and the rise of anti-clericism and the emergence of puritan sects in England, for example (Kelly, 2005). Others even trace some of the early stirrings of the Enlightenment, and specifically the tradition of skepticism that fed it, to the ‘Great Mortality’.

On the eastern flanks of the Mediterranean and in Asia Minor; meanwhile, societal reactions were different. Political elites escaped the kinds of popular challenges seen in parts of western Europe. The plague did not feed off factional rivalries, nor did it foster xenophobia and waves of anti-Semitic pogroms as it did throughout western Europe. This highlights the importance of the underlying social and political-economic conditions in societies battered by crises such as this. The plague penetrated every cranny of society, but in doing so it also interlaced with social dynamics. Dislodging it from that tangle of interactions is difficult, perhaps not feasible: ‘From the matrix of forces shaping the late medieval world, it is impossible to factor out those attributable to plague alone’ (Cohn in Herlihy, 1997:19).

### Search for meaning

Humans find it difficult to think of epidemics as phenomena that ‘happen’, as opposed to phenomena that are ‘made’ or perpetrated. This is understandable. Senselessness or arbitrariness on such a devastating scale upsets us. We seek order and meaning, and insist on detecting and plotting patterns in apparent randomness. And so, plagues are often interpreted as forms of reckoning, a spiritual accounting or a balancing of scales. Or they attract suspicions of insidious intent. Throughout modern history, new diseases have been answered with a hunt for scapegoats. Once the 14th century plague, which probably originated on the Central Asian steppes, arrived on the shores of mercantile Europe, for instance, the afflicted clung confidently to the belief that it was being spread deliberately. Intricate conspiracy theories were spun, fed with false confessions obtained under torture. The eye of suspicion fell on lepers and other social outcasts, but settled most firmly on Jews, and to tragic effect. Pogroms swept across western Europe; more than 350 massacres of Jews were recorded during the Black Death. ‘As ever’, as Andrew Rissik observes, ‘what matters wasn’t what was true, but what seemed at the time to make wider sense’. And so it is with AIDS, too. Swirling about it is an abductive suspicion that something this ghastly and relentless cannot be mere happenstance, even that HIV was a deliberate concoction, designed to exterminate blacks.

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18. Mary Lindemann has issued the same caution, pointing out that it was very difficult to disentangle ‘the effects of the plague from the other factors’ at work in a century marked by ‘endemic warfare, famine and declining populations even before the plague hit’; see Lindemann M (1999). *Medicine and society in early modern Europe*. Cambridge University Press. Cambridge, p 43.

19. The impulse is especially prominent in philosophical traditions in which the principle of culpability is prominent. Random mishap and many, lacking apparent purpose and the hand of agency, is both bewildering and unsatisfactory. Blame has therefore tended to accompany disease. Usually the blame is directed at the Other, sometimes at the victims themselves, although sometimes the victims and the Other are one and the same – as with India’s great cholera epidemic, which killed probably 25 million people in the mid-19th century. There, the colonial government attributed the outbreaks to the ‘loathsome habits’ of Indians. For more, see Watts S (1997). *Epidemics and history: Disease, power and history*. Yale University Press. New Haven.

20. Among the lore of the Black Death there is one instance where the plague indeed seems to have been spread purposively. When Mongol soldiers attacking the trading hub of Caffa (or Kaffa), on the eastern rim of Crimea, in the early 1340s, succumbed to the plague, their general reportedly ordered that the corpses be hurled into the city, in the hope that this would infect the defenders. The ‘confession’ by a Jewish surgeon, Malavigny, in Switzerland, proved particularly enthralling. His claim – that he had poisoned ‘Christian’ water wells with the pestilence – provided enticing texture to the conspiracy theories, which proceeded to decipher the plague as a Jewish plot for world domination, masterminded by a Spanish rabbi. See Joan Acocella, *The end of the world*, The New Yorker, 21 March 2005.
The circuitry of ‘denial’

Infectious diseases are met instinctively with attempts to demarcate danger and safety. These are cleaving maneuvers that seek to distinguish the ‘pure’ from the ‘contaminated’, typically by ascribing to people traits, behaviours and motives that either guard against or invite affliction. It is in order to establish and police these perceived boundaries that social strictures are imposed and disciplinary forays are mounted. Victimization and polarization typically rank among the outcomes. There’s nothing ‘innocent’ about these reactions. Invariably they also express other contests, ambitions and resentments. Look hard enough, and they betray their eminently political nature.

All this is plainly evident with AIDS, not just in the stigmatization of people living with HIV and the abandonment of those succumbing to AIDS but also in the virulent tendency to regard and treat women as vessels of contagion and ‘disease-carriers’. This is in keeping with the long, squalid history of male imaginings of the female – in which the nurturer/whore, angel/witch dichotomies, and the association of women’s bodies with impurity and contamination retain their prominence. It’s a disquietingly global phenomenon that is firmly lodged in South Africa too. Women are deemed to be the ones ‘who bring AIDS into the home’. The fact that it is often women who are the first to discover their serostatus – usually once pregnant – grants this prejudice even more reflexive force.22

In a persecuting society such as South Africa, awash with racialized intolerance and fearfulness, it is no surprise that popular understandings of AIDS should also be coloured with racist assumptions that draw on entrenched stereotypes and prejudices. Central in this have been the ‘pathologizing discourses’ in which black sexuality is constructed as rampant, unbridled and insatiable. These acquired their initial outline during the early periods of colonialism, and have featured strongly since also in medical science – with extraordinary luminosity during South Africa’s syphilis panics of the 1930s and 1940s, for example. For many whites, those scares reinforced stereotypes of black African men as voracious and insatiable sexual predators, a staple of racist prejudice. Similar imagery has circulated in AIDS discourse (Walker et al., 2004). These kinds of imageries of black Africans have served as a screen against which Western cultures have constructed their own, contrasting self-portraits which boast of restraint, purity, calculation and rationality, as Fanon famously observed.23

The linking of race, libido and death in colonialist discourses – and the apparent complicity of medical and social science in this – still resonates loudly in South Africa. It hovers as a kind of ‘contemporary past’, as histories that refuse to relinquish their footing in the present,24 as President Mbeki noted in late 2004:

I, for my part, will not keep quiet while others whose minds have been corrupted by the disease of racism, accuse us, the black people of South Africa, Africa and the world, as being, by virtue of our Africanness and skin colour – lazy, liars, foul-smelling, diseased, corrupt, violent, amoral, sexually depraved animalistic, slaves – and rapists.25

Earlier, in April 2002, Mbeki had described what he saw as a fundamental tension between the realities lived by black Africans and the images circulating in the domains of Western science:

22. The fact that HIV estimates in sub-Saharan Africa have been based largely on the testing of anonymous blood samples drawn from women attending antenatal clinics probably has inadvertently reinforced this blaming association between women and the spread of HIV.
23. See Thabo Mbeki, ‘Dislodging stereotypes’ (Letter from the President), ANC Today, 4(42), 22-28 October 2004. Available at http://www.anc.org.za/ancdocs/antoday/2004/0442.htm. President Mbeki was reacting in Parliament to a question from an opposition Democratic Alliance politician about HIV/AIDS and the role of rape in the epidemic. The response, which runs to three pages of text, makes only cursory reference to HIV/AIDS and to rape – the latter referred to as a ‘contact crime’, a clinical choice of language that contrasts with the impassioned declamations about race and racism. There’s a hint here of one of the overlooked hallmarks of South African ‘denialism’ – the overbearing man-e-ness of a discourse that is typically silent about gender injustices and inequality, and their role in the epidemic. At its core, this is a discourse by men about men, with women a shadowed presence. Lisa Vetten’s remarks about President Mbeki’s statements on rape seem apt here: ‘I[n] repeated and exclusively confining the debate to African men, Mbeki is deflecting attention away from the sexual predatoriness [sic] of men generally, regardless of colour … not once in these debates have the words “gender inequality” appeared in the President’s writings or utterances. In ANC Today he writes only in the most general terms about “contact crime” (rather than rape) and ascribes the causes of these crimes to poverty and community degradation. No onus is placed on South African men generally to examine and change their unequal relations with women.’ See Lisa Vetten, ‘Mbeki and Smith both got it wrong’, Mail & Guardian, 29 October – 4 November 2004. Available at http://www.csvr.org.za/articles/artvet15.htm.
Because of the pursuit of particular agendas, regardless of the health challenges facing the majority of our people, who happen to be black, in our country there is a studied and sustained attempt to hide the truth about diseases of poverty.

If we allow these agendas and falsehoods to form the basis of our health policies and programmes, we will condemn ourselves to the further and criminal deterioration of the health condition of the majority of our people. We cannot and will not follow this disastrous route. We are both the victims and fully understand the legacy of centuries-old and current racism on our society and ourselves.

We will not be intimidated, terrorised, bludgeoned, manipulated, stampeded, or in any other way forced to adopt policies and programmes inimical to the health of our people. That we are poor and black does not mean that we cannot think for ourselves and determine what is good for us.iii

Around the same time, a bilious tract titled ‘Castro Hlongwane, caravans, cats, geese, foot and mouth, and statistics’ flamboyantly claimed on similar themes. Distributed in senior structures of the ruling African National Congress (ANC) by Peter Mokaba (now deceased) but, according to some reports, penned with possible involvement from president Mbeki,iv it dismissed the ‘HIV/AIDS thesis’ as:

informed by deeply entrenched and centuries-old white racist beliefs and concepts about Africans and black people [...] . Driven by fear of their destruction as a people because of an allegedly unstoppable plague, Africans and black people themselves have been persuaded to join and support a campaign whose result is further to entrench their dehumanization (Anon, 2002).

Casting the government in the role of victimized heretic, the screed junked ‘as baseless and self-serving the assertion that millions of our people are HIV-positive’ and rejected ‘the claim that AIDS is the single largest cause of death in our country’ (Anon, 2002). Stirred in were calls for defiance against ‘the omnipotent apparatus’v that allegedly seeks to dehumanize Africans by recycling racist prejudices about ‘African sexuality’ and stoking unwarranted panic about AIDS.

Interventions of this sort confirmed that memories of encounters with colonial power and science linger strongly. One example was the rinderpest epidemic that struck the east coast of South Africa in late 1896. Following on the heels of ‘natural’ setbacks (including droughts),vi rinderpest scythed through black and white cattle-farming communities in what was then Natal and Zululand. Dubbed umaqmulana, the disease felled huge numbers of cattle, and prompted various responses. On the one hand, there were attempts to enforce customs deemed to shield against this apparently supernatural force; on the other hand, there were the panicked demands from white commercial farmers that the contagion be halted before it also decimated their herds.vii If the quarantine measures applied by the authorities were resented, the subsequent vaccination of black-owned cattle by roaming teams of veterinarians, court officials and police stoked angry distrust about the true motives of the exercise. Western medical science was being experienced as an invasive and destabilizing force. The fact that vaccinated cattle showed temporary symptoms of rinderpest, and that the most...
effective serum at the time protected cattle for only four months (after which the beasts were again susceptible to infection) deepened suspicion about this ‘white man’s disease’ (Carton, 2003:4). Measures ostensibly taken to ‘protect’ blacks seemed to achieve the opposite, leaving them worse off.

The distrust shaped reactions to flu vaccination efforts in the Eastern Cape during the 1918 influenza epidemic, too. Carton (ibid), for example, cites references to the vaccine as a genocidal tool, ‘a device of the Europeans to finish off the Native races of South Africa, and as it had not been quite successful, they were sending out men with poison to complete the work of extermination’. The parallel with claims circulating on the fringes of AIDS skepticism are obvious.

In the decades that followed, the use of science-based knowledge by the authorities in South Africa intensified. Sometimes it took the relatively ‘neutral’ form of promoting new cultivation, irrigation or contouring techniques in agriculture or livestock vaccination requirements. But it was also expressed as a blend of racism and Malthusianism that gave rise to the apartheid state’s ‘family planning’ initiatives among black South Africans.

In extreme fashion, it would manifest in the chemical and biological warfare experiments of Wouter Basson, and his search for ways to surreptitiously induce infertility in black South Africans. Just as South African history has fed a fervent suspicion about disease, science and power – and the loathsome ways in which they can be made to converge – AIDS has come to function as a kind of prism, vividly focusing these discursive trends and inviting the ‘denialism’ of which President Thabo Mbeki and others in the ruling African National Congress have been accused.

President Mbeki did not invent this tendency when, in 2000, he set about questioning the casual relationship between HIV and AIDS. The doubts dated back at least a decade, and had fuelled numerous rumours, including the stalwart claim that HIV had been concocted in laboratories and was part of a plot to exterminate blacks. But nowhere else were the doubts issued from such lofty heights, and with such insistence. By first ‘legitimizing’ and then politicizing errant doubts, President Mbeki and his circle of skeptics seemed to modify them into gestures of ‘dissidence’ and ‘rebellion’. Indeed, Schneider and Fassin (2002:549) have read South African ‘denialism’ as a form of ‘defiance’ against ‘official scientific knowledge’ and an ‘identification with those on the margins, whether of science or society’. But there is a strong case for arguing that it is both less and more than that. While there has no doubt been a pretence of broadcasting necessary and ‘courageous’ truths, these poses have been struck in the highest office in the land and from within the heart of the state. More appropriate than the folksy image of the underdog squaring off against massed power would be comparisons with other occasions when the state backed quack science (such as the Lysenko debacle of the 1930s, and the dogged interventionism of the George W Bush administration).

Although part of a wider reaction against the contumely, denigration and exploitation that Africa continues to endure, South

27 Medical science generally was an important adjunct of colonial projects, especially after the rise of bacteriology, which made possible the development of relatively effective drugs and treatments for many afflictions encountered in Africa, Asia and the Americas. England’s London School of Hygiene and Tropical Medicine and France’s Pasteur Institute were particularly active on those fronts.

28 Noteworthy, too, was the prophet Nontetha Nkwenkwe’s claim that the epidemic was divine punishment for sexual promiscuity and debauchery (Carton, 2003). There were many other examples where public health measures seemed indistinguishable from other efforts to extend the control of the colonial (and later, the apartheid) state over black South Africans, including the ‘demythologisation’ campaigns in Durban and the clearly discriminatory quarantining operations during an outbreak of the plague. See Youde J (2005). South Africa, AIDS, and the development of a counter-epistemic community. Paper prepared for the 2005 International Studies Association Conference. 1-5 March. Honolulu.

29 The analogy was not lost on President Mbeki who, in 2000, reportedly railed against South Africans being used as ‘guinea pigs’ for dangerous antiretroviral drugs which he likened to ‘biological warfare of the apartheid era’. He was referring to the provision of the drugs in the Western Cape, at that stage governed by the opposition. As we observe below, AIDS ‘denialism’ has been used routinely as a party political tool, at all ends of the spectrum. Mbeki’s remarks in this case were made shortly before the municipal elections. See Drew Forrest, ‘Behind the smoke-screen: The record reveals President Thabo Mbeki’s true stance on AIDS’, Mail & Guardian, 26 Oct 2000.

30 Reflecting on his experiences as Medical Research Council president, Dr Malegapuru Makgoba in 2002 suggested as much: ‘The politicization of scientific research, trying to do research according to political ideology and along party political lines, and trying to manage, recruit and appoint staff along these lines have never worked successfully anywhere where excellent science is being done. This approach has been a death knell to science [...] Innocuous as it may currently appear, the long-term effects of this are devastating and will take too long to rectify. I think it is therefore critical that we nip this pernicious problem in the bud early on. These are the challenges I faced and resisted and will resist for as long as I live. We should always remember what Lysenko did to Soviet science and the future generation of Soviet scientists.’ See ‘Dr Makgoba – a passion for excellence’, MRC News, August 2002, Vol 33 No 4, p 6. Available at http://www.mrc.ac.za/mrcnews/aug2002/makgoba.htm. For a caustic summary of the Bush administration’s conduct, see Mooney C (2005). The Republican war on science. Basic Books. New York.
In fact, the arguments draw on discrepant philosophical traditions. On science and poverty. To considerable extent, ‘denialism’ functioned as a grammar for other, overarching political engagements and pursuits. And AIDS serves such an enterprise not as a mere pretext, but because it draws into focus so many outrages and injustices.

‘Denialism’ functions, in the first instance, as a platform for pinpointing, denouncing and attacking racism. In this sense, AIDS has provided a necessary vent for the righteous but sublimated anger that was bottled-up during the 1990s, when it was subordinated to the imperatives of stability, conciliation and calm. The eruption of ‘denialist’ discourse reflects what seems like a shift from that interlude – with its bewildering silences and maddening overtures that seemed to suspend history itself – toward a more forthright confrontation with realities that cannot yet be consigned to the past. That shift should not be exaggerated, though. The chidings directed at business have been rare and delicate, for example, while the historical and contemporary crimes of capital have encountered little of the wrath unleashed around AIDS. To an extent then, ‘denialism’ seems to be doing service also as a substitute or a vehicle for other confrontations and condemnations. In this role, it fulfills an ideological function alongside other discursive devices that are designed to shore up affinities, loyalty and solidarity among the constituents of the ANC. It spotlights the ignominy that has marked so much of South African (and African) history, condemns racism and the ongoing injustices and indignities that millions endure, and advertises a determination to vanquish those blights.

Yet all this occurs against a background of policies, many of which demonstrably prolong and fortify the reproduction of inequality and circumstances of indignity. It happens alongside inscrutable accommodations with (former) administrators and beneficiaries of institutionalized racism. And it accompanies the embrace of (Western) consumerism and acquisitive zeal. As such, ‘denialism’ fits into a discursive project the ANC has proved especially adept at: blending the ‘old’ with the ‘new’, the orthodoxy with the heterodox, and employing sometimes-radical principles and perspectives associated with national liberationism in the service of conventional, sometimes-conservative agendas.

South African ‘denialism’ also has a more literal, ‘profane’ political heritage. Soon after the country’s democratic era began in 1994, critics of the new government settled on AIDS, crime and violence as their preferred routes of attack. A series of debacles in 1995-1997 seemed only to highlight the vulnerability of the ANC government on this front. The lights had hardly dimmed on the Sarafina controversy when the government’s apparent endorsement of virodene hit the headlines.

31 In fact, the arguments draw on discrepant philosophical traditions. On one hand, the reliability and veracity of HIV/AIDS estimates are challenged from within the empirical tradition, with observed and, if possible, enumerated facts deemed to constitute truth (see below). At the same time, the critique of scientific integrity mounted by ‘denialists’ fits also with the post-modernist enterprise of dismantling the idea of ‘truth’ and demonstrating the intimacy of ‘truth’ and hegemonic power. Science is deemed to pursue ‘truth’ in line with the logic and requirements of capital, in this view, and is thoroughly instrumentalized. Such critiques of science’s instrumentalization-subordination even-to the imperatives of capital accumulation owe much to the work of Herbert Marcuse and other Frankfurt School alumni. For a bracing overview of this tradition, written from a Marxist perspective, see John Bellamy Foster’s ‘Science in a skeptical age’, Monthly Review, 50(2), a review of John Gillot and Manjit Kumar’s book Science and the retreat from reason (Monthly Review Press, 1997).
Then came the disputes about the side-effects of zidovudine, with then-deputy president Mbeki wading into the fray (Marais, 2000). Conservative political opponents and the largely unreconstructed mainstream media prodded and pierced with relish. Soon another twist was added. As the government wheeled out its prevention-focused Presidential Partnership Against AIDS in 1998, the clamour for an antiretroviral treatment programme commenced (Schneider & Fassin, 2002).

Initially focusing on mother-to-child transmission (MTCT), and spearheaded by the Treatment Action Campaign (TAC), that quest soon dovetailed with a dogged international campaign, led by AIDS, health and social justice activists and targeting pharmaceutical corporations, G8 leaders and recalcitrant governments alike. Assailed by the left for pursuing a neoliberal economic programme, and now challenged from all ends of the political spectrum for allegedly disregarding the lives of its citizens, government’s reactions grew ever more livid. It is as if this indignation blurred perspective, allowing the wispy outlines of conspiracy to enter fields of vision. By 2000, what might have been a measured debate had degenerated into a brawl. The fact that AIDS had become the mobilizing issue for an avowedly progressive and, as it quickly became clear, tactically savvy formation seemed especially wounding. Here was a burgeoning social actor with the nerve to challenge the government in the name of that government’s constituency.

Soon after the TAC launched a court application to force the roll-out of nevirapine to reduce MTCT, it found itself at the receiving end of contumely seldom directed at other targets:

Thus does it happen that others who consider themselves to be our leaders take to the streets carrying their placards, to demand that because we are germ carriers, and human beings of a lower order that cannot subject its passions to reason, we must perforce adopt strange opinions, to save a depraved and diseased people from perishing form self-inflicted disease... But that is to quibble. Part of the appeal of ‘denialism’ resides in the fact that it incorporates important and heartfelt critical impulses that resonate in progressive traditions. The eclectic philosophical heritage of ‘denialist’ argumentation, for example, does not scupper the assertion that science, in many respects, is enlisted in and sometimes positively indentured to the quest to maximize profits. Similarly, when the Presidential AIDS Advisory Panel convened by President Mbeki is tasked, among other things, with examining the ‘prevention of HIV/AIDS, particularly in the light of poverty, the prevalence of co-existing diseases and infrastructural realities in developing countries’ it is difficult to demur without seeming to favour a narrow-minded view that ignores the sociology of disease. The importance of impoverishment and inequality in South Africa’s epidemic is not invalidated because ‘denialists’ try to displace the causal relationship between HIV and AIDS with those factors. Indeed, there seems little to dispute in a thesis that positions HIV/AIDS as an exceptionally devastating aspect of a larger, enfolding and

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32 The very idea of ‘Africa’ can be said to be a by-product of colonialism – by way of the struggle against colonialism.

33 It is not only within capitalism that science has been instrumentalized, as the infamous Lysenko affair of the 1930s in the former Soviet Union reminds. In that case, science was yoked to the programmes of particular political factions within the state.
ongoing outrage (much as Pierre Bois attempted to do with his revisionist history of 14th century Europe and the Black Death – see above). The epidemic and its impact are inextricably interlaced with the ways and the terms on which power, rights, resources and opportunities are distributed in society. The problem, of course, is that South Africa’s ‘denialist’ politicians do nothing of the sort: they go the whole hog, and deny the epidemic exists. They follow through not with defiant plans for dismantling the socio-economic and sociocultural causes of this wave of mortality, but with a staid determination to stay the course of economic orthodoxy, leavened with Keynes-lite ‘deviations’.

If we can’t achieve certainty, then surely the door must be held ajar for other possible explanations. But, one might ask, explanations of what exactly? Not, as it transpires, explanations of the technical and other reasons for differing estimates. Rather, the grasp is more ambitious: uncertainty is seen as proof of, at best, reckless guesswork and, at worst, fraud and deceit – all rooted in the residue of racism and contrived by vested interests and their lickspittles in science, duped activists, the media, and all manner of other ‘convenient fools’.

A special role is reserved for the pharmaceutical industry, seen as intent on seizing the vast profit-raising opportunities that antiretroviral provision in Africa represents. Such an arrangement might well provide a healthy motive for skullduggery and deceit. Although antiretroviral drugs feature nowhere near the industry’s top earners in industrialized countries, the sheer volume of need in Africa could change that, especially if treatment roll-out is financed through donor subsidies and grants – or so the argument implies. It’s odd thinking for people, many of who have had at least a brush with Marxist theory. The market’s remarkable capacity to absorb and capitalize on change – whether trivial, threatening or tragic – is a function of its systemic logic, its need to engulf and digest everything in its path. It doesn’t require a vast conspiracy – akin to faking a moon landing on a Hollywood soundstage – that involves ‘inventing’ an epidemic and, almost 15 years later, marketing ‘quack’, ‘life-threatening’ drugs as an effective form of treatment, in order to boost pharmaceutical turnover by a fraction. In reality, from the major pharmaceutical corporations’ vantage, Africa merited scant interest as a market for antiretroviral drugs: Africans who needed the drugs and could pay for them constituted pitifully feeble demand.

Pharmaceutical corporations were not all that keen on going to Africa; instead, Africa was brought to them. In the late 1990s, global activist demands for antiretroviral provision in Africa were creating an international public relations nightmare for those corporations, which had never quite managed to scrub the muck from their reputations. By 2000, the industry found itself lumbering in the path of several developments. One was the prominent place health and disease had assumed on progressive activist agendas around the world; in fact, not since the infant formula debacles plaguing Nestlé in the 1970s and 1980s had public health kindled such blazing resolve in international activism. Health and medicines were again being recognized as an important terrain on which to contest inequality and injustice. Alongside this came the burgeoning opposition to the drive to codify global regulatory regimes in ways that would unabashedly service the accumulatory needs of transnational capital. Foremost among these was TRIPS (the Agreement on Trade-Related Aspects of Intellectual Property Rights). For pharmaceutical corporations...
especially, a new patent regime was a strategic imperative, a gateway for achieving and preserving more securely key monopolies in a sector that was beginning to lift the lid on a pandora’s box of money-spinning discoveries. AIDS – and especially antiretroviral provision in Africa – marked the spot where those respective agendas clashed. To its dismay, the industry was thrust centre-stage in this drama, and cast, convincingly and justifiably, as a heartless ogre of mammoth proportions. If anything exemplified the case of the global social justice movement, it was the routine disdain with which pharmaceutical corporations put profits before people in Africa. This wasn’t just a run-of-the-mill public relations hiccup; at risk was a vital strategic objective of achieving an intellectual property rights regime that could boost and safeguard major corporations’ growth in the 21st century.

Those were the real stakes for the industry – not the marginal rise in turnover it could wrench from a continent where lack of affordability so firmly thwarted demand. For them antiretroviral drugs and Africa had ended up spelling trouble.\footnote{Also tempering pharmaceutical industry’s enthusiasm for antiretroviral drug provision in Africa was the concern that the anticipated emergence of new drug-resistant HIV strains would drastically trim the product-life of antiretroviral drugs the industry produced (and sold primarily in the industrialized world). Research and development of new drugs would then have to be accelerated and expanded, incurring additional costs that would eat into profit-margins in a climate where activist pressures were strong enough to force pricing restraint.} The compromise – facilitated by the G8 powers – was to relent to activist demands that antiretroviral prices be trimmed in Africa and other ‘developing’ regions, loosen some shackles on generic production, and accept the conditional relaxation of some TRIPS strictures (at the 2002 Doha round of the World Trade Organization).

\section*{Limits of understanding}

Our knowledge of the HIV/AIDS epidemics is sufficiently solid to provide a firm and confident basis for understanding, yet not sufficiently developed to enable untangling their many remaining mysteries.\footnote{This discursive tactic has become a staple of ‘denialism’. The ‘Castro Hlongwane’ text, for example, starts with a list of ‘unanswered’ questions, probably a self-consciously echo of an essay in the African National Congress’ Sechaba journal 14 years earlier, which had commenced in similar fashion with a list of questions before providing a thinly veiled conspiratorial exposition; see Mzala (1988).} This absence of seamless certainty, and the quest for it – an endless to and fro – is one of the hallmarks of science. It is also a perennial feature of epidemiology. The rapid spread of the 1918 influenza virus, which in North America (for instance) seemed to out-sprint returning service men and women, long baffled scientists (Kolota, 2000). Even the debate about what exactly caused the Black Death continues.\footnote{The comparative rareness of pneumonic plague still puzzles; so, too, the reasons for its often-sudden arrival and departure. It this absence of certitude, combined with the confidence that it can be filled, that has provided modernity with its dynamism.} The lack of absolute certainty is transformed into a refutation of the knowledge that has been assembled.\footnote{The fact that some questions remain unanswered cannot serve as grounds for dismissing those answers that have been arrived at; by such reasoning, the entire edifice of science should be dismantled.} Presented as the linchpin of the ‘denialist’ argument, the disputes over the accuracy of HIV and AIDS estimates are something of a Trojan horse. In casting doubt on the estimates, the aim is not to identify or achieve a more accurate picture of the epidemic but to demonstrate its alleged fraudulence. And yet ‘denialism’, reckless and damaging as it has proved to be, has served a useful purpose. It has illustrated how phenomena as traumatic as AIDS inevitably serve also as arenas for contests between rival systems of knowledge and rival claims to ‘truth’. It has shown that those skirmishes are always also distillations of other political and ideological struggles. And it has reminded us that scientific endeavours do not evolve aloof from society, answerable only to a remote search for ‘truth’, but to some or other extent are always buffeted by the roil of competing interests and forces.

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Gaps, cracks and blindspots

No epidemic in history has been studied and scrutinized to the extent that AIDS has in the past twenty-odd years. The information gathered and the knowledge gleaned from it continues to grow. Advances in the biomedical knowledge of HIV, AIDS and, increasingly, the functioning of various forms of treatment have been especially striking. In comparison, efforts to incorporate social research and analysis into the study of AIDS lag. Hitching ‘development’ to ‘AIDS’, for example, has become a reflex, although too often an empty, rhetorical one. AIDS research and analysis has assimilated very little of the critical knowledge that has accumulated in development theory and practice over the past quarter century, not to mention the other pertinent fields of sociology, social anthropology, political geography and economics. Precious little genuine, multidisciplinary rigour is evident in AIDS literature. The attempts to document, interpret and analyze the impact of AIDS in places with severe epidemics exemplify these shortcomings.

In trying to discern the likely impact of AIDS in South Africa, and the various ways and paths along which that impact would circulate through society, we have to acknowledge the limits both of current research output and the framing of that research, little of which is capturing the impact on systems and processes, or exhibiting understandings of the social dynamics with which AIDS intersects. The literature by and large has acquired a familiar and standard look, with common and recurrent features. Typically, AIDS and its impact are regarded as discrete phenomena that leave a trail of clearly discernible consequences in their wake. Impact is then gauged in distinct units and sectors of society, where it is quantified and enumerated, but with little sense of the jumbled interplay between them.

Much AIDS impact research and writing glosses over the intricate ways in which societies (re)arrange and (re)organize themselves, as we show in more detail below (see Ground Zero). Sometimes the conceptual baseline, the default point of reference is inappropriate, even alien to the reality being studied. The phrase ‘extended family’, for example, betrays an assumption that a compact, ‘nuclear’ family unit constitutes normalcy everywhere (when, in fact, the reverse holds). Likewise, the shifting arrangements of child-care beyond the father-mother axis in most of Africa earns cursory attention in orphans research (Stein, 2003). Numerous studies have quantified the impact of an AIDS illness and/or death within households, but little is known of the impact AIDS in one household might have on other, apparently unaffected ones. Households (and communities) tend to be pictured as homogenous entities. Few AIDS-related studies have examined relations of power inside households, and how these affect the allocation of resources, duties and entitlements – or how they might alter in the face of adversity. Tied to this is a tendency to exaggerate households’ adaptability, since the internal dynamics for the most part are left opaque and fuzzy. The reality can be disconcertingly inflexible – if roles and duties are rigidly assigned by gender, for example – and policy and programme design has to take account of this.

The concept of ‘vulnerability’ features prominently in AIDS literature. It is meant to refer to an exceptional state of affairs, to circumstances that should not be the norm. It marks frailty, disempowerment and insecurity – which, in the context of HIV/AIDS is translated into a likely inability to fend off possible infection or to cope with its effects. But what does such a concept reveal about a society in which perhaps half the population can be considered vulnerable – not just to HIV and the aftermath of infection, but to a barrage of routine adversity? Most damningly, the literature is almost bereft of attempts to locate the epidemic’s impact and people’s experiences of it within the context that determines how power, resources and opportunities are reproduced and distributed across society. These are limiting perspectives that stunt our understandings of the epidemic and of people’s encounters with it, and that distort the kinds of policy and programme responses which eventually find acceptance.
Chapter endnotes


iv For example, one in ten young South African women (who have had sex) have reported being forced to have sex, according to one national survey (Reproductive Health Research Unit & Medical Research Council, 2003).


vi John Pilger, for example, has noted that ‘in one six-month period in 1973, more tonnes of American bombs were dropped on Cambodia than were dropped on Japan during the Second World War’; John Pilger. The Guardian. 30 January 2004.


viii For a summary of two, more or less diametrically opposed views, see Miller JC (1998).

ix The Declaration was adopted at the Bandung Conference, a gathering of mostly newly-independent Asian and African states. It included trenchant defiance of colonialism and neocolonialism, and emphasised the need for self-determination within the context of economic and cultural co-operation between ‘third world’ countries. The meeting was held in Bandung, Indonesia.

x For a more thorough discussion, see chapter 8 in Marais (2001).

xi For more on this, see Marais (2001: 260-261).

xii For a thorough discussion of this period, see Marais H (2000). To the edge. AIDS Review 2000. Centre for the Study of AIDS. Pretoria.

xiii For excerpts from the letter, see ‘Reciting comfortable catechisms on HIV/AIDS is not good enough’. Sunday Times. 23 Apr 2000.

xiv For a thorough discussion, see chapter 8 in Marais (2001).


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xxviii As we shall see, the writings of Alex de Waal especially have served as welcome antidotes to this tendency.
Gauging the epidemic

‘Of what use are statistics if we do not know what to make of them? What we wanted at that time was not so much an accumulation of facts, as to teach the men who are to govern the country the use of statistical facts.’ (Florence Nightingale)

Facts don’t ‘speak for themselves’. The English nurse Florence Nightingale understood this when, during the Crimean War 150 years ago, she set about collecting mortality statistics of soldiers admitted to the field hospital of Scutari. Viewed from one obvious angle, the statistics reflected casualties of battle – a regrettable ‘fact of war’. Nightingale saw a more complex picture. Once analyzed, her data enabled her to show that injured soldiers were seven times more likely to die from typhus and cholera contracted in hospitals than from wounds sustained out on the battlefield. Wretched sanitary conditions in military hospitals were claiming more lives than bullets and shrapnel (Scott, 2005). A simple tally of the dead would have hidden this vital fact; analysis brought it to light. Facts don’t disclose their value themselves, and the important ones don’t automatically eclipse the dross.

Until very late, warnings that a serious HIV/AIDS epidemic was incubating in South Africa were either ignored, disputed or dismissed. It’s not hard to see why. HIV spreads with stealth, and for many years hides its presence from casual observation. An epidemic becomes ‘obvious’ long after it has become a fact of life and death. In our case, this was happening in a society wrenching itself free of apartheid and in a period when the future seemed there for the making. Seeing this gathering shadow of the epidemic for what it was implied a betrayal of hope, a kind of blasphemy. History could not be that cruel and cynical.

But it was. By the time voters went to the polls for the country’s second-ever democratic election in 1999, at least 3 million and possibly as many as 4 million South Africans were living with HIV.1 Forecasts of what lay ahead had been flying thick and fast. Uniformly grim, they were of varying quality, however. While many were being assembled with the best available data and the requisite rigour, a few were slipshod, even sensationalist. So it was perhaps inevitable that doubt would resurface when, to some, the anticipated doom seemed indiscernible from ‘routine’ wretchedness. Steadily, that doubt morphed into disbelief. Battlelines were being drawn between science and heresy, realism and denial, reason and flakiness. The middle-ground became no-man’s-land. Questioning the accuracy of statistics invited the label of ‘denialism’, defending the robustness of an estimate drew allegations of manipulation and deceit.

Were it not for the institutional location of some of the participants, this would have been a brief skirmish.2 Although in some respects still incomplete, the evidence-based understandings of South Africa’s epidemic pointed to one, indisputable conclusion: an extraordinary disaster was under way. South African dissidents’ grasp of HIV/AIDS epidemiology was un-

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1 The AESA 2002 model estimates 3.2 million South Africans were living with HIV in 1999; for reasons discussed below, this is probably the most accurate estimate available and incorporates data and research findings that were not available at the time. Using a more rudimentary model and less nuanced assumptions, UNAIDS/WHO (2000) estimated there were 4.2 million South Africans with HIV at the end of 1999.

2 Amar Hamoudi (2000), for example, set out to examine two questions that flowed from the claim that AIDS was a misnomer for various poverty-related conditions. Firstly, had mortality trends in the hardest-hit countries changed significantly compared with trends in other countries on the continent? And, secondly, could such discrepancies be attributed to factors other than AIDS – e.g. to malnutrition, parasitic diseases, illness due to poor sanitation, and unnatural causes such as violence or accidents? Focusing on southern Africa, Hamoudi found no statistically significant differences in log life expectancy for southern Africa compared with the rest of Africa in 1980. Fifteen years later, however, significant differences were evident (thus answering the first question). Yet, differences in incidence of malnutrition and access to sanitation were found not to be statistically significant between southern Africa and the rest of continent, while malaria had a comparatively less-severe presence in most southern African countries compared with the tropical regions of the continent. In addition, most of the burden of mortality caused by malnutrition, diarrhoea and parasitic diseases (such as malaria) is borne by infants and young children, yet significantly higher adult mortality was being observed in countries with severe AIDS epidemics. He concluded that the rising mortality rates seen in southern Africa could not be explained without factoring in the AIDS epidemics.
sure, their familiarity with key research findings cursory, and their handling of technical data often adventurous. But this was not only a battle about the substance and quality of knowledge; it was also about how knowledge is inflected with power, prejudice, memory and hope (see Introduction). And, as such, it also forced science off its remote perch.

Delayed images

HIV prevalence data indicate the total number of people infected with HIV at a particular point in time – and these are usually expressed as a percentage of the adult (15 to 49 year-old) population. As such, prevalence data can provide a good picture of the overall trend of an epidemic but a less satisfactory picture of recent developments, since they do not distinguish between people who acquired the virus very recently and those who were infected several years earlier. Some of the people testing positive at any given point would have been infected quite recently, others would have become infected at various, earlier points. So, HIV prevalence estimates point to HIV incidence trends – the rates of new infections – from several years earlier. It’s a delayed picture of incidence.

In South Africa, the steep rise in HIV prevalence through most of the 1990s was an echo of exceptionally high incidence rates; very large numbers of people were becoming infected each year – more than 600 000 when incidence peaked in the late 1990s, according to the ASSA 2002 projections (Dorrington et al., 2004). AIDS deaths, though, were nowhere near peaking in the late 1990s. This is because people do not develop AIDS-related symptoms until several years after first HIV infection; even without antiretroviral treatment, some can survive for a decade or more. Estimates of average survival time from sero-conversion vary; Statistics SA fixes it at between 9 and 11.5 years, depending on the age group (10.5 years for people aged 25-34 years and 11.5 years for those aged 15-24 years), while UNAIDS assumes a median survival time of 9 years.

It is once people with HIV become chronically ill and die in large numbers that the epidemic’s impact begins to register more visibly in society. In South Africa, where the epidemic has lagged behind those in East Africa and in other southern African countries, that phase only began in the late 1990s. The epidemic’s chain of effects is delayed in South Africa. The impact experienced halfway through the 2000s is the after-shock of new infection trends that occurred as far back as a decade ago, when HIV incidence had not yet reached its zenith and when HIV prevalence was still rising steeply (see Figure).

Limits of certainty

No AIDS epidemic on the continent has been as carefully and insistently probed as South Africa’s. This is due partly to the controversies swirling around it, but mostly due to the quality of the available data and to the efforts invested in deciphering the information. One may therefore expect to see a fairly snug consensus in various estimations of the extent of South Africa’s epidemic. But that’s not so. The estimates vary – and sometimes by wide margins, or so it seems. This

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3 This ‘incubation period’ varies, and the relative weight of the factors affecting it is not known with certainty. However, there are strong indications that the period is shorter in sub-Saharan Africa than in Europe and North America, possibly due to ‘the poorer health status of the general population, more virulent strain(s) of HIV, and repeated re-infections’ (Stover, 1997).
has encouraged a healthy tendency to interrogate HIV and AIDS estimates, and to examine more closely their respective strengths and weaknesses (see box above). Unfortunately, it has also triggered ham-fisted reflexes to dismiss the plausibility of all HIV and AIDS estimates, and even to discount the existence of the epidemic.

As with any unfolding epidemic, there have been inaccurate statements about HIV and AIDS trends and the epidemic’s scale, with projections of future trends perhaps the biggest culprit. Derived from limited data and incomplete, sometimes inaccurate, understandings of epidemic trends and patterns, early estimates sometimes overshot the mark. Indeed several epidemiologists involved in generating UNAIDS/WHO estimates have admitted that the focus on point estimates may have led readers to infer an unwarranted level of certainty about the estimates (Walker et al., 2004) – a diplomatic way of saying they had inadvertently oversold the precision of earlier estimates. Similar acknowledgements would apply also to estimates produced in the past by USAID and others.

Globally, and especially in sub-Saharan Africa, AIDS advocacy efforts have tended toward portents of doom, even when the epidemiological basis for some claims has been ambiguous, even questionable. This has prompted some observers to warn of ‘a danger that advocacy is getting in the way of objective assessments of the level and trends of the AIDS epidemic in Africa’ (Bennell, 2003). Often, the publicized versions of findings would not draw sufficient attention to caveats that tempered interpretations of the data. News media in particular have been guilty of such omissions, opting for sensationalism over rigour. Estimates couched in colourless qualifications make for mealy sound-bytes and dull headlines; vital, though sometimes remote, details found in annexes and footnotes tend not to intrude on most media accounts of the epidemic.

Overall, the tendency has been to highlight ‘point estimates’, despite their shortcomings, rather than to publicize the ranges or boundaries within which the actual number very probably lies. Even when padded with qualifications, ‘point estimates’ make an unmerited showing of accuracy when they declare, say, life expectancy to be 66.7 years or that the number of people living with HIV is 4.34 million. After all, the very notion of a precise estimate is oxymoronic. Better to present projections and estimates in ways that more plainly acknowledge the uncertainty that surrounds them. The fact that they are pointillist pictures of reality, not draughtsman’s drawings, does not diminish their value. Even if we cannot say with certainty that there are 5 million or 5.6 million or 6.5 million South Africans living with HIV, it matters that we can confidently state that, say, between 4.5 and 5.6 million South Africans are living with the virus.

So, part of the problem has been the manner of presentation. But the difficulties extend further. Various estimates and projections are also the products of different models and methodologies which extrapolate different sets of data (of varying quality sometimes), and that apply different assumptions about the many variables that are in play. There’s nothing sinister or mischievous about this. The discrepancies are easily explained, and some even dissolve once the data is studied carefully.

Data feuds

There is no practical way to determine exactly how many people have been infected with a virus like HIV. Scientists gather pertinent data, refine various assumptions about the manner and pace of HIV transmission and develop mathematical models that can approximate how many people have HIV or have died

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4 There’s nothing mysterious about this reflex. The paradoxically more accurate ranges of estimates are clumsy to work with. They clutter sentences, muffle the drama and can be wide enough to resemble guesswork more than science. Last, though not least, they lend themselves to lousy headlines.

5 A better metaphor might be the pixel imagery of digital technology. The ‘pixel densities’ of HIV and AIDS estimates and projections have been improving steadily, providing clearer images of situations and trends, but not yet achieving the crisp precision of highly-detailed and -accurate information. These images are invaluable when viewed at a certain distance but they tend to shed their informative power at closer range.

6 In December 2003, UNAIDS and WHO grasped this nettle by laying more emphasis on the ranges of estimates, rather than on the specific point estimates (in other words, South Africa has between, say, 4 and 6 million people living with HIV, as opposed to strictly highlighting the mid-point – 5 million – in that range). UNAIDS calculates country estimates every two years (UNAIDS/WHO, 2004).
It's now clear, for example, that fertility rates in South Africa are lower than in the rest of sub-Saharan Africa. In Kenya, meanwhile, the assumed ratio of HIV-positive women to men was initially misjudged. When a national household survey reported lower HIV prevalence than shown in other estimates, a review of antenatal clinic-based HIV data concluded that adult HIV prevalence in Kenya had been overestimated in previous years. The hitch? Earlier estimates had assumed too small a ratio of females with HIV to males with HIV. In Kenya, the ratio was found to be almost 2:1 – larger than in most other countries in sub-Saharan Africa, where the average ratio was 1.3:1. In other words, the numbers of males with HIV had been overestimated, yielding a too-high estimate of adult HIV prevalence.

Household surveys that include testing for HIV, on the other hand, can provide countrywide data on HIV prevalence for both sexes and for various age groups, and can include samples from remote rural areas. But they’re not the last word, either. If a significant share of respondents refuse to be tested, or they only answer certain questions, or they are absent at the time of the survey, a potential bias is introduced into the survey data. This has been a recurrent issue in household serosurveys carried out in sub-Saharan African countries recently, where non-response rates of 24-44% have been reported. Of course, the estimates can be adjusted if the salient characteristics of non-responders are known. But they’re usually not. The surveys cannot measure the possible association between a person’s absence or refusal to participate, and that person’s HIV status. It might be that a person’s refusal to participate or his/her absence from the household is correlated with a stronger likelihood of HIV infection. (For example, migrant or mobile workers are believed to face higher risks of infection, and are also more likely not to be home when the surveys are carried out.) There is a strong likelihood, therefore, that high non-response rates in household-based surveys could reflect HIV prevalence among women who have had unprotected sex; the data do not provide direct evidence of prevalence among men, nor among women younger and older than child-bearing ages, nor among women who are not having unprotected sex. However, when modulated with various assumptions, the data offer a basis for estimating such prevalence, which the Department of Health does annually. Still, there are many potential sources of error. The assumptions may be inaccurate, they may vary between parts of the country or they may change as the epidemic matures. These assumptions include estimates of different infection rates between men and women, in urban and rural areas, and in various age groups, as well as fertility rates, and more (Walker et al., 2004; Ward et al., 2004). HIV/AIDS estimates therefore are presented within ‘plausibility bounds’ or ‘ranges of uncertainty’.

In general, the more steps or assumptions have to be introduced to achieve a calculation, the less precise that estimate is likely to be. Estimates of the number of children orphaned by AIDS, for example, involve several other layers of estimates and assumptions, which can diminish their precision (Grassly et al., 2004).

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# References

lead to underestimation of HIV prevalence. Elsewhere in Africa, many household-based surveys have returned HIV estimates lower that those generated from antenatal clinic data.10

So there’s no golden mean, at least not yet (Ward et al., 2004). On the whole, estimates based on antenatal clinic data are a useful gauge of HIV infections trends among 15 to 49 year olds, while national household surveys can reveal more about the nature of the epidemic and can flesh out other important details including, possibly, incidence trends, if conducted in a comparable fashion at regular intervals. Considered in tandem, the various data can yield more accurate estimates of HIV infection levels and rates and of other estimates, such as AIDS deaths. The bottom-line is that all HIV-related estimates – whether they are based on a national survey or on sentinel surveillance data – need to be assessed critically, and their assumptions and data need to be reviewed consistently.

Why it matters

To some, questioning the accuracy of HIV and AIDS estimates is an unaffordable luxury, a reckless distraction. Whether or not 6 million or 4 million people are living with HIV, and whether or not 500 000 or 250 000 are dying of AIDS each year, a catastrophe is under way. This is so. At the levels of social justice and morality, it should not matter whether 2.5 million or 5 million South Africans are living with HIV. There is a manifest obligation to control an epidemic of such scale, to aid those whose lives it threatens, and to limit the ruin it can bring on households, institutions and society.

But there are also very practical reasons why it does matter. In an epidemic as severe as South Africa’s – and even the lowest estimations describe a grievous epidemic – proper planning requires as precise an understanding as possible of the status and likely trends of HIV and AIDS. The less precise our knowledge of the epidemic, the more our responses become a gamble and the more we rely on luck – and that’s an unaffordable luxury. The successful design and adaptation of prevention efforts require at least an accurate sense of the epidemic’s scale, trends and likely evolution in different age groups, among males and females respectively, and in various parts of a country. Potentially effective remedial steps require a fairly faithful estimation of the scale and the nature of that impact, and who is bearing its brunt. This need is obvious in the health sector, for example, where the complicated logistics of a sustained treatment programme require reasonably accurate information about how many people are living with HIV, how many are in need of treatment, and where they are. It’s also necessary to be able to anticipate and meet the demand for resources (diagnostic services, hospital beds, duration of admission, health staff). The ramifications spill a lot wider, too. Remedial strategies, particularly those that imply long-term institutional demands and fiscal commitments, are ill-served by shabby estimates. This affects a multitude of institutions and programmes, not least those tasked with economic matters, as well as fiscal issues (via skewed pressures on budget lines, increased take-up of state grants, shrinking savings, pressure on revenue systems, etc.) and economic strategies (via labour market changes, consumer demand trends, investment trends, productivity effects, etc.). Severe, long-standing epidemics can knock demographic patterns off kilter. Male-female ratios, for example, can shift dramatically enough to entrench or alter some social behaviour patterns, migration patterns can change in ways that require adjusting housing and infrastructure strategies or health service logistics, etc.

10 ‘Many’ but not all. Household HIV surveys have been conducted in Botswana, Kenya, Mali, South Africa, Tanzania, Uganda, Zambia and Zimbabwe, among others. In mainland Tanzania, a 2003-2004 survey of more than 13 000 adult men and women found 7% of adults were infected with HIV, compared with the UNAIDS’ end-2003 prevalence estimate was higher, at 8.8%. See ‘About 7% of adult Tanzanians HIV-positive, new survey shows’, Kaiser Daily HIV/AIDS Report, 11 April 2005, available at http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=29246. An earlier household survey in Kenya found 6.7% of Kenyans were living with HIV, lower than UNAIDS’ 8.0% estimate for end-2001. In Botswana, meanwhile, a population-based survey in 2004 returned much lower HIV prevalence estimates than antenatal clinic data suggested (National AIDS Coordinating Agency Botswana, 2005). However, the refusal rate was so high (44% of participants refused to be tested for HIV) that the prevalence findings probably were heavily skewed. Interestingly, in Uganda, a 2004 population-based survey (where the refusal rate was very low and the likely bias therefore more limited) found HIV prevalence was higher than indicated in estimates derived from HIV test data gathered at antenatal clinics: 7%, compared with the Ministry of Health’s 2003 national HIV prevalence estimate of 6.2% (Ministry of Health Uganda, 2005; UNAIDS/WHO, 2005).
So what do we confidently know about South Africa’s epidemic and its likely impact?

**Infection patterns and trends**

Each year, the Department of Health routinely tests approximately 16 000 pregnant women for HIV, the results of which provide the most regular sources of data on HIV infection in the country. The most recent survey indicated that 29.5% [range 28.5-30.5%] of women attending antenatal clinics were HIV positive in 2004 – which translated to an estimated 3.3 million [range 3.1-3.6 million] women overall. Leaving aside any further extrapolations, the data confirmed that HIV infection was rife in this sub-group of the South African population (i.e. pregnant women attending antenatal clinics). Prevalence peaked among women aged 25-34 years – more than one in three of whom was estimated to be living with HIV. Among women aged 20-24 years almost one in three was infected.

As the Figure below shows, HIV prevalence was highest among pregnant women in KwaZulu-Natal (40.7% in 2004), but remained exceptionally high also in Mpumalanga (30.8%), the Free State (29.5%), North West (26.7%), Gauteng (33.1%) and the Eastern Cape (28%). The most significant increases since 2000 have occurred in the Eastern Cape, KwaZulu-Natal, Limpopo, the Northern Cape, North West and the Western Cape (Department of Health, 2002, 2003 & 2004).\(^{11}\)

The data underscored two dominant features of South Africa’s epidemic: the astonishing speed at which it has evolved (national adult HIV prevalence of less than 1% in 1990 rocketed to almost 25% within 10 years; see Figure above) and its extraordinary scale. Between 3 million and 3.6 million women and between 2.6 million and 3.1 million men, as well as more than 100 000 babies were living with HIV in 2004. Fully 76% of the people living with HIV were 15-34 years of age (Department of Health, 2005).

\(^{11}\) For the ranges around these estimates, please refer to Department of Health (2005:8). Depending on the province, the ranges vary from 4% to more than 7% around these point estimates. The ranges are narrowest for KwaZulu-Natal and Gauteng.
There were no glimmers in the gloom. Among pregnant women in their late teens (15-19 years), HIV infection levels were just over 16%, belaying the Department of Health’s earlier claims that the possible ‘beginnings of a decline in HIV rates among women below 20 years’ were visible.\textsuperscript{12} HIV prevalence levels among 20- to 24-year-old pregnant women stayed steady and high in 2000-2004, hovering between 28% and 31% (Department of Health, 2002, 2003 & 2004). Beware, though. This doesn’t necessarily refute other indications (from household surveys, for example) that more young South Africans are protecting themselves against HIV and AIDS. The Department of Health data reflect HIV prevalence among women who are pregnant – and who, by definition, are sexually active and have had unprotected sex. The data do not tell us how representative these women are in their respective age groups; it might be that large numbers of young women are not having sex or are having protected sex. We’re not sure. Indeed, the biggest discrepancies between antenatal clinic-based estimates and those derived from household surveys is found among 15 to 24 year olds (see Figure below). Overestimation of HIV prevalence in this age group is a common bias in antenatal studies.

What was particularly striking in the latest data, however, was the pronounced rise in HIV prevalence among older women, all the way up to 40 years and beyond.\textsuperscript{13} This is unusual. It confirmed that women face extremely high odds of being infected with HIV when they forego protected sex (because they’re in steady relations or marriages and trust their partners, or because they wish to become pregnant, or because power imbalances deprive them of the ability to insist on safer sex).

\textbf{HIV prevalence by age group among antenatal clinic attendees in South Africa by province: 2000-2004}

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{hiv-prevalence-by-age.png}
\caption{HIV prevalence by age group among antenatal clinic attendees in South Africa by province: 2000-2004.}
\end{figure}

\textsuperscript{12} Department of Health (2002:12). HIV prevalence among 15-19 year-old pregnant women dipped from 16.1% in 2000 to 14.8% in 2002, then climbed back to 15.8% and 16.1% in 2003 and 2004, respectively. Declining prevalence in this age group might have indicated that prevention efforts were starting to bring positive results among young women. This is because HIV prevalence in the 15-19 year age group sometimes is regarded as a proxy for HIV incidence (the number of new infections), since people in this age group are likely to have been infected quite recently. Many epidemiologists, however, are reluctant to draw such inferences, and argue that the 15-24 year cohort offers a more reliable indication of possible incidence trends. If average age at first sex is very early – i.e. close to 15 or 16 years – then the 15-19 year age group could provide a tantalizing glimpse of possible incidence trends. But when average age at first sex is closer to 19 years, the 15-24 year age group data becomes more suggestive of incidence trends.

\textsuperscript{13} The Department of Health data also point to an important gap in prevention campaigning. The sharpest rises in HIV prevalence among pregnant women in recent years have been among women aged 25-40 years. This suggests that, whatever behaviour changes are being achieved among young women (15-24 years of age), once women are married or in long-term relationships, protected sex becomes more infrequent, and the odds of being infected increase. Prevention strategies that target young people in the main therefore are inadequate.
How well do the Department of Health estimates compare with others?

South Africa’s antenatal clinic network probably is the most extensive and geographically representative such system on the continent. Still, the data it provides can suffer significant biases and shortcomings. Sexual behaviour patterns vary and in some places a large percentage of young women are either not sexually active or are very rarely having sex. Extrapolations from the antenatal clinic data have to adjust for such variances; the catch is that sexual behaviour data provide relatively patchy pictures of reality. In addition, the data do not reflect infection levels among women using private health-care services (and thus introduce possible distortions of race and class). On the other hand, antenatal clinic-based data could also underestimate actual prevalence; since HIV is known to lower fertility, it is possible that significant numbers of HIV-infected women are unable to conceive and therefore do not pass through this HIV surveillance system.

As a rule of thumb, though, estimates based on antenatal clinic data seem to overshoott the mark, as comparisons with population-based surveys – such as the HSRC study – have suggested. Such weaknesses, as we shall see, have been addresed most concertedly in the ASSA 2002 model, which incorporates an extensive set of updated variables. Released in December 2002, the 2002 Nelson Mandela/HSRC Study of HIV/AIDS (HSRC, 2002) was the country’s first nationally representative household HIV survey. It arrived at several surprising findings that seemed to alter the picture of South Africa’s epidemic. In particular, it cast sharper light on the geographical, gender and racial patterns of the epidemic.

HIV prevalence among white and coloured South Africans was estimated at 6.2% and 6.6%, respectively. The 5-6% prevalence estimate for children baffled observers, and revived suspicion that significant numbers of HIV infections could be occurring through unsafe medical practices. (Subsequent research has discounted that explanation, though; see below.) Also surprising was the finding that the worst-affected provinces were the Free State, Gauteng and Mpumalanga (where prevalence was estimated at 14-15%), and not KwaZulu-Natal (11.7%). Adult prevalence in the Western Cape was found to be surprisingly high at 10.7%, outstripping that found in the Eastern Cape, Limpopo and Northern Cape provinces (where it ranged from 6.6% to 9.8%).

In other respects, the survey findings were in line with those of earlier studies. The age and sex distribution of HIV infection, for example, matched the patterns revealed in other studies. Thus women were more at risk (17.7% prevalence) than men (12.8%). Young women in particular were found to be considerably more prone to HIV infection than young men; among 15 to 24 year olds, HIV prevalence was twice as high among women. As elsewhere in sub-Saharan Africa, HIV prevalence was found to be higher in urban than in rural areas, but the finding that it was highest in urban informal settlements (an average of 21% but as high as 28% in some locations) highlighted some of the socio-economic dimensions of the epidemic. The two provinces with the highest HIV prevalence – Gauteng and the Free State – also had the highest proportion of persons living in urban informal areas. Prevalence was considerably lower in tribal areas (12.4%) and on farms (11.3%).

Much was being made, though, of the apparent contrast with other sets of HIV estimates. Adult (15-49 years) HIV prevalence was pegged at 15.6% (13.9%-17.5% approximate range), almost one-quarter lower than the 20.1% estimate UNAIDS had arrived at for 2001, and much lower than the 24.8% (range 23.6%-26.1%) of pregnant women who tested positive in the Department of Health’s 2001 antenatal sero-prevalence survey of the Department of Health were highly unrepresentative, since they were clustered mostly along major transport routes (where HIV prevalence is likely to be especially high), and therefore might have led to gross overestimation of HIV prevalence in KwaZulu-Natal. Whether or not that is the case is unclear. A recent study done in the Vulindlela district of the KwaZulu-Natal Midlands, where the antenatal clinics are not included in the Department of Health’s annual seroprevalence surveys, found very high HIV prevalence of 43%. See ‘South African HIV prevalence steadily rising; researchers investigate why some communities are harder hit’, Aidsmap, 17 June 2005.

14 The HSRC study authors tried to determine what proportion of the children (aged 2-14 years) were likely to have been infected through mother-to-child transmission. They discovered that only 6.1% of the 86 HIV-positive children had a biological mother who had died and a similar percentage (7%) had a biological father who had died. MTCT therefore seemed to be a minor factor in these infections (Garbus, 2003).

15 The KwaZulu-Natal finding was especially perplexing. It has been suggested that the province’s antenatal clinics sampled in the annual sero-
According to Dorrington, the 5.6% estimate would translate into about 11.4% (10%-12.7% range) of South Africans (of all ages) were living with HIV at the end of 2002. Extrapolate the end-2001 UNAIDS numbers to the entire population and one arrives at HIV prevalence in the total population of just over 11% – roughly the same as in the HSRC survey. The ASSA 2002 model put prevalence lower, at under 10% in 2002 (Dorrington et al., 2004). A subsequent study was conducted in the Free State province (Bennett, 2003), ignoring any other possible source of bias, the small sample size (8,428 respondents) stretched the confidence intervals in some instances. The HIV prevalence for whites and coloured people, for example, could be half or one-and-a-half times as high as the 6.2% and 6.6% respective estimates – i.e. it could lie anywhere between 3% and 9%.

Similarly, the 5.6% prevalence estimate for children aged 2-14 years was based on only 86 HIV-positive tests. (More recent HSRC research suggests that the prevalence levels found in this age group were aberrations.) While the HSRC study revealed important details in the epidemic, it was by no means the last word. Antenatal clinic-based estimates might be too high, while those derived from household surveys might be too low, but taken together, they offer the basis for a much more detailed picture of the epidemic.

One might expect estimates drawn from household surveys data to trump those arrived at by extrapolating from antenatal clinic data. But, as noted earlier, household-based surveys are not without shortcomings – and the HSRC study was no exception. Most significant was the fact that fewer than two thirds of the respondents identified for the survey agreed to take an HIV test,” a participation rate low enough to introduce considerable potential for bias in the results. The estimates could be adjusted to correct for bias if the salient characteristics of non-responders were known. But they’re not. The survey therefore could not measure the possible association between a person’s absence or refusal to participate, and that person’s HIV status. Some who declined to participate may have known or suspected they were HIV positive, while others who did not take part because they were not home may have belonged to potentially ‘high-risk groups’ such as military personnel, prison inmates and hospital patients (Bennett, 2003). It is quite possible, therefore, that the study underestimated HIV prevalence. In addition, the small sample size widened the bands of uncertainty around the estimates. According to Bennett (2003), ignoring any other possible source of bias, the small sample size (8,428 respondents) stretched the confidence intervals in some instances. The HIV prevalence for whites and coloured people, for example, could be half or one-and-a-half times as high as the 6.2% and 6.6% respective estimates – i.e. it could lie anywhere between 3% and 9%.

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Comparing the estimates – who gets it right?

Statistics SA, using a different methodology, estimated that 3.83 million South Africans were living with HIV in 2004 (Stats SA, 2004), while the HSRC arrived at a figure of 4.6 million and the ASSA 2002 model calculated 4.93 million for 2004 – all considerably lower than the Department of Health’s range of 5.7-6.2 million for the same year. Such variance seems to undermine confidence in any single set of estimates. But the discrepancies are actually less dramatic than they seem.

The Statistics SA estimate was for 15-49 year-olds only (Dorrington et al., 2004), while the others apply to the entire population. Using the ASSA 2002 calculations as a guide, approximately 500,000 people younger than 15 years and older than 49 years most probably were living with HIV in 2004. Add that, and it brings the Statistics SA estimate to 4.33 million – well within the range of the HSRC estimate, and much closer to the ASSA 2002 figure. Statistics SA also applies more conservative assumptions (it assumes, for example, a slower progression in the epidemic), which means that its estimate will tend to be lower than the others. By the same token, if male/female infection ratios are brought in line with newer research findings, the Department of Health estimates would be lower. The Nelson Mandela/HSRC study (2002) indicated that males were 74% as likely to be infected than were females, whereas the Department Health still worked with a ratio of 85%. Make the adjustment and the Department’s estimate of the total

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17 The HSRC survey indicated that 11.4% (10%-12.7% range) of South Africans (of all ages) were living with HIV at the end of 2002. Extrapolate the end-2001 UNAIDS numbers to the entire population and one arrives at HIV prevalence in the total population of just over 11% – roughly the same as in the HSRC survey. The ASSA 2002 model put prevalence lower, at under 10% in 2002 (Dorrington et al., 2004).

18 According to Dorrington, the 5.6% estimate would translate into about 700,000 children aged 2-14 living with HIV/AIDS and roughly 4,000 deaths of children aged 10-14 annually. The evidence for deaths on such a scale in that age group lacks, however: Extrapolating from the cause of death data captured by Statistics South Africa and adjusting for underreporting of deaths, we only have some 350 to 400 deaths due to AIDS and potentially AIDS-related conditions per annum’ (Bennett, 2003:3). A subsequent study was conducted in the Free State province to examine the unusually high rates of infections found among children (Shiano et al., 2005). It found high HIV prevalence among children aged 2-9 years (the age group studied). The overwhelming majority of infected children (98.6%) had HIV-positive mothers, making mother-to-child transmission the dominant mode of the HIV transmission. Among the 1.4% HIV-infected children with HIV-negative mothers, it was found that having been breastfed by a non-biological mother was highly associated with the child’s HIV status. Finally, the study noted the potential for nosocomial HIV transmission in public health facilities in the Free State provinces.
number of South Africans living with HIV in 2004 becomes more than 400 000 lower than the 5.7-6.2 million range it calculated.\textsuperscript{19}

\textbf{Comparison of antenatal data and Nelson Mandela/HSRC study data, HIV prevalence \% (2001)}

\begin{figure}
\centering
\includegraphics[width=\textwidth]{comparison_data.png}
\caption{Comparison of antenatal data and Nelson Mandela/HSRC study data, HIV prevalence \% (2001).}
\end{figure}


Other, potentially more accurate estimates of incidence are available, including the ASSA 2002 model\textsuperscript{20} and a recent model used by the HSRC. There’s still some intelligent guesswork required, because we don’t yet know exactly how to weigh the comparative influence of the various factors driving the South African epidemic. But the accuracy of such modelled incidence is being enhanced by incorporating new information on key variables, such as behaviour change (drawn from population-based surveys and site-specific studies) or the prevalence of other sexually transmitted infections, and more. Given the refinements and updated assumptions incorporated into the ASSA 2002 model, the latter currently probably provides the most accurate picture of South Africa’s epidemic.\textsuperscript{21} For 2005, ASSA estimates that about 5.17 million South Africans were HIV positive.

\section*{Fuzzy pictures}

AIDS advocacy has shown a strong penchant for pitching ‘with AIDS/without AIDS’ scenarios deep into the future. It’s easy to see why. The exercises conjure gripping illustrations of the havoc the epidemic could unleash. But these scenarios should be used with circumspection.

The variables that conspire over 20 or 50 years – and the relationships between them – are complex, contingent and inter-related. At the heart of ‘AIDS/no-AIDS’ scenarios is the fiction that a single factor (in this case an AIDS epidemic) can discretely be introduced into or removed from an equation without triggering a series of other effects – that all else indeed does ‘stay equal’, as the \textit{ceteris paribus} principle requires. There’s the epidemic’s scale and pace implies an accumulation of unforeseen costs and obligations that could threaten profits. Overestimating the epidemic can lead to overpricing medical schemes and life policies, thus undercutting competitiveness and potentially eating into market share. So the stakes are high.

\begin{itemize}
\item For its part, the Nelson Mandela/HSRC survey did not include data for persons younger than 2 years, thus missing as many as 100 000 or more babies and infants that were HIV infected.
\item For a summary of the model’s methodology and innovations, see http://www.assa.org.za.
\end{itemize}
also a philosophical hitch. A ‘with-AIDS’ scenario is an extrapolation of data that describe observed reality. As such, it can be tested against observable reality as that unfolds. A ‘no-AIDS’ scenario, on the other hand, is a counterfactual, a fiction which defies empirical validation or refutation. It is not a prediction of what-could-be, but a prediction of what-could-never-be. We can, once 2050 arrives, measure the total population or calculate average life expectancy and retrospectively pass judgement on how accurate a projection done in 2005 was. We cannot, however, test the accuracy of the counterfactual (the ‘no-AIDS’ scenario) – because that reality never happened.

The upshot? ‘AIDS/no-AIDS’ projections have considerable suggestive value. They can alert us to the power and extent of factors that are changing our world. But they do so as suggestive pictures of likely trends, not as detailed predictions of specific outcomes.

Dead-wrong

Still, the apparently contrasting estimates and the torrent of gloomy forecasts primed a backlash. If experts couldn’t agree on how many people were living with HIV and dying of AIDS, then how much store could one put in any of their estimates? Perhaps the epidemic was being exaggerated. More sinister currents were being divined, too. Some in the ruling African National Congress (ANC) and government felt attracted to the notion that HIV/AIDS estimates were being manipulated for aims that had nothing to do with the health and lives of South Africans. By early 2000 it had become clear that powerful political figures shared such views, and that President Thabo Mbeki was willing to carry the torch for AIDS dissidents or (as they would come to be called) ‘denialists’ in South Africa.

Just how seriously President Mbeki was invested in this enterprise was underlined when he ordered a re-examination of South Africa’s social policy spending priorities in August 2001. The cue was a 1995 WHO data set, which the president had apparently tracked down on the internet and which indicated that AIDS was the cause of just 2.2% of deaths in South Africa. In a letter to the health minister, Manto Tshabalala-Msimang, President Mbeki predicted that the move would ‘provoke a howl of displeasure and concerted propaganda campaign from those who have convinced themselves that HIV/AIDS is the single biggest cause of death’ in the country. He had earlier referred to the data when interviewed on BBC World television’s Hardtalk programme, when he claimed that accidents and violence – not AIDS – were the primary cause of death in South Africa:

TM: Do you know what the largest single cause of death in South Africa is? The largest single cause of death as we sit here is what in the medical statistics is called external causes and that is violence in the society. For instance I’ve seen figures that say that if you take the male age cohort from 16 to 45 years, 54% of the people who die in that age cohort die from external causes.

TS: Violence isn’t going to threaten the lives of seven million South Africans ...

TM: I’m saying that the majority of the people in the country are dying from that and you cannot say to me I must ignore that and not take into account the fact that the majority of the people in that particular age cohort, which is a working population, is dying from the violence that is so terrible in this society. The government must respond to that.

It was a puzzling statement. In the mid-1990s already, the government had grown incredulous of crime and violence statistics – so much so that it instituted a temporary moratorium on the public release of crime statistics. Now data from that period were being enlisted in an attempt to disprove the scale of the AIDS epidemic. The WHO statistics would crop up again in the ‘Castro Hlongwane’ pamphlet (see below), where the author(s) declared them ‘the truth about the health of our people’ (Anon, 2002).

Deploying 1995 cause-of-death estimates in discussions about the impact of AIDS in 2001/2002 was dead wrong. Given median survival time of 8–11 years after first infection, most deaths attributable to AIDS in 1995 would have stemmed from HIV infections acquired during the very early stages of
South Africa’s epidemic – in the mid- to late-1980s. Even in 1990, HIV prevalence among pregnant women attending antenatal clinics was still less than 1%. In seriously-afflicted countries elsewhere on the continent, mortality trends have shown a steep rise in adult mortality starting roughly 4-5 years after HIV spread has become widespread in the general population.22 In South Africa’s case, this meant sharp increases in mortality would have started occurring only in the late 1990s – as modelling indicated and the Mortality and causes of death in South Africa report (Statistics SA, 2005) would confirm.

Suspicious and doubt, however, had given way to outright incredulity that was being broadcast with rare fervour. Locally and internationally, the reactions were reproachful, and the exchanges grew increasingly exuberant and florid. As two opposing and mutually dismissive camps took shape, the prospects of dignified dialogue between them all but dissolved. In the manner of a medieval religious dispute, those subscribing to orthodox interpretations of the epidemic presented themselves as guardians of established verity, while sceptics struck the pose of free-thinking rebels. The former entered the fray armed with the ostensible authority of science, which the latter appeared consistent with a serious heterosexual HIV/AIDS epidemic (Dorrington et al., 2001). Later, after analyzing more up-to-date data, the MRC found a real increase of more than 40% in the number of adult deaths on the population register between 1998 and 2003.23 Among women aged 20-49 years, the real increase exceeded 150% (MRC, 2005).

Research institutions, too, were being drawn into the fray. When, in September 2001, the Medical Research Council (MRC) produced estimates attributing 25% of all deaths (and 40% of deaths among adults) during 1999/2000 to AIDS, the release of the document was unexpectedly delayed, possibly due to pressure from within government. The report was leaked to the media, which shared with the public the MRC’s conclusion that AIDS had become the leading cause of death in South Africa.24 A clear shift in age distribution of deaths towards young adults was demonstrated. After taking into account population growth and more comprehensive death registration, the pattern appeared consistent with a serious heterosexual HIV/AIDS epidemic (Dorrington et al., 2001). Later, after analyzing more up-to-date data, the MRC found a real increase of more than 40% in the number of adult deaths on the population register between 1998 and 2003.23 Among women aged 20-49 years, the real increase exceeded 150% (MRC, 2005).

Government spokespersons declared the findings ‘alarmist’ and ‘inaccurate’, a view apparently echoed in the President’s reaction led to the document’s withdrawal from official circulation inside the ANC, but the episode had highlighted the fact that powerful figures in the ANC (and government) believed the epidemic was a hoax or, at least, massively exaggerated.23

**Seeing ≠ believing**

The alchemy of conspiracy theory, historicized indignation and Afro-nationalist pride evident in the ‘Castro Hlongwane’ pamphlet has continued to resonate. Reacting to media coverage of debate about the accuracy of AIDS mortality estimates, for instance, ANC Youth League spokesman Khulekani Ntshangase
brushed aside AIDS statistics in an article that also featured a thuggish attempt to equate the Treatment Action Campaign with the vigilante group Pagad.\textsuperscript{24}

Today, South Africa is the ‘HIV and AIDS capital of the world’. We are told that the biggest killer in this country is HIV and AIDS. But every honest person knows that the overwhelming majority of our people die from accidents and violence. The second biggest killer is TB, pushing HIV/AIDS into the third place. The government has consistently explained this and yet some sections of the media and those in business use all means possible to divert the attention.

A few months later, President Mbeki told the Washington Post, in an interview, that ‘Personally, I don’t know anybody who has died of AIDS.’ Asked whether he knew anyone with HIV, answered, ‘I really honestly don’t’.\textsuperscript{25} Such utterances, and the dissidents’ claims generally, seem morbidly distant from the realities ordinary South Africans have been experiencing and community health workers, hospital staff, school administrators, prison officials and cemetery supervisors have been relaying. Almost one third (31%) of the respondents in the 2004 Afrobarometer survey reported losing a close friend or relative to AIDS – almost twice as many as the 18% in 2002 and the 16% in 2000 (Afrobarometer, 2005a). Localized research has been unearthing the same trends. Conducted in rural northern KwaZulu-Natal in 2000, one such study found ‘a sudden and massive shift in adult mortality’, due largely to AIDS. Adult mortality was so high that the probability of dying between the ages of 15 and 60 years was 58% for women and 75% for men. AIDS deaths in 2000 would have been roughly in line with HIV prevalence in the area five years previously; in other words, while the epidemic was still growing there (Hosegood et al., 2004).\textsuperscript{25} Meanwhile ‘natural’ deaths in South Africa’s prisons reportedly quadrupled between 1995 and 2002. An increase in the number of inmates could explain only part of that trend. According to the Inspecting Judge of Prisons, the natural death rate among prisoners had risen from 1.65 per 1 000 in 1995 to 7.75 per 1 000 prisoners in 2002 (various media reports, September 2003).

As late as February 2004, though, President Mbeki was still insisting that ‘We do not know what [kills] South Africans’. Asked, during a nationally televised interview, whether he felt irritated when people expected him to ‘expatiate on HIV/AIDS’, Mbeki replied:\textsuperscript{26}

South Africa does not have, up to today, does not have it. Doesn’t exist. We don’t know the causes, what are the things that kill South Africans? Now, not from mathematical models or extrapolations, but from Home Affairs. Home Affairs receives notices of death by law.

The reasoning seemed sound, and sat squarely within the empiricist tradition. If AIDS was killing people then it seemed obvious that one should be able to record and tally those deaths, which is what Statistics SA had been ordered to do in 2001:

We have collected all of these notices of death from Home Affairs from 1996 to June 2003, altogether two and a half million. We have given them to people to say: Now, can you please work on this, sort out all of these things systematically, to say: in 1996 so many people died and this is what killed them [...] So, when that process is done ... for the very, very first time you will get a picture based on actually what has been recorded by the medical profession in this country in terms of causes of mortality. For the first time. So, you will see the numbers and all of these things will be checked ...\textsuperscript{27}

Implicit in that reply – and in most of the skepticist forays around HIV and AIDS in South Africa – is the notion that truth

\textsuperscript{24} Khulekani Ntshangase, ‘Pagad and TAC two sides of the same coin’, The Sowetan, 22 April 2003. Pagad was a violent and socially conservative vigilante group, with its stronghold in Cape Town. According to Ntshangase, ‘both Pagad and TAC come from Cape Town and are formed for the single mission, to mobilise people against the African National Congress [...] They also get funding from the same source and employ the same strategy and tactic [...] Pagad was destroyed so will be TAC!’ See a copy of the article at http://www.tac.org.za/newsletter/2003/ns22_04_2003.htm#Strange.

\textsuperscript{25} The study ascribed patients’ deaths to AIDS when the medical notes reported immuno-compromised, retroviral disease, Kaposi’s sarcoma, or Cryptococcus meningitis. As well, patients with suspected HIV and those referred to HIV counselling were classified as dying from AIDS if they presented with an AIDS disease pattern. For more detail on the methodology and explanations of ostensible anomalies in the findings, please refer to the document.
South Africans will have died (some of them of AIDS), and ZZ thousands of South Africans will have become infected with HIV. The strictly empirical data would have to be extrapolated, using various assumptions, if this gargantuan effort is to yield a relatively accurate estimate of the number of people living with HIV at the time of the exercise.

In the case of AIDS-related deaths, recorded reality provides only a partial picture which needs to be filled out by tracking trends in the numbers and patterns of deaths and their causes, and by using supplementary methods, such as mathematical modeling (MRC, 2004). A small percentage of people living with HIV in South Africa are aware of their sero-status. Unless documentary evidence of the deceased’s HIV status is available to the certifying official, the death certificate typically ascribes the death to the immediate illnesses and conditions (and not the possible underlying HIV infection). In addition, there is much anecdotal evidence that both social stigma and the risk of forfeiting funeral and/or life insurance payouts disinclines disclosure of HIV status on death certificates (Groenewald et al., 2005). With respect to AIDS deaths, routine official death statistics therefore serve as a guide to the actual state of affairs.

Stepping outside and ‘counting’ facts does not guarantee a firm grasp of ‘truth’.

Body count

In early 2004-2005, South Africans were presented with several accounts of the epidemic’s death toll – one the result of a literal tallying exercise, others the result of extrapolation.

In one, based largely on Statistics SA death registration data, researchers pinpointed conditions that were associated with marked increases in mortality. When an increase in deaths matched the age patterns typical of an AIDS epidemic, a proportion of those deaths was treated as misclassified AIDS-related deaths. The researchers concluded that the substantial increase in deaths observed between 1996 and 2000-2001 (the mortality rate had increased by more than 30%) was largely AIDS-related, and that the actual number of deaths due to underlying HIV infection was more than double that reported on the death certificates (Groenewald et al., 2005).

Another study, using death notification, census and household survey data, highlighted three ominous developments. After factoring in population growth and improved registration of deaths, the authors found a real increase of more than

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26 The empiricist tradition insists that authentic information about the world must be acquired by a posteriori means, i.e. that nothing can be thought without first being observed. Empiricism functioned as an invaluable corrective to the speculative indulgences of metaphysics. Its principles were later extended and applied in logical positivism, a philosophical trend that achieved ascendancy in the first decades of the 20th century, before losing influence. Despite appearing to be self-evidently ‘true’, the approach suffers several weaknesses. The most obvious problem is that descriptions of reality – i.e. the language of expression – require agreement on certain basic concepts which cannot always and entirely be derived from observed reality. Reality, in other words, is necessarily also constituted by a priori concepts and formulations. Scientific knowledge therefore is not merely the product of recording and analyzing that which is observable, but requires hypotheses and assumptions that guide and structure those enquiries. 27 The 2005 AIDS article attributed about 80% of adult AIDS-related deaths in males and 70% in females to TB and lower respiratory infections. In children under 5 years, 85% of AIDS-related deaths were attributed to lower respiratory infections, diarrhoea and malnutrition.

28 This seemed to yield a figure quite close to the projections of some models – as close as 93%, according to the authors. But when compared with the data in the later Statistics SA report (released in February 2005), the authors’ conclusion seemed a little generous. Total deaths in 2001 were 451 936 (not 556 585 as estimated by the MRC researchers). Even if AIDS were responsible for 25% of deaths in 2001, the number of AIDS-related deaths in that year would be 78 000 less than estimated by the authors of the AIDS article. However, this does not alter the overall trend findings.
40% in the total number of deaths between 1998 and 2003.\textsuperscript{29} In addition, the age distribution of deaths was shifting significantly toward younger people. For women aged 20-49 years, there was a real increase in mortality of more than 150%. And, finally, the causes of death profile was rapidly changing (with large increases in deaths due to HIV, TB, pneumonia and diarrhoea – all indicator conditions of AIDS) (Bradshaw et al., 2004a). Changes in the age distribution of total deaths and the unusually steep rise in total deaths shown in both studies matched the anticipated effects of a severe epidemic.

Then came the long-awaited \textit{Mortality and causes of death in South Africa, 1997-2003} report from Statistics SA (2005), a harrowing compendium of data that left no room for doubt that South Africa lay in the grip of an eviscerating scourge.

From 1998 to 2000, the total number of deaths rose by 13%, and from 2000 to 2002, it climbed a further 30% – in other words, a rising trend.\textsuperscript{30} Based on information from nearly 2.9 million death notification certificates, the report showed that in 1997 some 870 people died per day, compared with 1 370 in 2002 – a 57.5% increase.\textsuperscript{xxii} The bulk of that increase occurred among people 15 years of age and older, among whom deaths increased by 62% in that period, with women accounting for a steadily larger proportion of deaths. In five years (1997-2002), the number of deaths among South Africans aged 25-44 years more than doubled, as the Figure below illustrates. Having accounted for less than one quarter (23%) of all deaths in 1997, that proportion grew to 30% in 2000, and reached almost 34% in 2002. In other words, more than onethird of all deaths were among people who, generally speaking, should have been in the prime of their lives (Stats SA, 2005).\textsuperscript{31} An extraordinary phenomenon was under way.

\textbf{Total number of deaths by age group and year of death, 1997-2002}

\begin{figure}
\centering
\includegraphics[width=\textwidth]{total_deaths_by_age_group_year_of_death_1997-2002.png}
\caption{Total number of deaths by age group and year of death, 1997-2002.}
\end{figure}

\begin{table}
\centering
\begin{tabular}{|c|c|c|c|c|}
\hline
\hline
0-4 years & 180 000 & 160 000 & 140 000 & 120 000 \\
25-44 years & 120 000 & 100 000 & 80 000 & 60 000 \\
45-64 years & 60 000 & 40 000 & 20 000 & 10 000 \\
65-84 years & 10 000 & 8 000 & 6 000 & 4 000 \\
\hline
\end{tabular}
\caption{Total number of deaths by age group and year of death, 1997-2002.}
\end{table}

Source: Statistics SA (2005). Based on data in Figure 3.3.

\begin{itemize}
\item \textsuperscript{29} The number of adult deaths on the population register rose by 68% in the six-year period. Population growth was approximately 12% while improvements in the registration of persons on the population register and of deaths was unlikely to exceed 10%, which leaves a real increase of over 40% (Bradshaw et al., 2004a).
\item \textsuperscript{30} The data compiled in the 2005 Statistics SA study suggested that other estimates of total deaths had been erring on the high side: ASSA 2002 ‘change’ model (540 000 deaths in 2000), HSRC (550 000 deaths) and Stats SA 2004 mid-year population report (460 000 deaths), compared with the Statistics SA study’s tally of 414 000 deaths in the same year. Were one to assume 10% under-reporting, then the two Statistics SA reports were more or less in agreement, though. Note that the report listed two figures, one drawn from the Population Register (366 121 for 2000) and the other described as ‘valid forms received’ (413 969 for 2000). The discrepancy is explained by the fact that people lacking ID numbers are not recorded in the Population Register, and neither are their deaths (Stats SA, 2005:4).
\item \textsuperscript{31} The proportion of total deaths occurring in the 25-44 year age group increased as follows: 23.2% (1997), 25% (1998), 27.7% (1999), 29.9% (2000), 31.7 (2001), 33.6% (2002).
\end{itemize}
As projected by various models and now tabulated by the Statistics SA report (2005), South Africa was experiencing an extraordinarily steep increase in the annual number of deaths. Could an increase in non-natural deaths (trauma, accidents, suicide, etc.) be responsible for the observed trends? No. On the contrary, they’re associated with a steadily shrinking proportion of deaths. We know that political violence claimed a rapidly-decreasing number of lives from 1994 onward (the toll fell from 2 476 people in that year to 470 people in 1997, for example).\(^{32}\)

‘Non-natural causes’, according to the Statistics SA report, declined in absolute number in 1997-2002, and accounted for an ever-shrinking share of total deaths (down from 17% in 1997 to 11% in 2001) and of deaths among 15-24 year olds (declining from roughly 55% in 1997 to 38% in 2001).\(^{33}\)

Could more complete death registration records provide an explanation? More comprehensive capturing of mortality data contributed, although mainly up to around 1999, after which many of the improvements in the system had been introduced and death registration was 90% complete. Those improvements probably accounted for a small part of the increase in total deaths observed over the study period. What about the increase in the total population? Population growth (which has been running at approximately 12% and appears to be slowing) accounts for a part of the increase in total deaths, but it cannot explain shifts in the distribution of deaths between various age groups.

Source: Statistics SA (2005). Based on data in Table 3.4.

Take a look at the graph on the next page. It shows that, in 1997, a similar number of males – between 10 900 and 12 600 – died in each age cohort from 25-29 years all the way to 70-74 years. By 2002, that pattern had disappeared. Deaths were now peaking sharply among males aged 30-44 years. Go back to 1997 and it’s clear that roughly similar numbers of women were dying from 25-29 years up to 55-59 years, with deaths then increasing markedly among older women.

By 2002, that distribution of deaths had tilted dramatically. Most women were now dying between the ages of 25 and 39 years – three times as many as five years earlier. Deaths in those age cohorts accounted for 15.1% of all female deaths in 1997; in 2002, they comprised 27.7% (Stats SA, 2005:13-16). South Africans were dying in patterns closely matching those predicted by HIV and AIDS models. And those deaths attributable to AIDS reflected HIV infection rates in the early 1990s, when the epidemic was commencing its exponential growth.

But how many of the observed deaths could confidently be attributed to HIV infection? The 2005 Statistics SA report proceeded literally, only counting those deaths explicitly declared HIV-related on the death notification form by an official (usually a medical officer or doctor, although in some rural areas certificates are sometimes completed by headmen). In most cases, such classification would have occurred only when explicit proof (such as documentation) of the deceased’s HIV-positive status was at-hand, thus ‘misclassifying’ those deaths where HIV featured among the underlying causes. The report found that only 9,479 deaths in 2001 were associated with HIV diseases, about 2.1% of all deaths in that year. The study commentary delicately described this as ‘most likely’ an underestimation and noted the need for modelling exercises to yield a more accurate figure.

A closer look at the data shows that a significant and ever-larger share of deaths were officially attributed to conditions associated with AIDS. Tuberculosis was the leading underlying natural cause of death from 1997-2002, accounting for 6.9% of deaths in 1997 but 11.3% in 2001. Influenza and pneumonia ranked second in 2001, when they comprised almost twice as big a share of deaths (7%) compared to 1997 (3.6%). ‘Certain disorders of the immune mechanism’ ranked ninth in 2001, and were deemed responsible for 2.6% of deaths. Among adults aged 15-49 years, such patterns were especially vivid. Taken together, tuberculosis, HIV, influenza and pneumonia and ‘certain immune disorders were associated with just over 20% of deaths in 1997 but 32% in 2001 (Statistics, 2005).

A baneful reality

Six months after the release of Statistics SA’s Mortality and causes of death in South Africa, 1997-2003 report, neither President Mbeki nor his government had offered substantive comment on its findings. That despite the earlier claims that the report would put to rest the speculation about what killing South Africans. There’s nothing curious about this silence.

The report shows an astonishing rise in deaths, with diseases and afflictions commonly associated with poverty and deprivation prominent among the main killers – tuberculosis, HIV/AIDS, diarrhoea, malnutrition, etc. – all this occurring in a period marked by economic growth and increased service provision. There’s not much room for grandstanding amid figures showing that just under 10% of 1-4 year-olds who die are killed by malnutrition, or that the toll taken by tuberculosis (whatever the underlying cause) among 15-24 year-olds doubled in just five years. In effect the report paints political denialism into a corner. Read its litany of scourges literally, and it indicts government’s ability to safeguard people’s most elementary right, their right to live. Or analyze the data and discover that it traces the passage of a ruinously severe AIDS epidemic.
There is no disputing this grizzly fact: South Africans are dying in unprecedented numbers, at exceptional rates and at unusually young ages. Statistics SA's Mid-year population estimates (2004) showed total annual deaths increasing by 44% in 1995-2000 and 39% in 2000-2005, while ASSA 2002's best-case projections showed that toll growing by 39% in each of those periods. According to the Mortality and causes of death in South Africa, 1997-2003 report (Statistics SA, 2005), the total number of adult deaths (people aged 15 years and older) increased by 62% in 1997-2002. Adjusting for the misclassification of underlying causes of deaths, the MRC's National Burden of Disease Study 2000 projected a total number of deaths in 2004 of 700 000 – well in line with an extrapolation from Statistics SA's mortality and causes of death in South Africa, 1997-2003 data.

When it comes to assigning causes to deaths, the various studies don't vary by large margins either. Like the MRC, Statistics SA has attributed about one third of total deaths in 2000 to AIDS. In 2005, it estimates, that share will have swollen to just over one half – which is more or less midway between ASSA 2002's 45% and the HSRC's forecasted 58%. No matter the data set one selects, by 2005 AIDS will have killed at least 1.8 million South Africans and possibly as many as 2.5 million since the epidemic began. AIDS has become the single largest cause of death in South Africa.

This, unfortunately, is just the beginning. Even if prevention efforts grow stronger and more effective, AIDS deaths will keep increasing at least until 2010 and very likely well beyond then. The ASSA 2002 model estimates that some 900 South Africans will have died each day of an AIDS-related illness during 2005, and suggests that this death toll would keep rising at least until 2014. A massively expanded antiretroviral programme can force this trend onto a slightly lower path, but the toll will still be horribly severe (see Figure). Even with a national antiretroviral treatment programme, approximately 400 000 people will die of AIDS each year until at least 2015, according to ASSA 2002 projections. We’re left with this cruel fact: when South Africans should have been striding clear of a wretched past, we are again slipping into the shadow of a baneful and murderous reality.
Chapter endnotes


ii Stats SA (2004); UNAIDS estimate from personal communication with UNAIDS Secretariat, Geneva.


iv USAID in 2001, for example, projected that, by 2003, South Africa (as well as Botswana and Zimbabwe) would be experiencing negative population growth. They’re not. See Roy Anderson’s keynote address at the March 2003 ‘Scientific Meeting on Empirical Evidence for the Demographic and Socioeconomic Impacts of HIV/AIDS’, held in Durban, South Africa.

v http://www.eldis.org/fulltext/BennellHIVAfrica.pdf. See also Hein Marais USAID in 2001, for example, projected that, by 2003, South Africa (as well as Botswana and Zimbabwe) would be experiencing negative population growth. They’re not. See Roy Anderson’s keynote address at the March 2003 ‘Scientific Meeting on Empirical Evidence for the Demographic and Socioeconomic Impacts of HIV/AIDS’, held in Durban, South Africa.

vi With a confidence interval of 95%, this mean there is a 95% probability that the actual number lies within that range.

vii A full description of the methodology and assumptions can be found at http://www.assia.org.za.

viii Note, however, that the correlation between HIV infection levels and poverty is more complicated than this might suggest. Earlier studies suggested that HIV prevalence levels among more poorly skilled and paid workers were higher than among their better-skilled counterparts, but the differences between the levels were comparatively small (Abt Associates, 2001).

ix Of the 13 518 individuals who were selected and contacted for the survey, 9,963 (73.7%) agreed to be interviewed and 8,840 (65.4%) agreed to provide a specimen for an HIV test (HSRC, 2002:11). According to the HSRC, the total sample size was limited by financial constraints, and a 65% response rate is generally considered adequate for this type of survey. The latter claim, though, does not address the potential bias introduced by a non-participation rate of 35%.


xii The table ranked deaths by cause. Top of the list, as reported by Anon (2002), were deaths caused by ‘external causes’ (accidents, violence, etc., 20% of all deaths), followed by ‘diseases of the circulatory system’ (17.5%), ‘signs, symptoms and other ill-defined conditions’ (13.6%), ‘malignant neoplasms’ (9.9%), ‘TB’ (5.3%), ‘bronchitis, emphysema, asthma and other respiratory’ (4.6%) and ‘pneumonia’ (4.3%). ‘HIV disease’ was deemed to account for 2.2% of deaths in 1995.


xiv The leak so incensed government that it reportedly demanded that the MRC institute a forensic enquiry to identify its source. MRC President Dr Malegapuru Makgoba seemed to be referring to this when he later remarked that ‘the so-called forensic investigation of scientists and the erroneous notion that “MRC employees are government employees” continue to erode the confidence and the autonomy of the MRC’; see ‘Dr Makgoba—a passion for excellence’, MRC News, August 2002, Vol 33 No 4, p 6. Available at http://www.mrc.ac.za/mrcnews/aug2002/makgoba.htm.


xvi The quote appeared in the 24 September 2003 edition of the Washington Post. The Government Communication and Information System (GCIS) later ‘clarified’ President Mbeki’s remarks, saying they were in reply to a question whether ‘he knew of anyone in his family or amongst his close associates who had died of AIDS or was infected by HIV’. See Govt clarifies Mbeki-a passion for excellence’, GCIS Words and Action, Vol 10 No 4, p 6.

xvii The interview, conducted by Redi Direko and John Perlman, was screened on SABC2 television on 8 February 2004. The full text is available at http://www.info.gov.za/speeches/2004/04021809461003.htm.


xix Note that multiple causes of death can be listed on the death notification forms. About half the reported deaths in each year of the study were attributed to one cause only.

xx ‘Due to inadequacies in the medical certification of the cause of death as a result of both insufficient detail provided by medical doctors and the certification by traditional headmen in some rural areas, it was necessary to make adjustments for misclassification of underlying causes’ (Bradshaw et al, 2004b:139).

xxi The figures are drawn from Statistics SA’s Mid-year population estimates, South Africa 2004. Statistical release P0302, Table 8, page 16. of a severe epidemic would be reflected in a change in both the overall number and age distribution of total deaths, regardless of any misclassification of or protocol defining a death from HIV or AIDS’. Report in SouthScan: Funding boosted as AIDS devastation becomes clearer. Vol 20 No 4. 25 February 2005.


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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 pandemic 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. 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

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1 Following a path lit by World Bank AIDS impact research, the literature often places supply and demand dynamics as the core of analysis, and assumes that an inherent rationality guides all decision-making, for example.
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 Côte 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.

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) household members, and by imposing additional financial and labour needs. These effects and the responses they elicit usually are hatched 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 longer-term 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 households 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 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. 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 quarters, 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. 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). 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. It has also been 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.

**Over-reaching**

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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 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. 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 alongside 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 doltilsh 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. 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 quite 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

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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. 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 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. Distressed households 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). The poorest households, especially those headed by women, find themselves pushed back in the queue 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.

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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 supplant 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. 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). 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).

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).

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. Psani (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. 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).

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).

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’.\(^\text{15}\)

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 reciproc-

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,\(^\text{16}\) 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.

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8 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 reliable rule-of-thumb, but it, too, will be subject to exceptions.
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). 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. 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. 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...
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’.

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. 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. 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.

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).

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. 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 noted.


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. 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 household and community ‘resilience’, ‘perseverance’ and ‘ingenuity’. Ritually talked up are interventions that can ‘empower’ households, strengthen kinship and community safety nets, and support the ‘coping strategies’ households deploy. Like motherhood 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 theoretized 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). 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. This notion of famine as a unique, singular shock would later be adopted in the AIDS impact literature, even after a more refined under-

13 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.
14 There is another similarity worth pointing out. Just as contemporary 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), mananthur (an epoch-changing famine) (ibid.).
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 backdrop 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 sun-dered, 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 epide-mics disproportionately target, and their harm is dispropor-tionately 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.15 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 1994.16 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).16 In Ekurhuleni, for instance, significantly more house-holds 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 itself17 are controversial, partially due to disputes about the comparability of various data sets. But subjective experiences

15 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.

16 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%.

17 Poverty is often still defined in terms of income, which tends to under-
It may also be that pensions and state grants were missed and not counted.

From R48 291 per annum in 1996 to R71 835 in 2001 (SA Cities Network, 2004:13). 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. 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). 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 failing 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 (Woolard et al., 2002). (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 HIV-positive 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

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 existence 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 households’ 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. 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. 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). 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.

19. It may also be that pensions and state grants were missed and not counted as ‘income’.
20. 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.”21 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 quarter of rural households had no toilet.22 Almost a million urban households did not have water on-site in 200122 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).23 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.23

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.24 Income levels appeared to drop significantly after an AIDS death – due mainly, it seemed, to high funeral expenses (Booysen & Bachmann, 2002).25 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).24 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

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21 The same survey found that more two thirds of the care-givers were female, and one quarter of them were older than 60 years.
22 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).
23 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].
24 The narrow definition, as used by Statistics South Africa, regards as unemployed those persons within the economically active population 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.
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,xxxvii 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).

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.)xxvii 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

25 According to Mather et al. (2004:31), ‘panel surveys in Kenya, Malawi, and Rwanda show that while household dissolution does occur as a result of adult mortality, the rate of dissolution due to mortality is not as high as that found in some of the literature’. 

[60] Ineckling – 2005
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) (Saldu, 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 quarter 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. 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 (Saldu, 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’. 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

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26 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.

27 ‘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.28

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 appliances29 – 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).30 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).31 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 – Ijumba & 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.30 31

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.32 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 aid scheme (SA Cities Network, 2004). The racial disparities 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.

28 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).
29 Mainly stoves, refrigerators and TV sets – non-productive assets. A tiny number of households parted with productive assets, such as cattle.
30 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).
31 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 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.
society, stokvel or with a commercial insurance policy (De Swardt et al., 2003). Other research (in Mount Frere, Ceres and Cape Town) found that between 54% and 73% of households had burial life insurance (De Swardt, 2003).

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 (Saldu, 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 (Saldu, 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). 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.41 However, there is very little South African research available to validate this. Booyen (2003) found only ‘relatively weak evidence’ that HIV status featured in migration from urban to rural areas among

32 The average cost of a funeral was R5 513. The study was conducted in Free State, Gauteng, KwaZulu-Natal and Mopumulanga provinces (Steinberg et al., 2002).
33 In Mount Frere, 8% of households had life insurance, in Ceres 20% and in Cape Town 9% (De Swardt, 2003).
34 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 uMhlathizwe (Richard’s Bay and Empangeni), Rustenburg and Polokwane (SA Cities Network, 2004).
Free State communities. 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; 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 envisions 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

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35 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/article.php?jid=49&id=19509&layout=abstract.

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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 Declaration, 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’. 

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, while community-based care is seen as a way of drawing on and enhancing communal solidarity and mutual assistance. 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 care-givers, 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 widespread 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 resilience’, above). In practice, in a society like South Africa, the

36 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

37 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).
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 amputated options and foreclosed alternatives is backhandedly endorsed as 'the way things are'.

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'. 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 sap 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.

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.

38 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.

39 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’. 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 exploitation 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.

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 hardness 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-for-granted 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. 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 care-giving has been likened to levying a tax on women.

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-
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).  

In South Africa’s health-care system, the principle of universalism lacks even a toehold. 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 provision 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 quizzed, 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.

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41 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. See UNDP (2003b:254-257).
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 quickly 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. 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. 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).

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42 Assessments of care-giving projects in Khayelitsha, Gugulethu and Delft (Cape Town), for example, exemplify these experiences; personal communication. Among the surveyed care-givers, 95% were women who ranged in age from 18 years to 69 years.
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 inequalities. 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).18

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.18 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).

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. 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-carer does not 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). 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 care-giver 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 children; 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 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

43 As Giese et al. (2003) point out, in some cases the vernacular definition of an orphan refers not to the parental status of the child but to fact that the child is being neglected by his or her parents.
where life is often “short, nasty and cheap” (Pharoah, 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 maladjusted, 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, 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 numbers, as the AIDS epidemic worsens. High AIDS mortality will lead to a massive increase in orphans, large numbers of whom will grow up with untended traumas, stunted schooling, 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 numbers, as the AIDS epidemic worsens.

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 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).

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). 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 phenomena.

**Footnotes**

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 tens 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.’

nomens 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 executable 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.46 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’.47

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.’48 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 normality 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.49 These trains of thought tend to regard the deprivation, hurt (and, for many also, abuse) that frame childhood 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:

[...] Many 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 normality48, 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.

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46 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), 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 Frederiksson GM (2002). Racism: A short history. Princeton University Press. Princeton. But more endemic and enduring is the imagery that pictures young male Africans as turbulent members of civilized society, always at risk of straying across the threshold of depravity and irrationality.

47 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.

48 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 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. 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. 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 grief and bereavement in the context of the AIDS epidemic require strengthening. The African research is scant and our understandings therefore draw heavily on research findings from elsewhere, especially the industrialized world.

49 Stein also makes the important observation that the research foundations for our current understandings of how children in Africa deal with their grief and bereavement in the context of the AIDS epidemic require strengthening. The African research is scant and our understandings therefore draw heavily on research findings from elsewhere, especially the industrialized world.
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).

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 child-headed 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 neigh-
bours. 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’. 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.\textsuperscript{Lxxi}

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.)\textsuperscript{Lxxii} 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 consist-
ently 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 associ-
ates 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.

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**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.\textsuperscript{Lxxi}

Rather than describing an expedient
way forward, the idea that child-headed households
constitute a potential ‘coping mechanism’ stands as an
indictment of society.
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.\textsuperscript{50}

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.\textsuperscript{50} 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).\textsuperscript{50}

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

\textsuperscript{50} 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 non-orphans, 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). 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).

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 non-orphaned children – i.e. orphans were being discriminated against, especially in households that were already struggling to make ends meet. The most decisive variable turned out to be the relationship between the orphan and the decision-making 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 non-orphans 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.

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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

51 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 channelled 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 school-going 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 has confirmed, some schools are levying extra fees to help finance themselves, a situation that occurs across the country. 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. Other 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 recouping or improving an AIDS-orphaned child’s wellbeing. 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 she 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). But this pattern of burden-sharing 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%. Usually these fostering households are headed by women.

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).

The travails of the elderly are not limited to material needs. The Committee to the Minister of Social Development’s country-wide 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 queues 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 index-linking 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


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 stabilise ridges; 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.

x FAO (2001). FAO/GIEWS – Food Outlook No.4 – October 2001. Available at http://www.fao.org/documents/show_cdr.asp?url_file=document/2627ey0627e03.htm. Cassava was originally introduced into Africa by Portuguese colonials. 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/CsR.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).


xvi Psani (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%).


xix Conducted in the iIdutywa 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’ (1998:413).


xxi In 17% of the cases, household 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).


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).


nity responses to the HIV/AIDS epidemic in the rural areas of sub-Saharan Africa. UNAIDS Best Practice Collection. Geneva.


A significant proportion of households escaped poverty, if only temporarily, due to an increase in income from pensions, state grants or remittances.

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 (Wooldard et al., 2002).

The same survey found that, on average, a person sick with AIDS was chronically ill for a year before dying (Steinberg, 2002:ii).

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).

These findings were based on observations six months into the study.

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.

A total of 771 households were surveyed in parts of Free State, Gauteng, KwaZulu-Natal and Mpumalanga.

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).

The figures were drawn from the 2004 General Household Survey, see "Fever people on medical aid". Health-e. 16 July 2005.

Households participating in the Financial Diaries project were in Langa, Diepsloot and Lugangeni.


Booyzen 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.int/aboutWHO/Pages/WHO/Policy/20010827_1.pdf


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'. Mal & Guardian Online. 11 July 2005. Available at http://www.mg.co.za/articlepage.aspx?area=breaking_news/breaking_news_national/ &articleid=245083

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

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.

Recall that some antiretroviral drugs, like many medicines, should not be taken on an empty stomach.


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).


Until 2003, the age limit was set at 15 years in UNAIDS calculations.


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.

See Stein (2003:3) for some illustrative references.

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 (Sullivan, 2003). See below for a more detailed discussion of the evidence.

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 orphansed children will determine the long-term social stability of the country" (Bradshaw et al., 2002).

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.


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 (1998)

As confirmed also by the nine studies reviewed by Stein (2003:14-15).

Please see "Out of sight ...", above.


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'.


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 and Southern Africa (2003) provide proof for this commonplace assertion.


For a thorough discussion, see Fiske & Ladd (2004).


Note that it’s not necessarily the deceased’s ‘own’ children – they, too, may have been fostered.


According to May (2003), some 42% of black South African households are headed by women.

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).

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).

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.
Fall-out

There is an abiding fiction that disasters do not discriminate – that they crush with a kind of democratic disregard for status, power and means. This is not so. Typically, the toll disasters take is concentrated among the poor, among those forced to juggle limited options in ways that often put them in the path of peril. Epidemics like AIDS do not buck this trend. And yet the customary picture is of AIDS as an undifferentiating scourge; ‘we’re all in this together’ is the rousing claim.

The US National Intelligence Council (2000), for example, has warned that the economic and demographic impact of AIDS would ‘undermine civil society, hamper the evolution of sound political and economic institutions, and intensify the struggle for power and resources’. Youde (2001) warns that AIDS will weaken democracy in heavily affected countries by undermining the capacity to manage and administer election processes, slowing economic growth and eroding civil society. Focusing on southern Africa, Fourie and Schonteich (2001) envisage AIDS meshing with other destabilizing factors and, in Manning's summary (2002:12), spurring:

heightened competition for limited resources and exacerbating inter-group tensions, and also weakening the capacity of government and governing institutions, especially on delivery of social services, by sapping human and financial resources. In addition, if the government is perceived to [be] poorly addressing HIV/AIDS-related issues, the epidemic could 'produce a heightened sense of marginalization amongst affected populations and a stronger sense of deprivation and resentment towards the government' which may result in spontaneous violence or the manipulation of dissatisfied groups to contribute to partisan violence.

The claims sometimes veer toward opportunist punditry, as when US presidential candidate John Kerry in 2004 reportedly warned that countries heavily affected by AIDS ‘could well become the home base for terrorists or criminal elements looking for a safe haven, or even for those trading in weapons of mass destruction’. Another comment (Neilson, 2005) points to the possibly emergence of a ‘disturbing new formula’: ‘AIDS creates economic devastation. Economic devastation creates an atmosphere where stable government can’t function. When stable government can’t effectively function, terrorism thrive.’

This highlighting of AIDS as a (state) security threat is relatively new. More prominent in the late 1990s and early 2000s was the tendency to couch AIDS impact in terms of its anticipated effects on development – with the epidemic customarily (and hyperbolically) fingered as the ‘greatest threat’ to Africa’s development. That discourse has shifted toward an emphasis on the alleged security dimensions of AIDS. Frequently aired now are claims such as this:

The war on terrorism has drawn attention to non-conventional threats to security, even as it led to conventional warfare in the case of the attack on Iraq. HIV/AIDS is arguably an even greater threat to security, with the effect of destabilizing the social and economic order to the extent that the very survival of entire nations is at stake (Altman, 2003).

Fall-out

1 Trevor Neilson was also quoted as urging that the ‘AIDS orphan issue’ be regarded not as ‘just another “humanitarian” issue, but rather as a legitimate security concern’. The quote is drawn from a media release for Neilson’s discussion paper (2005), published by the Global Coalition on AIDS. The media release is available at http://www.businessfightsaids.org/site/apps/nl/content2.asp?c=gwKXJfNVJtF&b=1009038&ct=1365471. The full paper is available at http://www.businessfightsaids.org/atf/cf/%7B4AF0E874-E9A0-4DB8-BA2B-96C38C31180A%7D/AIDS%20Econ%20Terror%20Final.pdf

2 Thus, the UN Security Council in July 2000 adopted Resolution 1308 which fingered AIDS as a potential threat to peace and security, especially in the context of peacekeeping operations. UNAIDS has tried to finesse the shift by deeming AIDS to be a ‘security issue, whether one is looking at the more traditional meaning of security (threats to defence of the state, with those threats emanating from other states) or the newer concept of “human security”:’ see ‘HIV/AIDS and security’, available at http://www.unaids.org/en/infocus/hiv_aids_security+and+humanitarian+response/hiv_aids+and+security.asp. The International Crisis Group has declared AIDS a threat to ‘personal, economic, communal, national and international security’: see http://www.crisisgroup.org/home/index.cfm?id=1831&l=1.
The gradual ‘securitization’ of development discourse generally dates back to the 1990s already, but the process accelerated after the terror attacks of September 11, 2001, with reality increasingly viewed through a cognitive screen of ‘security’. AIDS has followed that drift. This subtext of AIDS discourse does not, in itself, invalidate the forecasts as to what might unfold. But it does call attention to the ways in which dominant understandings of the epidemic and its impact are constructed, and how AIDS has become discursively located ‘in the broader context of global neo-liberal economic and political restructuring’ (O’Manique, 2004). The popularized thinking about what AIDS holds in store for a society such as South Africa (and how its impact is framed) also bears the imprint of broader political-economic contests and concerns.

Lacking substantive empirical evidence, the scenarios are as panoramic as they are generic. There is little evident regard for the specifics of societies, for the inequitable manner in which misfortune hits home, or for the interplay of AIDS-related effects with other social, economic and political dynamics.

An epidemic that threatens to prematurely bring to an end the lives of one fifth or more of a country’s population will change that society. But, as the earlier discussion of other shocks on this scale in history suggests (see the Introduction), the nature of such change and its extent are not easily forecast. One of the most far-reaching outcomes of the ‘Black Death’ in England, for example, was its reorganizing of social relations, which eventually erupted in the form of peasant uprisings that reconfigured society. That sequence of outcomes, however, was neither automatic nor inevitable. It required a combination of insulated hubris and tactical buffoonery (on the part of the ruling elites), and vibrant self-awareness of prospect and need (on the part of the peasantry) to achieve combustion. The consequences were historically and socially specific; different histories unfolded in those parts of Italy that were as hard-hit by the epidemic, as they did in the Netherlands and in the countries of the Middle East affected by Plague. Even epidemics of such ferocity, it seems, do not lend themselves to grand overarching punch-lines. It’s at the more parochial levels that the likely effects come into much sharper focus.

**Shaking the foundations**

Especially vulnerable, it seems, are those sectors of the state most closely involved in the reproduction of ‘human’ and ‘social capital’, such as the education and health systems. Much research has focused on how the epidemic will affect those sectors, as well as the ministries responsible for policing and agricultural services; oddly, the effects on social welfare and social services have attracted less attention. Nevertheless, a jolting impact is expected overall.

At the institutional level, South Africa’s epidemic will leave its mark as higher morbidity and mortality rates cause increased absenteeism and personnel losses – in line with trends observed elsewhere in the region. In Malawian ministries, for example, total annual attrition in 1990-2000 rose almost six fold from 347 at the start of the period under review to more than 2 000 in the final year. Death was the highest cause of attrition, accounting for 40-58% of staff losses, depending on the specific ministry (Cohen, 2002). Across the public service as a whole, mortality increased by a factor of 10 during the period of the study, with deaths ‘disproportionately high among young adults of both sexes’ – a strong indication that AIDS was largely responsible (Cohen, 2002:9).

Similar trends are under way in South Africa’s public sector. The public health care system is expected to be overburdened by AIDS, with both the demand for and cost of health services likely to increase, and health workers coming under greater strain. According to HSRC research, an estimated 13% of deaths among health workers in 1997-2001 were due to AIDS, a toll that is almost certain to rise (Shisana et al., 2003). It has

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4 Ministries surveyed were the Ministry of Education, Science and Technology; the Ministry of Agriculture and Irrigation; the Ministry of Health and Population; Malawi Police Service; and the Ministry of Water Development. Together, they accounted for about 80% of public sector employment.
been projected that a country with stable 15% prevalence could expect to see 1.6-3.3% of its health-care personnel die of AIDS each year – a cumulative mortality rate over five years of 8-16% (Tawfik & Kinoti, 2003). A 2002 survey of health-care personnel in private and public facilities found HIV prevalence of 16%, which matched the adult HIV prevalence reported in the Nelson Mandela/HSRC (2002) household survey of the same year (Shisana et al., 2003). Nursing staff are likely to be hit hardest, with AIDS joining emigration and a shortage of new trainee nurses as the factors thinning the ranks. Although apparently less at risk of HIV infection, doctors have also been voting with their feet. Increased illness-related absenteeism and attrition will aggravate the effects of the ongoing drain of health-care personnel. Longer work hours, deteriorating working conditions, lower morale and, as a consequence, poorer quality of health care are likely to be some of the consequences. Yet the need for well-trained health personnel arguably has never been greater in South Africa: according to the Health Systems Trust, complete roll-out of the government’s antiretroviral treatment programme would require an additional 3 200 doctors, 2 400 nurses, 765 social workers, 765 dieticians, 112 pharmacists and 2 000 data capturers in the public health system by 2009 (Ijumba, Day, Ntuli, 2004).

While staff capacity ebbs, care needs surge. The HSRC survey of public and private healthcare facilities found that an estimated 28% of patients in medical and paediatric wards were HIV positive (46% in public hospitals), and their hospital stays were almost twice as long as those of non-AIDS patients (13.7 days compared with 8.2 days). A much greater number of AIDS patients were being admitted in 2000, compared with 1995 (Shisana et al., 2003). Total bed occupancy rates have stayed roughly stable, which suggests that AIDS patients were ‘crowding out’ non-AIDS patients in the public sector. Earlier studies in the Hlabisa district of KwaZulu-Natal found clinic visits had increased by 88% in 1991-2001 and hospital admissions by 81% (Dedicoat M et al., 2003; Floyd et al., 1999). Both workloads and stress were growing, with almost three in four health-care workers reporting an increase in their workloads. About one third of them said their workloads had increased by 75% or more in the previous year (Shisana et al., 2003).

All this, though, is overlaid with broader inequity. South Africa devotes a significant share of its gross domestic product – approximately 9% – to health care. However, the spending occurs in a two-tier system: some 60% of those funds are devoted to paying for the health care of the 15% of the population that has private medical insurance. By way of comparison, in the 1970s, during the heyday of apartheid, roughly one third of all health care expenditures were funneled toward the 20% of the population that carried private health insurance (Benatar, 2003). Annual per capita expenditure on health care in the private sector is almost six times larger than that in the public sector. There have been attempts to temper these trends, but to limited effect: as a general rule, income determines access to health care, its use and its quality.

Household data indicate the continuing influence of barriers to access on health-care demand. These include distance to the nearest health-care facility and cost of care, medication and transportation, especially given that many lack a basic income to cover food and other essential non-food spending requirements. Lower socioeconomic groups seek care less frequently than other groups, despite their generally worse health status, even though primary health-care is free. There is a growing burden of chronic illness, including HIV/AIDS, and

5 The HIV prevalence range was 12.2%-19.9%. The survey was conducted in the Free State, Mpumalanga, KwaZulu-Natal and North West.
6 Astonishingly, Shisana et al. (2003) reported that four in five managers of the 220 surveyed health facilities had not seen the 2000-2005 National HIV/AIDS Plan (a strategy they are meant to help implement). About half the public hospital managers and just 8% of private health sector managers said they had seen the document.
7 2000 was relatively early in South Africa’s AIDS epidemic: people succumbing to AIDS-related illness will have acquired HIV up to eight or more years earlier, just as the HIV infection levels were beginning to soar.
8 In the public sector, bed occupancy rates had stayed between 85% and 95%. If more AIDS patients are being admitted and their hospital stays are longer than average then, all else being equal, other patients in need of hospital-based treatment and care are not receiving it.
9 Benatar (2003) states that 18% of South Africans have medical insurance. That figure appears to date back to 1995; more recent Statistics SA data (in the 2004 General Household Survey) suggest that the proportion has shrunk to 15%; see Fewer people on medical aid. Health-e. 16 July 2005. Almost 70% of whites belong to medical schemes, compared with just 7.2% of Africans (and 18% of coloureds and 36% of Indians).
10 Fully 80% of specialists and at least 60% of general practitioners now work in the private sector (Ijumba, Day, Ntuli, 2004). Benatar (2003) estimates the percentage of physicians working in the private health sector at 66%, up from roughly 40% in the 1970s.
injuries, even whilst poverty-related illness persists. As a consequence, poor African households in particular have had to cope with the triple burdens of health system restructuring, increased levels of chronic illness and broader economic shocks over the last decade. (Roberts, 2005:489)

The Health Systems Trust estimated that just 12-13% of South Africans in need of antiretroviral (ARV) treatment were receiving it in 2004; by mid-2005 as many as 870 000 people in need of treatment were not receiving it (Ijumba, Day, Ntuli, 2004; Ijumba & Barron, 2005; WHO/UNAIDS, 2005). The short-fall is particularly acute in poorly resourced provinces where health systems are malfunctioning due to human resource and infrastructure shortages, as well as inadequate management capacity (Ijumba, Day, Ntuli, 2004).

In the education sector, according to an HSRC cross-sectional study, as many as one in eight teachers are living with HIV (Shisana et al., 2005). HIV prevalence was almost 13% overall but varied by age, income level, race and area. Among educators in KwaZulu-Natal participating in the survey, and among those aged 25-34 years nationally, one in five was HIV positive. Extrapolations from the HSRC survey suggest that at least 10 000 South African educators would be eligible for immediate ARV treatment. Rapid treatment roll-out will make a difference, but it will not be a panacea for the school system. ARV coverage of 60% would reduce by 18% the number of deaths by 2015 among educators younger than 45; 90% coverage could cut AIDS-related deaths by half.14

Along with contract termination and resignations, mortality now ranks among the top causes of staff losses. The total number of in-service deaths among educators rose by 30% between 1997/98 and 2003/04. In KwaZulu-Natal, 790 educators died in 2002/03, an 80% increase over the 441 deaths in 1997/98. It’s likely that a large share of the increase in deaths is associated with the worsening AIDS epidemic. Other corrosive factors, meanwhile, persist. According to the HSRC study, more than half the educators polled said they intended to leave the profession. Even more worrying was the fact that the educators most keen to abandon the profession were those with the highest qualifications, and that two thirds of technology, natural sciences, economics and management teachers said they wanted to leave. Most commonly cited as reasons were low job satisfaction, job stress and violence at schools (Shisana et al., 2005). Those are not idle threats. By 2002/2003, approximately 21 000 educators were leaving the public school system each year, about half of whom had resigned (which suggests they moved to other employment). About one third of those who left returned to the public school system after six or more months. It has been estimated that about 30 000 educators would need to be trained annually to maintain current staffing levels and ensure swift replacement. But training college cutbacks and other restructuring in the sector have left training capacity lagging behind need. Management and administrative skills are especially in short supply. In addition, the profession is not attracting newcomers in sufficient numbers, partly due to concerns about employment insecurity (Vass, 2003a). On such trends, AIDS will exacerbate dysfunction in the public school system.

As absenteeism and personnel shortages in the public school system worsen, educators’ morale and job satisfaction are likely to dip further. At the same time, the demand for their skills in the private education system and in other sectors will rise.

11 Estimates range between 750 000 and 840 00 at the end of 2004, while WHO provided an estimate of 870 000 for mid-2005.
12 The response rate in this survey was relatively high, with 83% of participants having agreed to have an HIV test.
13 Highest HIV prevalence was among African educators (16%), while among other racial groups it was much lower (less than 1%). For a discussion of possible sampling and statistical factors influencing that finding, see Shisana et al. (2005:117). Educators with low socio-economic status had much higher HIV prevalence than did their better-off counterparts: among those earning R132 000 or more a year, HIV prevalence was 5.4%, but among those earning less than R60 000 a year, prevalence was 17.5% (Shisana et al., 2005:118). Interestingly, HIV prevalence was higher among educators in rural areas than in urban areas – a pattern that runs counter to that observed in the general population. The authors surmise that this could be because educators in rural areas would tend to have higher disposable income compared to other adults, and because they might be less likely to have moved with their spouses or regular partners.
14 If a CD4 cell count of below 200 was used as the guideline to commence treatment, 10 000 teachers would require antiretroviral therapy; while if a CD4 cell count of 350 or lower were used, more than 23 000 would require treatment.
15 Seemingly illustrating the pervasiveness of job-related stress was the finding that the most frequently reported diagnoses in the previous five years among educators were high blood pressure (16%) and stomach ulcers (9%). The burden of absenteeism among educators was most closely linked to high blood pressure, tobacco use, being HIV positive, stomach ulcers, arthritis or rheumatism, and high-risk drinking (Shisana et al., 2005).
16 See also Akoojee S & McGrath S (2003), where the authors locate restructuring in the education sector both within the need to restructure the inherited apartheid education system and the government’s accommodation to neoliberal policy structures. They note, for example, that one of the consequences of such ‘rationalization’ in the late 1990s was a 40% decline in enrolments for teacher training courses in 1998-1999.
– increasing the odds of educators being lured out of the public school system.\(^{17}\) Compounded attrition can be expected. In the longer term, such effects will spill into the wider labour market (Vass, 2003a). If the education sector’s capacity to provide basic education suffers, the springboard for higher education and skills training weakens – to unhappy effect in an economy that has been geared to rely much more heavily on top-end skills. Channels for quality educational advancement will, of course, be available but they would be largely in private hands, limited in number, restrictive in access, and expensive – a dual and discriminatory system, in other words. What might this mean for inter-generational social mobility? If the quality of public school education deteriorates further against a backdrop of continuing marginalization of the poorest households – and of overall polarization – social mobility will be hobbled, deepening the mire of chronic poverty. Whether South Africa can avert these kinds of trigger effects will help decide what kind of society coming generations will inherit.

It is generally assumed that AIDS will reduce school enrolment. Much of that effect would occur as increased infant mortality limits the number of children who reach school-going-age. Effective programmes aimed at preventing mother-to-child transmission of HIV could reduce this effect substantially. There is also the expectation that school enrolment will shrink as families withdraw children from school in order to compensate for labour losses caused by AIDS (UNAIDS, 2004). There is very little evidence currently about the extent to which this might be happening in South Africa. However, analysis of evidence from elsewhere on the continent suggests that the direct effects of AIDS on school enrolment might be exaggerated at the expense of attention to other, often policy-related, variables – ranging from school and related fees, to livelihood security, employment opportunities and broader macro-economic strategies. After reviewing literature and modeling evidence on the impact of HIV/AIDS on schooling in Tanzania and Uganda, Gould and Huber (2002:1), for example concluded that:

> Enrolments in primary and secondary schools in the past and in projections to 2010 are more likely to be affected by policy variables (notably financial support for expansion in the education and health sectors) and by constraints associated with rising poverty (including increasing differentiation of HIV and non-HIV households) than by direct demographic demand.

Educational attainment was strongly associated with household wealth in KwaZulu-Natal, too, according to a recent study that also identified pregnancy as a major cause of educational underachievement in women, especially poor women (Hallman & Grant, 2004). The upshot is self-evident: the temptation of what Gould and Huber (2002) have termed ‘demographic determinism’ should be resisted and AIDS impact needs to be analyzed and responded to alongside the other factors that blight the public education system. The damaging role of AIDS is not easily – nor necessarily fruitfully – detached from the complex circuitry of cause and effect in which it is entangled.

Already saddled with hulking workloads and compromised capacity, the police and the correctional and judicial services are especially vulnerable to additional debilities. According to South Africa’s Public Service Commission, teachers and police appear to be worst affected by AIDS, although as late as February 2005 the Commission did not yet have a strategic plan for dealing with the epidemic. AIDS could also dent South Africa’s peacemaking and peacekeeping ambitions. HIV prevalence among members of the South African National Defence Force (SANDF) has been estimated at 17-23%--high enough to compromise the prominent role South Africa hopes to play in regional peacekeeping efforts. According to SANDF testimony to Parliament in 2004, HIV status was one of the factors that caused almost one third of soldiers to fail the physical standards requirements for deployment on foreign peacekeeping missions.\(^{18}\)

Public and political institutions probably will be affected by other, less obvious factors as well. It’s likely that the need for, demand for and uptake of some services could become more

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\(^{17}\) Badcock-Walters et al. (2003) came to a similar conclusion when examining educator mortality in KwaZulu-Natal.

\(^{18}\) According to a briefing by General Pieter Oelofse of the SANDF to the National Assembly’s defence portfolio committee in August 2004, see HIV/AIDS in military given as 23 percent. SouthScan, 19(17). 20 August 2004. Recall that the epiphany that reportedly stung Uganda’s president Yoweri Museveni into action against AIDS was the realization that the epidemic was weakening the army. Uganda’s military became aware of HIV spread in army ranks when the Cuban authorities insisted that Ugandan soldiers earmarked for training in Cuba first be screened for HIV (Amrith, 2001).
unpredictable. In some respects, the scale of such changes could be anticipated: the demand for hospital beds or antiretroviral treatment in a particular district, for example, could be estimated on the basis of HIV prevalence data in that area. But it would be harder to predict the possible effects on, say, housing and housing subsidy programmes. In such respects, AIDS will very likely contribute to a gradual grinding-down of institutional capacities and performance, undermining the ability to deliver services – and, according to some of the more floriad predictions, even precipitating a pervasive melt-down:

If a ministry of finance fails to develop the correct models for revenue, expenditure, and economic growth (or decline), the wrong policies will be instituted, with dire outcomes. If the ministry of education fails to train enough teachers, allocate them efficiently to schools, and to pay them on time, the nation’s educational system will go into decline, with important consequences for the future of the country. The paralysis of a police or judicial system can contribute to a crime wave. In turn, these governmental failures can contribute to popular discontent and unrest. The breakdown of discipline and authority in an army will have far-reaching consequences for national security. The weakening of state capacity combined with its decreasing legitimacy would be a recipe for popular pressure for democratization [...]. It seems unlikely that regimes’ capacity for self-preservation will be undermined significantly [...].

A disabling effect on the democratic process is also foreseen by some observers, with Robert Mattes (2003:5), for example, warning that:

[T]he weakening of state capacity combined with the pandemic is likely to devastate large portions of policy-makers, national legislators, local councilors, election officials, soldiers and civil servants [...] A shrinking proportion of civil servants, policy-makers and legislators will be at their jobs long enough to develop the specialized skills, expertise and professionalism needed to do their jobs. It will be increasingly difficult for legislatures, ministries and government agencies to pass on the skills that they do have. There will be fewer experienced officials available to train younger personnel in key formal skills (such as programme design, budgeting, cost/benefit analysis, monitoring and evaluation, and personnel management); or pass on more informal standard operating procedures or norms such as ministerial accountability, bureaucratic neutrality and official ethics.

According to Idasa research, almost 1.5 million registered voters died between 1999 and 2003, with the annual number of deaths among voters having risen by 66% in that period. It’s impossible to say whether or how this could be affecting voting outcomes, although Idasa does not expect AIDS to badly impair the technical administration of elections in South Africa. Is the epidemic likely to weaken political institutions and elected bodies? Again, the substantive evidence is scarce. One of the few enquiries on this front found sharp increases in councilor absenteeism in the eThekwini (Durban) Metropolitan Council in 2001-2002 (Manning, 2002), but the causes were fuzzy. Meanwhile, Idasa has pointed out that the 102 by-elections held in Zambia between 1985 and 2003 were more than double the 46 staged between 1964 and 1984. The suggestion is that the increase was largely due to AIDS. In the 1964-1984 period, 14 (or 30%) of the 46 by-elections were related to deaths, as were 39 (or 38%) of the 102 by-elections in the 1985-2003 period – an 8% increase, which will have been caused by a variety of factors, probably including, but certainly not limited to, AIDS.

Though it would be foolhardy to dismiss them out of hand, the ‘collapse’ scenarios require more cautious interpretation. At face value plausible, they often are at least partly the fruit of fanciful intuition, draw on slight empirical evidence and...
seldom express a solid analytical method. Highlighted is the need for more-rigorous examination and analysis of the socio-logical fall-out of a severe AIDS epidemic. One of the most telling shortcomings of current prognoses is their neglect of the ways in which AIDS impact is tempered or aggravated by unequal access to resources and services. A substantial proportion of public servants and politicians is, by virtue of their skills and status, likely to have quality medical insurance coverage, to receive regular medical check-ups and to be able to afford antiretroviral therapy. In such cases, an HIV-positive status does not necessarily equal a ‘death sentence’. The extent of AIDS-related absenteeism and personnel losses in these higher tiers almost certainly will be lower than among their less-privileged colleagues.

**A new wave of mobilization?**

Aired occasionally is an expectation that AIDS will intensify sheer, desperate need and enflame challenges aimed at the state. Indications from elsewhere in southern and East Africa are that such needs-driven or entitlement-driven mobilization and activism is relatively rare. However, South Africa’s more-recent history of large-scale and diffuse political activism might position it in a special category – as the dramatic emergence of the Treatment Action Campaign (TAC) in the late 1990s would seem to suggest.

An independent association of organizations and individuals, the TAC has used the discourse of human and socioeconomic rights– and thus, by implication, also the discourse of the South African liberation struggle – to successfully challenge government policy, raise public awareness of AIDS and AIDS treatment, and initiate alternative grassroots projects. An early breakthrough came when the TAC (as a ‘friend of the court’) joined a court case brought by 39 pharmaceutical corporations against the South African government. By helping mobilize an impressive gallery of legal and health expertise domestically, by tapping into international networks of ‘anti-globalization’ and AIDS activism, and by highlighting the ferocious profiteering of the pharmaceutical industry, the TAC helped shame the corporations into withdrawing their court challenge. This sort of tactical craft became a hallmark of TAC activism. Combining court-based thrusts with direct action and grassroots mobilization, and forging tactical alliances with other social formations (especially the trade union movement and organized religion), the TAC conjured up the most successful adaptation of liberation struggle traditions seen since 1994. Especially astute was the ambivalent relationship it initially struck with the government, with the TAC positioning itself simultaneously as critic, watchdog and supporter. By 2003, however, that tactical agility was waning as the government’s intransigence (first on the roll-out of a prevention of mother-to-child transmission plan, then on a national antiretroviral treatment strategy) forced the battle-lines to be drawn more emphatically. Still, a programme that brought together grassroots training and mobilization, tactical activism, canny use of the media and a strong policy research and analysis capacity has reaped several major victories—not least the mid-2003 decision of the South African government to expand considerably treatment and care provision through the public health system.

Does this herald a wave of wider radical mobilization and organization in pursuit of social change, with AIDS acting as a kind of prism for wider-ranging grievances and unmet needs? Possibly, but not very likely. No doubt, the TAC helped legitimate and validate progressive rights-based criticism, protest actions and policy interventions at a time when these had been routinely demonized from within government as the gestures of reactionary, wrecking tendencies. Largely due to the TAC, health (and specifically AIDS) has become the only arena in which the state’s monopoly on policymaking authority has been visibly and successfully challenged in a sustained way since 1994, as Greenstein (2003) has observed. But it remains to be seen whether the TAC can adjust strategically to current realities as adroitly as it adapted tactically to opportunities in its early years. And, although the TAC itself cannot be blamed for the relish with which many observers in the early 2000s eyed it as a new social movement in-the-making, the fact remains that that expectation has not (yet) been realized.

There are other reasons, too, why AIDS might, in sociopolitical terms, prove to be less combustive than some anticipate. Many of the hardships and grievances most obviously and explicitly associated with AIDS tend to be experienced not as a communal issues but as ‘private’, ‘domestic’ ones – to which AIDS, in addition, attaches a premium of stigma and shame. As well, in Loewenson’s (2004:31) view:
Activities within the extended family sector are often not brought into the social or public domain unless this is organized by community leaders, civil society or the state. In fact, there is some evidence that such demands are more likely to be made by middle- and higher-income households than by low-income households.

In a context of pervasive poverty and social violence, many NGOs and CBOs fulfill vital welfarist roles at community level, with religious and cultural organizations especially prominent. Both manifest need and the surge of AIDS-related development funding has spurred the emergence of new layers of support organizations, many of them trying to manage some of the consequences of ineffective or absent state policy and provision. Generally, however, such association-based support mechanisms tend to focus on mutual support and are not necessarily amenable to radical social mobilization. In addition, they contain motley interests, are inflected with the inequalities that pervade the communities they emerge from, and often are entangled in local patronage networks. Their utility as autonomous nodes of grassroots sociopolitical activism and challenge should not be exaggerated (Pieterse, 2003). These organizations are also very vulnerable to attrition. Destabilization brought on by staff losses has been a familiar part of CBO and NGO life for the past decade.22 AIDS now looks set to compound those difficulties. Even in the best of circumstances, NGOs and CBOs tend to rely heavily on a few, key individuals. The past decade has seen this sort of dependency reinforced – with organizational knowledge, networks and experience ever more concentrated around a handful of individuals. Losing these organizational ‘pillars’ could be disastrous for NGOs and CBOs, and for the communities that rely on their services. Yet, these kinds of effects on civil society have not attracted nearly as much research attention as the anticipated impact on the economy.

**Pounding the economy**

It seems indisputable that an epidemic as severe as South Africa’s will affect the economy – but how and to what extent is less easily gauged (Barnett & Whiteside, 2000). Some projections seem almost to trivialize AIDS impact, suggesting that even rampant epidemics would have a negligible effect on economic output.23 ING Barings (2000), for example, estimated that South Africa’s gross domestic product (GDP) would be just 2.8% smaller in 2015 than it would have been in the absence of an AIDS epidemic, while the Bureau for Economic Research (BER) concluded that real GDP growth would be 0.3-0.6% less per annum in the AIDS scenario (BER, 2001). Other exercises point towards much greater economic impact. Financial analysis by ABSA Bank has forecast that GDP would be 9.6% smaller in 2015, while Arndt and Lewis (2000) concluded that GDP would be 17% lower in 2010.

Nattrass’ (2002) review of three modeling exercises (ING Barings, Arndt & Lewis, and BER) illustrates how contingent and rickety economic impact estimates can be. The estimates diverge mainly because they emerge out of models that employ different assumptions about the epidemic’s demographic impact, about the channels along which AIDS is likely to affect the economy, and about the nature of the effects themselves. For example, it’s safe to assume that AIDS will alter the size and efficiency of the labour force in South Africa, and that it will also reshape consumption patterns. Beyond that, though, the consensus more or less dissolves. The BER model, for example, assumes that wages for higher-skilled workers will rise (as increased scarcity and demand converge) and that this would roughly cancel out the effect of reduced employment on aggregate household income. The ING Barings model, on the other hand, sees lower household incomes draining consumption, overall system in a complex interplay of kick-on and feedback effects. ‘With AIDS’ and ‘without AIDS’ scenarios have important illustrative value and can broadly indicate the scale and dynamics of epidemic’s impact, but should not be used as literal ‘forecasts’ of, say, gross domestic product growth in 2010, or the exact number of orphans in 2015.

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22 From 1994 onward, hundreds of key NGO staff were lured into post-apartheid government departments and parastatal institutions and, later, the private sector. Along with funding difficulties, this dimmed the effectiveness and even accelerated the demise of many progressive NGOs and CBOs. Those that survived soon encountered another trend. Large companies, keen to advertise their acquiescence to the ‘new South Africa’ (and under pressure to heed affirmative action requirements), began courting (black) NGO staff and snatching newly graduated talent.

23 Most models used to estimate the economic impact of AIDS countericie ‘with-AIDS’ and ‘without-AIDS’ scenarios, in line with the ceteris paribus (‘all else remaining equal’) principle. The principle is applied for methodological reasons, but it yields a plainly distorting abstraction. Other factors affecting the economy do not freeze in place, and their largely unpredictable undulations affect one another as well as the
which cuts into demand that, in turn, causes lower growth (Nattrass, 2002).24 Each assumption meanwhile rests on additional layers of conjecture that draw on particular (sometimes ideologically inflected) interpretations of empirical evidence. Just under half the drag on GDP growth in the Arndt and Lewis (2000) estimate was attributed to a ‘crowding out’ effect, which ostensibly sees greater government spending (mostly on health) inflating the budget deficit and discouraging private investment.25 Economists of Keynesian bent, on the other hand, take a different view; the ING Barings and the BER scenarios predict that increased government spending would boost consumption and spur economic growth. There, the punch-line is that tight fiscal policy would further choke demand and bring growth to a halt once the AIDS epidemic is in full-swing.26

The assumptions also differ with respect to how firms react to higher AIDS-related costs: do they pass the costs onto consumers, or do they absorb some of them (thus cutting into profit margins and possibly reducing future investments), or do they attempt to mechanize more of their operations (and reduce their labour dependency), or outsource more of their labour requirements, or cap or reduce wages, or cut back on worker benefits, or introduce various combinations of those options? Whether it incorporates all such variables or not, each model implies answers to such questions – but on the basis of very little empirical data.26 Ultimately, grand economic impact estimates pack illustrative punch, but add little substantive insight; enquiries into the likely economic effects of the epidemic tend to be more rewarding when they zero in on the details.26

**Ducking the blows**

In theory, the direct costs of AIDS to businesses will arrive in the form of higher health-care costs and more expensive workers’ benefits, while the indirect costs will occur in the shape of reduced productivity, loss of skills, experience and institutional memory, and (re)training and recruitment time and expenses. Indirect costs are significantly higher for skilled workers, compared with their less-skilled counterparts, while employee benefit costs tend also to be higher for skilled workers (Whiteside & O’Grady, 2003). Ultimately, these costs add up to a kind of hidden employment or payroll tax (De Waal, 2003b).27 However, companies have a great deal of scope for averting or deflecting such costs (see below). As a result, the impact is likely to be felt most sharply by those companies that are vulnerable to substantial drops in consumer demand.

By slashing the working and income-earning lives of millions of people, AIDS could squeeze consumer markets and cramp economic growth. A small proportion of companies already claim to be feeling that pinch. In one of the largest HIV/AIDS surveys conducted to date among South African companies, less than 12% of them (mostly in the financial services and retail sectors) reported that the epidemic was affecting their business. (BER, 2004). This should not surprise us. An epidemic that discriminates, as AIDS does, un-leashes uneven effects that will tend to cluster among particular sectors and ventures. Overall, it’s the retail

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24 The ING Barings model also assumed that HIV susceptibility is spread evenly across all sectors and skills levels in the economy. Available evidence suggests this is not the case (see below). Increasingly, studies find HIV prevalence to be higher among lower-skilled workers than among their better-skilled counterparts, and prevalence in some sectors (notably mining) appears to be considerably higher than in others (such as financial services). Anglo American estimated that about 23% of its workforce was HIV positive in 2002, while telecommunications and financial companies have reported HIV prevalence of 7% and 5% respectively. See Vass J (2003a). The impact of HIV/AIDS, in HSRC. Human Resources Development Review 2003. HSRC: Pretoria, p 191-192.

25 The ‘crowding out’ argument is a favourite saw of neoliberal economics, and was used to strong effect in promoting and, later, defending the 1996 Growth, Employment and Redistribution strategy in South Africa. See Bond (2005) and Marais (2001a).

26 The models suffer other limitations, too. The differential ways in which the epidemic is experienced seldom feature in the scenarios, value produced in the non-market economy of the household and community (including child-care, elder care, other home-based tasks and volunteer work) is not reflected, and the potential kick-on effects of losses in one sector on others are not factored in. They also tend not to capture the possible depreciation of human and social capital, and its effect on economic output. Some modellers have sought to incorporate more elements, prompting exceptionally gloomy predictions that call to mind MacPherson’s claim (2000:11, cited in Whiteside, 2003:323) that the effect of savings and efficiency losses would be akin to ‘running Adam Smith in reverse’. One recent exercise attempted to incorporate and quantify the effects of AIDS on both human capital and on the stock of experience, skills and education that help prime an economy’s growth potential. Applying the model to South Africa, the authors concluded that, within a few generations, AIDS could bring the South African economy to near collapse (Bell, Devarajan, Gersbach, 2003). The forecast is not widely regarded as credible.

27 The outlines of such a ‘tax’ have emerged in a few studies, among them Rosen et al. (2003), which focused on six Botswana and South African companies where HIV prevalence among workers ranged from 8% to 25%. Applying a conservative set of assumptions, the authors concluded that an ‘AIDS tax’ of 1-6% of labour costs per year was being incurred.
sector—and especially those enterprises that rely on products and services aimed at mass consumer markets or markets that are close to saturation—which seem most vulnerable (BER, 2004).

Studies among poor households show that the bulk of household expenditures are on food, energy and debt. De Swardt’s research (2003) in Mount Frere, Ceres and Langa (Cape Town), for example, found that between 37% and 44% of monthly income was reserved for buying food; 4-11% went towards paying for energy, and 5-12% was spent servicing debts. Goods purchases comprised only 5% of monthly household income in Mount Frere, 8% in Langa and 10% in Ceres. These households have very little latitude for shuffling their expenditures when their finances come under additional strain; something has to give. Food expenditures tend to be protected, but once under pressure these, too, are cut back to bare essentials. Enterprises that rely heavily on sales to the poorest two, perhaps three, quintiles of society therefore are likely to be hit hardest. Most vulnerable will be informal retailers and spaza shops that depend on sales of food and other basic goods (including cigarettes, personal care products and beverages) in largely poor communities. One effect would be to cut further into the already-feeble livelihood strategies of households that rely on so-called ‘micro-enterprise’ retail efforts.

Shrinking or unstable incomes would further prevent poor households from purchasing durable goods, as well discourage purchases of clothing, shoes and other semi-durables. A significant share of durable and semi-durable goods purchases in South Africa involve hire purchase arrangements or some other form of credit provided by the retailer. Many of these include an insurance component which either writes off or settles outstanding payments in the event of the customer dying. Higher mortality rates renders these forms of credit more costly (since more debtors are likely to die before settling their debts), and firms are having to decide whether to absorb part of the additional cost themselves or to pass it on entirely to consumers (at the risk of surrendering price competitiveness in a tight market).

While some producers and retailers will suffer, others will be able to take evasive action, and some might even gain.

Vulnerable companies that can expand operations abroad (especially elsewhere in Africa where markets for their products and services are not yet saturated) will be tempted to do so. Other companies seem to be adapting their product lines to appeal more to the wealthier market segments which they assume are less affected by the epidemic (Whiteside & O’Grady, 2003). Indeed, if wages and salaries for the top skills levels increase (and income inequality widens), the durable and luxury goods market overall might not be that badly affected. The effects will cluster elsewhere. If firms react to AIDS by continuing to reduce their reliance on unskilled labour and by moving out of economic sectors with customer bases comprising lower-income consumers, then poor households will find themselves ‘doubly disadvantaged’: not only will their access to the labour market be reduced further, but the products they purchase may become more costly (Nattrass, 2002). Deflecting the impact

In tackling the epidemic’s effects on workforces, companies have four basic strategic options, according to Rosen and Simon

28 In the Free State study, AIDS-affected households spent less on food than their unaffected neighbours. Other research suggests that food expenses are often reduced by avoiding more expensive and protein-rich items (such as meat, eggs and milk)—which could further compromise nutritional status.
29 Michael (1999) briefly touched on this aspect, which has attracted surprisingly little research attention.
30 The possible impact on the cellular phone industry tempts speculation. Since erupting onto the scene in the early-1990s, the industry has had a presumably major (though poorly researched) effect on personal expenditure decisions in poorer households. People using contract systems spent an average of R384 per month on their cellular phones, according to the 2005 study The impact of mobile technologies on the South African consumer (see ‘South Africans love their cells’, Mail & Guardian, 9 June 2005). It is likely that cellular phone costs currently absorb a small but significant share of income in poorer households in urban areas, where the phones often substitute for inaccessible landline services.
31 An 1998 assessment of AIDS impact on the market share of a major southern African furniture and household company, for example, forecast that its customer base would shrink by almost one fifth by 2015. The company has diversified its operations into other regions. It’s not clear whether or to what extent the expansion of its operations into the Czech Republic, Hungary, Poland and Slovakia was triggered by the study findings, although Whiteside & O’Grady (2003) have suggested a link. See also ‘JD, Ellerine aim to convince skeptics’, Sunday Times, 14 May 2000; and ‘AIDS threat sparks business into action’, Sunday Times, 11 November 2001.
“Skills” usually refer to formal education and training levels, a definition which devalues the skills and experience acquired on the job and elsewhere. Thus, low-skilled workers might lack formal qualifications, but in the course of their working lives they accumulate skills and experience that are not quickly replaced. The notion that unskilled and low-skilled labour losses are overcome easily and seamlessly ignores the varied textures of “skills”. Even “soft skills” - such as workplace socialization, a familiarity with organizational culture and work ethics - often have to be nurtured afresh, especially in a labour market like South Africa’s, where a large proportion of unemployed men and women younger than 30 years have never had a formal job.

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33 Interestingly, 10% of building and construction firms offered the same reply, despite the sector’s manifest shift over the past two decades towards using ‘casual’ semi- and ‘un’-skilled workers. More than 60% of the mining companies and over 40% of the manufacturing companies participating in the survey reported that AIDS had already reduced labour productivity, increased absenteeism and caused a rise in worker benefit costs (BER, 2004). Generally, by far the biggest share of fixed capital investment generally goes towards “machinery and other equipment” - and that share has grown larger, from an average 40% in 1990-1994 to 49% in 1995-2002 (UNDP, 2004). Most tax codes are designed to encourage investment in physical capital, for example via generous depreciation terms and other discounts; South Africa is no exception.
still need the ability to fast-track skills acquisition and training, which is costly. Poaching or importing skills might be the easy way out (Vass, 2003b).

Meanwhile regressive changes to workers’ health-care benefits and pensions continue to be made. Many of these manoeuvres form part of wider, ongoing restructuring efforts; AIDS is providing additional impetus to them. According to a World Bank survey, the shifts toward casual labour and mechanization, for example, accelerated in the mid-1990s partly in reaction to new, progressive labour legislation. Medical benefits are now customarily capped at levels (or even replaced with fixed cash pay-outs) far too low to cover the costs of serious ill health or injury. In 1997-1999 already, more than two thirds of major South African companies either cut workers’ health care benefits or increased workers’ contributions to medical schemes (Rosen & Simon, 2003). When surveyed in the late 1990s, more than three quarters of 56 randomly sampled large South African companies were cutting back death and disability benefits, limiting employer contributions, and requiring that workers pay a larger share of the premiums for the same benefits. On average, more than one third of the workers with access to such medical schemes had withdrawn from them because of the costs they entailed. In addition, most large companies have replaced defined-benefit retirement funds with defined-contribution funds, often with the support (and in some cases the encouragement) of trade unions who believed that defined-contribution funds were in their members’ interests (Barchiesi, 2004; Van den Heever, 1998). The former variant provides long-term support for the spouses of deceased workers (at significant cost to companies). The latter comprises a one-off pay-out equal to the combined amounts contributed by the employer and the worker up to the last day of employment. It is of scant value to younger workers and provides little longer-term help to families – but it shields companies against future obligations.

By 2000, almost three quarters of 800 retirement funds had defined-contribution funds, compared with just over one quarter in 1992. These kinds of adjustments betray the fundamental tension between private profit and the public good. Their net effect is a constant whittling of real wages and benefits for those South Africans with formal employment – at a time when they and their families are at increased risk of severe illness and premature death. Much more worse off are ‘casual’ or ‘non-permanent’ workers, who have access to feeble or no retirement, death and disability benefits, who earn much lower wages, and who work on terms weighted inordinately in the favour of employers.

In this context, AIDS could affect the labour market in several ways. It probably will contribute to other pressures to cap or reduce real wages for non-unionized workers, and hoist wages and salaries of skilled and highly skilled workers. AIDS risk might inhibit private-sector investment in training and education, with companies more inclined to poach or lure top skills from elsewhere in the world, especially from other African countries (Vass, 2003b). This would reinforce the barriers that block mobility into higher-skilled employment, with Africans (especially women) worst affected.

Such a sequence of reactions need not even show up as a drag on economic growth in specific sectors; it could appear to boost productivity and cut costs for some enterprises, widening profit margins, and buoying equities. The adjustments amount to a large-scale redistribution of risk and an abdication of responsibility for social reproduction – with the costs socialized, that is to say deflected into the ‘domestic’ sphere and, to a lesser extent, those zones of the state and civil society active in social development and welfare activities. It defies any notion of a social contract and strips bare the pretences of corporate

34 Some of the changes to health care benefits are AIDS-specific. Rosen and Simon (2003), for example, report instances elsewhere in Africa where HIV infection has been classified a ‘self-inflicted condition’ in some medical schemes and therefore is not covered. A South African company reportedly also lowered its ceiling for HIV-related claims per family from R100 000 (roughly US$20 000) in 1997 to R15 000 (US$2 500) in 1999; see Center for International Health. The cost of HIV/AIDS to business in Africa (forthcoming), cited in Rosen & Simon (2003:132).
social responsibility. From every vantage point besides the bottom line, the outcome is nefarious. Companies enjoy considerable scope to reduce their social obligations, and they will continue to exploit those opportunities until prevented from doing so:

The private sector has a clear incentive, and some ability, to shift the burden unless governments take action to prevent it. Deliberate decisions on social policy must be made, and enforced, if the ultimate allocation of the burden is to be socially desirable (Rosen & Simon, 2003:135).

The sum effect would be to increase inequality and trap more people in poverty. Firms could continue to reduce their dependency on an unstable supply of labour by mechanizing more of their operations (thus increasing unemployment), cutting the wages of un- and semi-skilled workers, restructuring and trimming job benefits, and/or out-sourcing more of the their labour requirements. Young people and older women who try to enter the labour market (but who lack sought-after skills and attributes, including physical strength) will not only find work difficult to find but will probably end up competing heavily on the lowest rungs of the market for exceptionally low wages. At the same time, increased demand for an already-limited pool of skilled and highly skilled labour would push up wages and salaries at that end of the labour market. Skilled workers could benefit from an increase in demand for their labour, with a potentially profound effect on the fortunes of trade unions. Those representing less-skilled workers, especially in sectors where labour requirements are being adjusted radically, will come under greater pressure. But unions representing the more-skilled sections of the work force probably could see their bargaining hands strengthened. Meanwhile, in both the public and private sectors, we are likely to see work increasingly contracted out to consultants.

More broadly, for the poorest sections of society, access to and the quality of essential services (such as education and health) are likely to be compromised even further, as the epidemic takes its toll in the public sector. Beyond this, current trends suggest that it is the poorest South Africans who are least likely to receive antiretroviral and other life-prolonging treatment. AIDS will entrench existing inequalities; very likely, it will deepen them substantially.35

More broadly, for the poorest sections of society, access to and the quality of essential services (such as education and health) are likely to be compromised even further, as the epidemic takes its toll in the public sector. Beyond this, current trends suggest that it is the poorest South Africans who are least likely to receive antiretroviral and other life-prolonging treatment. AIDS will entrench existing inequalities; very likely, it will deepen them substantially.35

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35 Oddly, except for some rare attempts, the impact of AIDS on income inequalities has not been carefully examined. Greener et al. (2000) projected that in Botswana household per capita income would decrease by 8-10% and the percentage of households in poverty would increase by 6-8% as a result of AIDS over the next decade. Despite this, the authors concluded that income inequality, as measured by the Gini coefficient, was unlikely to be affected by AIDS.

36 Just how unequal is South Africa? According to the government, South Africa’s Gini coefficient was 0.59 in 2000 (Government of South Africa, 2005) – although Leibrandt et al. (2004) calculated it at 0.72 and the HSRC (2004) put it at 0.77, making South Africa one of the most unequal societies in the world. Inequality among Africans widened from 0.62 in 1991 to 0.72 in 2001 (HSRC, 2004). However, according to Van der Berg (2002), if social grants and services are factored in, the coefficient eases considerably, to 0.44%; according to the government, it declines to 0.35. Yet, even the more conservative calculations evoke a shocking reality: in 2000 the poorest 20% of households accounted for 2.8% of total expenditure, while the wealthiest 20% accounted for 64.5% (Government of South Africa, 2005). See Leibrandt M et al. (2004). Measuring changes in South African inequality and poverty using 1996 and 2001 census data. Working Paper No. 84. Centre for Social Science Research. University of Cape Town, and Van der Berg, S (2002). Poverty, fiscal incidence and social outcomes. Paper commissioned by the German Agency for Technical Cooperation, both cited in Friedman S (2004). ‘Understanding poverty: the limits of data’. In Brown S & Folscher A (eds.) 2004 Transformation Audit. Institute for Justice and Reconciliation. Cape Town.

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**Worlds apart**

The demographics and pervasiveness of poverty in South Africa, where a majority of Africans live below any acceptable minimum poverty line, means that even if HIV infections were distributed evenly between the five income quintiles, the vast majority of infected people would be poor, and a large part of them would be extremely poor. As it is, AIDS does not threaten and afflict all and sundry alike or in equal measure; it feeds off and aggravates existing inequalities.36 The epidemic affects South African society differentially. These patterns reflect embedded, structural vulnerabilities and social relations forged over the past 150 years. Rooted in the colonial and apartheid era, the ongoing, severely-unequal distribution of economic opportunity, social power, resources and livelihood options provides the epidemic with a great deal of its dynamism and helps generate the patterns of HIV transmission in society.

A welter of sector- and workplace-level studies show HIV prevalence tends to be higher among people with fewer skills, lower incomes and poorer access to basic services. Among health workers in private and public health facilities in four provinces, for example, HIV prevalence was just under 14%
among professionals and over 20% among non-professional staff (Shisana et al., 2003). An HIV prevalence study among employees of the Buffalo City Municipality in 2004 found higher prevalence among temporary than permanent staff, with infection levels highest in the lowest skills levels (Thomas et al., 2005). The gold mining company Harmony stated in 2004 that 34% of its labour force was infected with HIV, while Anglo American reported that approximately 24% of its workers were infected. Meanwhile, the mainly white-collar employees in the financial services sector appear to be much less affected; a survey in 2003 of workers at four major banks (ABSA, FirstRand, Nedcor and Standard Bank) found HIV prevalence of 3.4%. Among South African workers participating in a three-country seroprevalence survey of 34 major companies in 2000-2001, HIV prevalence was 15% for unskilled workers, 18% for their semi-skilled counterparts and 20% for contract employees – compared with 7% for skilled workers and 4% for management staff (Evian et al., 2004).

For the majority of households affected by the epidemic, AIDS arrived alongside ongoing dispossession and hardship. According to the Human Sciences Research Council, in 2001, 57% of South African households were living in poverty (unchanged from 1996) (HSRC, 2004). In mainly African townships around Cape Town, research conducted by the Programme for Land and Agrarian Studies (PLAAS) found that three quarters of households lived below the poverty line and that 52% of them lacked regular wage incomes. Levels of education did not appear to influence significantly people’s chances of finding paid work. In 1999, there was no-one with a job in 38% of households nationally; in the poorest quintile, 83% of households had no-one in formal employment (Everatt, 2003). The gender and racial contours of poverty remain shocking: approximately 57% of Africans are poor, compared with 1% of whites, and the poverty rate among female-headed households is twice that of male-headed households (Committee of inquiry into a comprehensive system of social security for South Africa, 2002). Surveys consistently uncover scandalously high proportions of people admitting that they lack the money to buy food for themselves and their kin. In 1999, 22% of South African households said members went hungry because they could not afford to buy food (Everatt, 2003). A 2001 survey of 500 poor households in Limpopo (then Northern province) found that 51% of the households had lacked enough food to eat for up to 6 days in the previous month, and 5% said they had gone hungry continually for most of that month (Van den Ruit et al., 2001).

What is to be done?

It is obvious that households’ abilities to guard food security, care for and protect children, and achieve secure livelihoods are in urgent need of bolstering. At an elemental level, this means preventing more effectively the spread of HIV, and keeping those persons who are infected with HIV alive and healthy for as long as possible. This implies expanded programmes to prevent the transmission of HIV from mother to child, universal and affordable access to antiretroviral (ARV) therapy, and ensuring that vulnerable households have food security. Given that AIDS-related death rates are upward of 90% in the absence of antiretroviral treatment, the extent of the epidemic’s impact will be shaped also by the speed and extent to which ARV treatment is made available, and the degree to which treatment is adhered to. It doesn’t mean that ARV treatment will prevent HIV-positive people from dying of AIDS, but it can extend their lives for an indefinite period. (Less than a decade after the widespread introduction of effective ARV therapy in industrialized countries, we don’t yet know for how long ARVs can prolong people’s lives.) Progress on this front has been sluggish. By mid-2005, according to WHO estimates, between 97 000 and 138 000 persons were being treated with antiretrovirals in South Africa (10-14% coverage)
The irony is that South Africa historically has offered little basis for such an aspiration. The school system currently does not add much to the upward mobility of the poor in the labour market (Altman, 2005). However, the binary perspective that equates unemployment with poverty and employment with relative well-being matches reality less and less, even if it continues to underpin the jobs ‘debate’ (Barchiesi, 2004). The majority of wage-earners in South Africa are low-skilled and low-paid. Their wages are vital, but they’re earned on such insecure terms and so often without attendant benefits that earning a wage does not, in itself, guarantee a relatively secure livelihood or serve as a barrier against privation when misfortune strikes. Of the 11.9 million workers officially classified as employed, almost 18% (2.1 million people) work in the informal sector, just over 7% (850 000 people) are domestic workers, and more than 4% (514 000) are engaged in small-scale subsistence farming – insecure, low-paying work typically lacking in benefits and rights protection. Among domestic workers, 43% earn less than R1 000 a month (Statistics SA, 2005a). Among Africans, the official unemployment rate was 31.6%, compared with 5.1% among whites; 37.6% of African women were jobless. When workers who have given up on looking for jobs are tallied, the unemployment rate reaches 40.5%: 8.1 million people (Statistics SA, 2005a). For most of the employed, not having a job is not a temporary circumstance: almost three quarters of the unemployed had never had a job, and among those who had been employed previously, 41% had been jobless for three or more years, according to the 1999 October Household Survey. The fact that 34% of the unemployed (official definition) have completed high school suggests that the school system currently does not add much to the upward mobility of the poor in the labour market either (Statistics SA, 2005a; Van der Berg, 2002). All that is solid, melts into air

Access to paid employment is among the most important factors affecting the poverty status of households; joblessness accounts to a large degree for the extent of impoverishment in South Africa. The official (narrow) unemployment rate was 26.5% in March 2005, down slightly from 27.9% in March 2004, according to the March 2005 Labour Force Survey. Among Africans, the official unemployment rate was 31.6%, compared with 5.1% among whites; 37.6% of African women were jobless. When workers who have given up on looking for jobs are tallied, the unemployment rate reaches 40.5%: 8.1 million people (Statistics SA, 2005a). For most of the employed, not having a job is not a temporary circumstance: almost three quarters of the unemployed had never had a job, and among those who had been employed previously, 41% had been jobless for three or more years, according to the 1999 October Household Survey. The fact that 34% of the unemployed (official definition) have completed high school suggests that the school system currently does not add much to the upward mobility of the poor in the labour market either (Statistics SA, 2005a; Van der Berg, 2002). However, the binary perspective that equates unemployment with poverty and employment with relative well-being matches reality less and less, even if it continues to underpin the jobs ‘debate’ (Barchiesi, 2004). The majority of wage-earners in South Africa are low-skilled and low-paid. Their wages are vital, but they’re earned on such insecure terms and so often without attendant benefits that earning a wage does not, in itself, guarantee a relatively secure livelihood or serve as a barrier against privation when misfortune strikes. Of the 11.9 million workers officially classified as employed, almost 18% (2.1 million people) work in the informal sector, just over 7% (850 000 people) are domestic workers, and more than 4% (514 000) are engaged in small-scale subsistence farming – insecure, low-paying work typically lacking in benefits and rights protection. Among domestic workers, 43% earn less than R1 000 a month (US$77), as do 33% of workers employed in the informal sector. Approximately two thirds of workers with jobs are employed in the formal sector (7.8 million). Almost one in five of those workers (18%) earn less than R1 000 a month (Statistics SA, 2005a). Between 1995 and 2002 real wages were stagnant or they declined (depending on the skills level), which translates into a welfare loss for poor households (Altman, 2005).

38 This is an area where women do appear to be gaining greater benefit than men: statistics from Free State and KwaZulu-Natal provinces show approximately two thirds of people receiving antiretrovirals through the public health system were women. The figures are line with general under-utilization of health services by men (Ijumba & Barron, 2005).

39 The official (narrow) definition unemployment refers only to those economically active persons who sought employment in the four weeks prior to the survey. The expanded definition includes economically active persons who are deemed to have been discouraged from seeking work. Note that informal sector employment estimates in the Labour Force Survey (LFS) tend to be higher than those in the October Household Survey. As Charles Simkins (2004) has pointed out, ‘the LFS criterion for counting as employed is very lenient: just one hour of work in the past week, which can be spent on a range of non-market activities as well as work for pay or family businesses’.

40 As with AIDS, so with unemployment. In May 2005 President Mbeki questioned the official joblessness statistics, saying they would imply ‘at least four million South Africans walking about in our villages, our towns and cities’. Earlier, Finance Minister Trevor Manuel had chimed in with similar reservations: ‘if you look at the surge in expenditure (on consumer durables or the white goods sector and take that as a proxy for a series of things ... I think the story that comes out is that this is not a country with unemployment at 32% or 40%’. Trevor Manuel quoted in Paul Stober. ‘SA’s four-letter word: JOBS. Employment isn’t what it used to be’. Sunday Times. 12 December 2004.

41 The irony is that South Africa historically has offered little basis for such a viewpoint; until the ascendancy of the trades union movement from the early 1980s onward, wage incomes and benefits provided a paltry barrier against impoverishment.
While official discourse prefers to treat employment creation as a ‘down-stream’ effect of economic growth, critical discourse tends to regard poverty reduction and improvement in livelihoods largely as functions of formal-sector employment. Both, in a sense, fetishize formal-sector employment, even though it has become increasingly insecure, wage- and benefit-poor, and less easily distinguishable from informal-sector employment. It’s not that job creation is not desperately needed – it is – nor that joblessness doesn’t constitute a national crisis – it does. But given the surfeit of working poor, the porous division between formal and informal employment, and the resolute grab-back of workers’ benefits by employers, a job often does not ensure the rudiments of well-being – a secure living income, affordable access to essential services and insurance, food security, etc. As the AIDS epidemic peaks, our perspective needs to broaden to take in the entirety of the challenge. The jobs ‘debate’ has become something of a proxy for what should be a debate about social rights and about the various ways of realizing them in a society in which millions are impoverished in the midst of abundance.

**Breaking the fall – social transfers**

Generous compared with many other countries of the South, South Africa’s state social security net rests on the assumption that able-bodied adults can earn a living through wage labour (Nattrass, 2004). State assistance therefore is available mainly to those who cannot be expected to fend for themselves – disabled persons, the elderly and children. Imbedded in the system, in other words, is a double fiction: the idea that employment is available to those who seek it, and the notion that wage incomes guarantee well-being.

Poor households rely heavily on social transfers – all the more so those affected by health crises, according to a Free State study (Booysen & Bachmann, 2002). Almost three quarters of households with an HIV-infected member were receiving government grants, compared with under a half of those without an HIV-infected member, according to one pilot study in Soweto (Naidu, 2003). Overall, by the end of 2004, approximately eight million South Africans were receiving some form of social assistance (up from 2.6 million in 1994, according to government figures), a number that could exceed 10 million once eligibility for the child support grant is extended from 11 to 14 years (Government of South Africa, 2005).

Welfare spending in 2005 absorbed 14% of non-interest budget expenditure, and more than 3% of gross domestic product. According to the Finance Ministry, continued expansion is fiscally unsustainable; grant provision and take-up would need to slow down again and track population growth.

Four types of social transfers can have a direct bearing on the destinies of poor households in general and on the recovery prospects of those affected by shocks such as AIDS: the old-age pension, foster care grant, child support grant, and the disability grant.

The old-age pension often serves as a lifeline for entire households. Frequently described as a poverty alleviation tool, the pension (worth R780 per month) enables many households which otherwise might have sunk into destitution to remain afloat – as long as the recipient is alive. About 2 million pensioners were receiving the pension in early 2005. Yet, significant numbers of the poorest South Africans live in households without any access to pensions; it is the relatively better-off among the poor who are most likely to be receiving pensions (Leibbrandt, Bhorat & Woolard, 1998; Sender, 2000). The challenge is to consolidate and extend the kinds of benefits this grant provides, bearing in mind the main trends that have to be contended.

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43 Remittances were also found to be a more common source of income in households affected by AIDS, compared with those not affected, in the Free State and the Soweto studies (Booysen et al., 2002; Naidu, 2003).

44 Since its introduction in 1998, child support grant eligibility criteria have been steadily broadened; the initial cut-off age of seven years was first extended to 11 years, then to 14 years (in 2005). The latter extension entails an additional R9.8 billion expenditure – or, to put it in perspective, two thirds as much as the R15 billion in tax cuts the Finance Ministry announced in 2003 (Idasa, 2003). The number of beneficiaries of the disability and foster care grants have doubled since 2001 – from 700 000 to 1.4 million.
with. Firstly, the numbers of South African living in poverty are not decreasing; in some places, including some cities, they are increasing. Secondly, rising numbers of old persons are taking on care, fostering and child-rearing duties. Thirdly, far more women than men are assuming these roles. Fourthly, as the AIDS epidemic approaches its most intense phase, the elderly will lose more of the financial and other support younger relatives used to provide. The need for the old-age pension is growing, not diminishing. Given the overall dearth of income-earning opportunities for women, and the burdens they bear, lowering the eligibility age for women to 55 years should be considered (Legido-Quigley, 2003). There is a hitch, though. A disproportionate reliance on the pension could backfire because of the demographic distortions that are being generated. Over the next 20-30 years, proportionally fewer households in need will be benefiting from pensions – because proportionally fewer adults will be reaching pension age. Clearly, while the epidemic lasts, welfare needs will keep growing.

What about the other grant instruments?

In early 2005, about 5.5 million children were benefiting from the child support grant. However, its potential benefit is diminished by its size (at R180 a month, it hardly approaches minimum child-care costs) and by its premature cut-off point. Eligibility ends when a child reaches 11 years, though this was due to be extended to 14 years in 2005. Still, terminating grant eligibility at the point when schooling and other expenses burgeon defies all but fiscal reasoning.

About 200 000 people were receiving the foster care grant in mid-2004, more than double the number two years earlier. That trend looks set to continue for the next decade at least, as the orphan crisis worsens. Already social workers are being swamped by the volume of applications and cases crossing their desks, which often prevents them from performing other key tasks (such as monitoring the well-being of children placed in foster care and probing cases of alleged abuse). With AIDS sapping administrative capacity in the public sector and simultaneously increasing the need for foster care, the management of this grant – and of child protection services in general – will come under extreme strain. Meanwhile, many eligible households are either unaware of this grant or encounter huge difficulties in accessing it. In northern KwaZulu-Natal, for example, fewer than 10% of double orphans were benefiting from any sort of social grant, and just 2% were benefiting from a foster-care grant, according to Case et al. (2005). The grant (which is available until an orphan reaches 18 years of age) can be accessed only if the child has been placed in the care of foster parents by the children’s court after a cumbersome and protracted process. Acquiring the requisite documentation is a routine problem for applicants. Persistent grumbling from officialdom about ‘welfare fraud’ probably means those requirements will be tightened rather than relaxed.

The grant is entangled in a bigger conundrum, though. Worth three times as much as the child support grant (R530 per month), the foster care grant is being used by social workers to assist poor households that care for orphans. Its original role – protecting children in distress – is being eclipsed by this broader welfare function. Demand and eligibility for the grant will keep increasing, but the laborious procedures it entails will limit the number of beneficiaries and quickly overload capacity. A significant share of welfare resources is being funneled into a grant channel which can benefit a very limited number of children (Meintjies et al., 2003; Desmond & Gow, 2002). It is not an efficient social security mechanism. Meanwhile, neglect and abuse of children (including orphans) are widespread enough to demand a child protection system, a role the grant no longer performs effectively (Meintjies et al., 2003).

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45 Take-up rates can improve further, though. A significant proportion of needy and eligible children have not been benefiting from this grant: by one estimate, between 28% and 39% of poor children younger than nine years were not accessing the grant in 2003 (Foster, 2004). Part of the problem lies with the documentation requirements, which include the birth certificate of the child and the care-givers’ bar-coded ID docu-ment. Ignorance about the availability of the grant seems widespread, too (Desmond & Gow, 2002).
46 Recall that the foster care grant was designed specifically to aid those orphans who are bereft of any support, or are subject to abuse and constant neglect - hence the intensive screening and the legalistic placement process.
47 Financial grants can serve as powerful incentives for the fostering of orphans. However, they can also lead to situations where applicants provide minimal, nominal care for orphans in order to access financial support that can be used to sustain families that are already in distress; see Loening-Voysey H (2002). HIV/AIDS in South Africa: Caring for Vulnerable Children. African Journal of AIDS Research, 1, cited in Stein (2003).
There are ways around this logjam. One option would be to release the foster care grant from its happenstance poverty relief function, and revert to its original, specialized task of protecting children in distress. This could be achieved by equalizing the amounts of the child support and foster care grants (thus reducing the incentive to opt for the latter over the former), and by boosting the ranks of social workers and improving their resources (Idasa, 2003). Another option would be to shift away from targeting orphans and instead adopt a universalist approach that can benefit all children in need. This would entail providing a child support grant to all children and dropping the current means test—a variant, in other words, of the Basic Income Grant proposal (see below) (Meintjies et al., 2003). The goal would be to provide some form of social security to many more South African children, vast numbers of who live in dire circumstances. The overriding ethic would be one of universalism and equity.

Meanwhile, demand for the disability grant (worth a maximum R780 a month) has ballooned to such an extent that the Treasury has voiced concerns about its fiscal implications. Strictly speaking, the grant is available to ‘severely physically and mentally disabled persons’ between the ages 18 and 65 years. The estimated number of South Africans meeting the varying criteria rose to 1.28 million by mid-2004 (up from 954 000 in 2003, and double the 627 000 in 2001).48 AIDS is responsible for a significant part of that trend, though not all.49 There are no AIDS-specific eligibility criteria for the grant, but some provinces, including the Western Cape, have set a CD4 count of under 200 as the threshold, while others opt for a diagnosis of Clinical Stages 3 or 4. In the meantime, many AIDS-sick beneficiaries are encountering an odious dilemma (Nattrass, 2004). Those who opt for and receive ARV treatment are likely to see their CD4 counts rise beyond the 200 mark, thus rendering them ineligible for this grant once their eligibility status is reviewed. Yet, it is the grant that often enables them to afford the treatment (and better nutrition), and that helps sustain their households.50 One survey in Khayelitsha, Cape Town, found that disability grants contributed 40-50% of total income in those households receiving the grant (Nattrass, 2004). There is a fear that some people might opt to discontinue ARV treatment in order to retain their disability grants—exercising a literal, pitiless choice between ‘the money or your life’.51 Besides compromising health, this would also boost the chances that drug-resistant HIV strains could become prevalent enough to undermine the ARV treatment programme.

However, as Nattrass (2004) has highlighted, a moral conundrum arises if HIV-positive persons are allowed to retain their disability grants after their health has been restored by antiretroviral therapy. In essence, HIV status then functions as a criterion for access to financial support, with equally needy but HIV-negative persons (without other disabilities) not qualifying for the grant. The conundrum can be solved, Nattrass argues, by introducing a universal social assistance instrument, such as the Basic Income Grant (BIG), a device championed by trade unions, church organizations and much of the NGO sector for several years already. Such a grant would be worth approximately R100-R200 and would be available to all.52 Although spread thinner, its benefit would extend far wider than, for instance, the expanded public works programme, which is expected to create an estimated 200 000 temporary jobs (8 million South Africans are out of work). Although the government remains opposed to a BIG, the case for such an intervention has not diminished. Financial simulations indicate that even a modest BIG of R100 per month for all South Africans could contribute

48 Amid endemic poverty, proponents argue, targeting orphans is neither equitable nor cost-efficient: it misdirects scarce and vital resources, risks scuttling the child protection system, and is based on dubious understandings of children’s circumstances. Extending the child support grant to all children up to the age of 18 years would enable the removal of grants targeted at specific categories of children: a blanketing approach would spread the benefits widely enough to help reinvigorate various neighbourhood and community support networks (Meintjies et al., 2003).
49 Nattrass (2004) implies that the sharp 2002-2003 increase might be anomalous, and notes three other, possible contributing factors besides AIDS. Eligibility appears to have been more leniently assessed in the Northern and Eastern Cape provinces, a court order forced the government to reinstate temporary grants that had been cancelled without following all procedures, and fraud allegedly swelled the number of recipients (2004:9). However, between 2003 and 2004 a further 300 000 recipients were added, suggesting a continuing, steep trend.
50 Bear in mind that treatment involves numerous costs besides the drugs themselves—transport, income lost when seeking health care, consultancy fees, etc.
51 Once ineligibility halts access to the grant, and the person’s failing health again drives his or her CD4 count below 200, it can take six or more months before grant payments resume—a delay that could spell life or death.
52 Disabled persons could receive the BIG plus a slightly reduced disability grant of, say, R650, Nattrass suggests.
substantially to reducing poverty and inequality in South Africa.\textsuperscript{53} The likely costs and various financing formulas will continue to enervate and frustrate,\textsuperscript{54} but the debate, as Nattrass (2004: 18) reminds ‘ultimately boils down to whether reasonable people can tolerate living in a society that forces people living with AIDS to choose between income and health’.

Even in their current guise, state grants not only reduce poverty but have a variety of other developmental effects (EPRI, 2004). There is evidence that poor children, especially girls, are more likely to attend school if they are living in households that receive social grants, for example. (The old-age pension has proved especially effective on this front, possibly because women outnumber men as recipients and seem more likely to prioritize children’s education.) In such households, a larger share of expenditure also tends to go towards food (EPRI, 2004). More broadly, grants tend to function as minor demand-side catalysts in the food, clothing and personal care sectors of the economy (which also tend to be more labour-intensive and have higher local content).

The poverty-reducing effect of the old-age pension, though, is probably almost exhausted – mainly because take-up is already high (upward of 85%). Only a larger amount would significantly boost that effect. A 50% increase in take-up of the disability grant could, by one calculation, reduce the total rand poverty gap by almost 2%, while full take-up would narrow that gap by more than 5%.\textsuperscript{55} But it’s the child support grant that appears to have the strongest effect. Extending the eligibility age to 14 years (planned for 2005) could reduce the poverty gap by more than 16%. If calls for a further extension to 18 years are heeded, the gap would be reduced by 21%. The combined effect of the child support grant (with a cut-off age 14 years), and full take-up of the old-age pension and of the disability grant would be to reduce the poverty gap by 29%, according to EPRI, which notes that:

South Africa’s system of social security substantially reduces deprivation, and the progressive extension of the magnitude, scope and reach of social grants holds the potential to dramatically diminish the prevalence of poverty in South Africa (EPRI, 2004:2).

\textbf{Blaming the victim}

Allegations of welfare fraud have become a recurring refrain and are likely to remain so as the Treasury tries to limit social welfare expenditures. A national social security agency is to be established (supplanting the provinces’ responsibility for transfers) as part of a bid to introduce ‘tighter controls’, and more restrictive eligibility criteria are almost certain to follow. Fraud is doubtless part of the social transfers landscape, though it’s unclear how many fraudulent applications are impelled by sheer desperation.\textsuperscript{56} For example, according to a 2003 study by the Planned Parenthood Association of South Africa, one in ten teenagers who become pregnant do so in an effort to access a child support grant (worth R180 a month).\textsuperscript{57} The heartless might interpret that as a form of ‘welfare fraud’; most, though, will recognize in it the stamp of desperation.

The ‘welfare cheat’ refrain, though, reflects more than a quest for probity. It’s part of a perspective that regards social grants as welfarist gestures which, while necessary within limits, risk fuelling an ‘entitlement’ culture that ‘crowds out’ education and health spending, threatens fiscal rectitude and can destabilize the labour market\textsuperscript{54}, thus undermining economic growth.\textsuperscript{55}

\textsuperscript{53} Finance Minister Trevor Manuel in late 2004 told members of the national Council of Provinces that introducing BIG would ‘bankrupt the country’. Manuel claimed BIG would cost the fiscus R83 billion (US$14 billion). BIG advocates, on the other hand, claim the scheme would cost between R24 billion (US$4 billion) and R40 billion (US$6.6 billion), depending on how some of the costs were recuperated through the tax system. (By way of comparison, in late 2005 plans were afoot to construct a controversial new rail link – the Gautrain – between Johannesburg International Airport, Johannesburg, Sandton and Pretoria, at an estimated cost of R20 billion; see Linda Enor. ‘High-risk Gautrain could be white elephant’. Business Day, 10 November 2005.) Shortly after Manuel’s comments, Archbishop Desmond Tutu was quoted as remarking that people should not allow themselves to be ‘ browbeaten by pontificating decrees from on high’ and that ‘we cannot glily on full stomachs speak about “handouts”’ to those who often go to bed hungry’. See ‘South Africa: Debate rages over proposed basic income grant’. UN Integrated Regional Information Networks (IRIN). 23 November 2004

\textsuperscript{54} By discouraging grant beneficiaries from entering the labour force. This concern has been leveled even against the old-age pension. The claims that social transfers distort the labour market (by discouraging participation) and thereby act as brake on economic growth are not supported by recent research; see, for example, EPRI (2004) and Nattrass (2004). However, some grants do appear to have some adverse labour market effects, chiefly among the less poor, although EPRI claims these ‘stem from distortions on the social security targeting mechanisms [...]. A more comprehensive system of social security provides fewer opportunities for distortions to be generated by the incentive effects created by the social grants’ (2004:19).

\textsuperscript{55} Hence the mutterings that ‘government now needs to stem the damage caused by ballooning social grants’ (emphasis added); see Carol Paton. ‘Social welfare spending: no end in sight.’ Financial Mail. 25 February 2005.
Grants are seen to be justified principally for the elderly, vulnerable children and the disabled; the rest of the population in theory should be able to fend for itself. For salvation, this perspective looks toward increased employment opportunities (as a by-product of economic growth) and a surge in small-scale entrepreneurial activities.

The mirage of microfinance

Touted for their alleged poverty-alleviating potential, microfinance schemes have been gaining favour also as tools for cushioning the AIDS epidemic’s impact and helping households recover. Microfinance has boomed in South Africa over the past 10 years, so much so that the number of positively indebted households more than doubled between 1995 and 2000 (Daniels, 2003). Even in rural areas, development orthodoxy emphasizes the growth of smallholder agriculture and self-employment in rural micro-enterprises as a feasible exit route from poverty (Sender, 2000). Proponents argue that these schemes are easily adapted to reach women (who often are excluded from credit systems), that they can benefit people and operate in areas that are bypassed by the formal banking system, and that they can be adapted easily to specific circumstances. Schemes can also be slotted into wider, multifaceted development initiatives that transcend credit provision and extend the benefits. Recent innovations include the provision of death insurance for terminally ill patients, flexible saving arrangements, emergency loans and special efforts to attract female clients.

In settings with chronically high unemployment, limited income-earning opportunities, and pervasive ill health and early death it might seem churlish to question the optimism surrounding microfinance. Yet a tacit but fundamental premise of microfinance is that the viability of poor households depends on their becoming (greater) consumers of credit. It is unclear how deeper indebtedness is meant to boost and safeguard economic security when households are losing caregivers and workers, and when surviving members (typically widows and the elderly) often are stretched to the limit, with little time for novel income-generating ventures. In a sense, microfinance schemes distill neoliberal ideology quite pithily, by presenting a household-level analogy of international finance institution emergency loans – with deeper integration into the market economy and adherence to its strictures as the conditions for relief (Baylies, 2002).

The jury is out on the benefits the very poor derive from such schemes (Baylies, 2002; Mosley & Hume, 1998; Sender, 2000). According to a USAID study of microcredit schemes in Zimbabwe, India and Peru, the programmes did help very poor households meet basic needs and protect themselves against risks. However, household incomes didn’t rise in Zimbabwe, and income sources didn’t diversify in India, nor did food consumption improve there. The assessment also found ‘limited impact on the ability to cope after [financial] shocks had occurred’ (Snodgrass & Sebstad, 2002). Research on Uganda’s Women’s Finance Trust found that microfinance projects were not reaching the poorest of the poor (Wright et al., 1999, cited in Hoang, 2002). Generally, the very poor appear not to invest the funds in small enterprises, but rather spend them on essential expenses (especially food) or use them to settle other, overdue debts; their extremely limited resource base tends to discourage ‘risk-taking’. In such cases, the credit can tide a household over, but since it’s not necessarily income-generating it adds to their overall debt load and becomes an additional encumbrance. Needless to say, in such cases poverty reduction is not the outcome: research in India and Malawi has found that extremely poor borrowers ended up worse off financially.

56 This veritable cult of small enterprise has flourished also in industrialized countries, despite survey evidence from OECD countries that ‘the predominant trend in self-employment is downward’ and that ‘increases in the proportion of self-employment appear to produce lower not higher GDP’ (Blanchflower, 2000:12, 22; cited in Sender, 2000).
57 The latter is an especially sage approach, given the evidence that women are more likely to devote additional income to meeting their children’s needs (Hunter & Williamson, 1998, cited in Mutangadura, 2000). Households benefiting from Uganda’s Women’s Finance Trust, for example, were found to spend more money on health and education than other households. (Wright et al., 1999, cited in Hoang, 2002). 
58 In the fashionable theoretical framework, as John Sender has observed, the rural poor are seen as self-employed ‘agents’ struggling in imperfect markets; what they need, it’s claimed, are more ‘assets’, purchased through access to micro-credit, to ‘smooth their transition into the ranks of the petty bourgeoisie’ (Sender, 2000:38).
Microfinance would seem appropriate and potentially effective only when productive capacity exists and access to markets is available – conditions that cannot be assumed – and seems most appropriate for supporting existing economic activities rather than starting up new ones (McNelly & Dunford, 1996). But in many parts of South Africa, those capacities and traditions are frail. De Swardt’s (2003) study of poor households in rural areas of the Eastern and Western Cape and in Cape Town, for example, highlighted the marginal value of self-employment as a source of income. In Mount Frere, Ceres and Langa, wage labour was by far the major source of household income, followed by social grants. Similar to Sender’s (2000) findings in Mpumalanga, in Mount Frere there was an evident failure of land-based livelihood strategies and subsistence agriculture, with food purchases comprising the bulk of monthly expenses. In periods and places with extraordinarily high levels of morbidity and mortality, the usefulness of microcredit is open to further question. In a heavily affected poor community, participation in such a scheme involves taking on additional debt at the same time as disposable income shrinks further and competition intensifies in that community. Often these income-generating schemes also lack distribution and marketing support – one of the reasons why craft schemes, a staple in many impoverished communities targeted with donor largesse, tend to bring scant and fleeting financial benefit to households. Emergency relief, possibly in the form of expanded access to social grants, or start-up grants would seem more suitable and potentially beneficial (Baylies, 2002; Hoang, 2002). Sender’s (2000) research among poor women in rural Mpumalanga suggests that where people rely heavily on insecure waged incomes, steps to extend and protect the labour rights of casual and seasonal works would be more appropriate.61

Epilogue: Fragmentation, introversion, erasure

The South African struggle for liberation was a struggle against the banishment of millions into penury and sickness, against polarization and exclusion – and for a just society. It’s on this template of ideals and aspirations – and rights – that the effects of the epidemic must be mapped and examined. That AIDS mangles and ruins is clear. But when it does so in a society with South Africa’s characteristics, these miseries are not distributed indiscriminately. The glacial crush of the epidemic exaggerates the social relations that constitute society. In that, AIDS unmasks the world we live in and reiterates the need to transform it. In South Africa, it specifically underscores the need for an encompassing social package as part of an overarching programme of redistribution and rights-realization. Such a package would rest on several pillars, including job creation and workers’ rights protection, safeguarded food security, and the affordable (and decommodied) provision of essential services. Other pillars would include pensions and other social transfers which are administered efficiently and set at levels that correspond to unfolding needs. In all this, the principle of universalism should hold sway.62

60 Of the six main monthly expenses in Mount Frere, food comprised 44%, education 13% and health 11%. More than 80% of the households said they had had too little food available in the previous year. Education and health fees were also major expense items, testament to the extent to which cost-recovery-based state service provision was squeezing impoverished households (De Swardt, 2003).

61 Part of the problem lies with vague and slack use of the concept ‘poverty’, and with the tendency to ignore differentiation within communities and households classified as ‘poor’. As a consequence, projects intended to assist the most vulnerable households can end up being cornered by households that are relatively better off, as Sender (2000) found in Mpumalanga. Off the agenda, meanwhile, are measures to protect seasonal agricultural labourers, migrant domestic servants and other hyper-exploited categories of workers.

62 Exempting the poor (through means testing) can bring advantages if it allows poor households access to essential services. The problem is that, in general, policies that exempt only certain categories of users from fees tend to improve access for the poor only marginally. Using free health-care services, for example, still can still entail transport costs and income losses that might discourage the poor from seeking care; see Goudge & Govender (2000). Targeting also carries a danger of further polarizing society by promoting dual structures and systems for social services – some funded by the state and aimed at the poor, the others provided chiefly by the private sector. It serves as another nail in the coffin of universalism, of an inclusive society. Targeting AIDS-affected households with specific social packages introduces additional hitches, some of them potentially harmful. Providing food and/or nutritional supplements to AIDS-sick patients (or to households with AIDS-sick members) seems, at face value, an attractive course of action. But problems abound, not least the conditionality of AIDS illness that’s applied. For one, the exceptional status this accords to AIDS is discriminatory and is likely to trigger any number of perverse effects (including further stigmatizing AIDS-affected households). More obviously, the death of the AIDS-sick member of the household might discontinue its eligibility for food and nutritional support but not its need for that support. Such a conundrum has been observed in Zambia, for example; see Bond V, Tihon V, Muchimba M (1999). ‘Food givers or care givers? The distribution of food to TB patients by home-based care programmes in Lusaka.’ ICASA Abstract book 13BT4-3, cited in Baylies (2002).
On current trends, however, the epidemic will exacerbate inequality, worsen impoverishment, and further corrode the prospects of a better life. In its wake we can expect intensified polarization, with privilege no longer guaranteeing mere comfort and indulgence, but buying life itself and cornering the future. The very poor, the 10 million or more people who earn less than 5% of total income, will have to contend with compromised services and with the fraying of those bonds and circuits of obligation and reciprocity that should help stave off destitution.

Like many scourges, the Plague included, AIDS pits the living against the dead, and the healthy against the sick (Herlihy, 1997). That AIDS-related stigma does so in ways that diminish and wound others is not unusual, neither is the enthusiasm with which men direct it at women; what is atypical is the ferocity with which it is aimed at loved ones, kin and friends. A distillation of everyday obsessions – about trust, desire, betrayal, contamination, sex, death – stigma also derives its energy from the ‘invisibility’ of HIV and the license it provides for suspicion and judgment, in other words for self-definition. Stigma is a binary instrument; it’s used to draw distinctions and establish boundaries. It includes and excludes, validates and condemns, affirms and obliterates. Wounding as AIDS-related stigma can be, it’s hardly an aberration; it’s a grotesque example of the devices we use to traverse the social terrain, to situate ourselves within society, to assign or remove status, to build bonds and assemble affinities. To pretend that AIDS-related stigma somehow can be neatly excised from this social functionality is to misunderstand how deeply it is in the arrangement and exercise of social power.

There is a hope such extraordinary tribulation might spur new social arrangements, and new forms of popular organization and activism. This is possible. But the current trends are not cheering. These point to petrifying arrangements and possibly even a kind of social contraction, as the capacities of the poor to extend generosity diminish and the reciprocal arrangements that sustain social life wane further (De Waal, 2003a). Responsibilities and entitlements, it seems, are not being reallocated more equitably in households and communities; social roles seem to be ossifying, instead of growing more pliant. Rather than trigger a ‘re-imagining’ of ‘womanhood’ and ‘manhood’, AIDS is cementing the schizoid typology of women as angels of mercy and/or sullied whores. It is women who are accused of ‘bringing the disease’ into homes, girls who are subjected to ‘virginity testing’, and women who tend the sick and the frail and the survivors. Men seem to hover along the fringes of this drama, leaving women ubiquitous yet trapped between blame and the praise they earn for the forbearance shown within the confines of domestic space and duty. AIDS lays bare the coercive subtext nestled in the notion of ‘mothers of the nation’. Collectively assigned the duty of care, nurture and salvation, women oblige with stoicism and courage but at the cost of an obliterated individual autonomy. The home-based care model, so flimsily supported at present, codifies this exploitation of women’s labour, financial and emotional reserves. Women’s organizations, oddly, have avoided tackling this convergence of vulnerability and exploitation (Albertyn & Hassim, 2003).

A similar process of ‘erasure’ occurs among children who endure systematic deprivation, trauma and stigmatization. The tendency of traumatized children is less to ‘explode’ their hurt than to invert it, and to collapse into themselves, into a private twilight that might offer some solace (Richter, 2004; Stein, 2003). People at the mercy of pain live at the extreme limits of that experience. The necessary aversion to the phrase ‘AIDS sufferers’ cannot undo the reality that unthinkable numbers of people do suffer horribly, and in ways that almost literally remove them, living from the world. Their pain, as Elaine Scarry has written (1985), erases the world and them in it:

What from the inside is experienced as an increasingly insubstantial world may look from the outside as though the world is intact but the person is growing insubstantial, and so the experience is often represented as solid world ground on which the person no longer has a place [...] As one’s world is obliterated, one’s externalized self and therefore one’s visibility is obliterated.***

Polarization, implosion, erasure and the dismantling of the social – all this forms the undertow of the epidemic, its secret thrust. At the core of this unfolding horror is the prospect that an epidemic this intense, layered atop a reality this unjust, imprisons vast numbers of us in a kind of eternal present, unmaking the ability and perhaps even the desire to imagine a different, better world.
Chapter endnotes


vii Ibid

viii For these and other differences between the ING Barings, Arndt & Lewis, and BER scenarios, see Nattrass (2000:7-12).

ix Arndt & Lewis (2000:857) admit as much, saying that ‘the parameters used in specifying the various AIDS effects are based on fairly limited empirical evidence ...’


xvi Based on Everatt’s analysis of data from the 1996 and 1999 October Household Surveys, and from Transforming the Present (Committee of Inquiry into a comprehensive system of social security for South Africa (2002).


xviii See ‘Labour market may be showing signs of stability’. Sapa. 29 September 2004.

xix See Table A7 (Statistics SA, 2005a).

xx See Table 3.5 (Statistics SA, 2005a).


xxv For a detailed exposition of the methodology used to arrive at these figures, see EPRI (2004:7).

xxvi Eastern Cape and KwaZulu-Natal provinces are regarded as the worst offenders. According to one report, a forensic audit found that 90% of disability grant applications on KwaZulu-Natal’s south coast were ‘fraudulent’. See Carol Paton, ‘Social welfare spending: no end in sight.’ Financial Mail. 25 February 2005.


xxix For a detailed exposition of the methodology used to arrive at these figures, see EPRI (2004:7).

xxx See Table 3.5 (Statistics SA, 2005a).


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Centre for the Study of AIDS

The Centre for the Study of AIDS (CSA) is located at the University of Pretoria. It is a 'stand alone' centre which is responsible for the development and co-ordination of a comprehensive University-wide response to AIDS. The Centre operates in collaboration with the Deans of all Faculties and through Inter-faculty committees to ensure that a professional understanding of the epidemic is developed through curriculum innovation as well as through extensive research.

Support for students and staff is provided through peer-based education and counselling, through support groups and through training in HIV/AIDS in the workplace. A large number of student volunteers are involved in the programme, as are many community groups, ASOs and NGOs.

To create a climate of debate and critique, the Centre publishes widely and hosts AIDS Forums and seminars. It has created web- and email-based debate and discussion forums and seeks to find new, innovative, creative and effective ways to address HIV/AIDS in South African society.