

# Rhetoric to action



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**HIV/AIDS in South Africa**  
a guide for donors and grant-makers

August 2003

## Sector Report

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# Rhetoric to action

August 2003

**Sector: Health and disability**

**Sub-sector: AIDS (South Africa)**

## Executive summary

*"The challenge is to move from rhetoric to action, and action at an unprecedented intensity and scale. There is a need for us to focus on what we know works."*

- Nelson Mandela

- **This report provides a guide to grant-makers and donors seeking to understand and address the problem of HIV/AIDS in South Africa.** Its research shows how well-placed philanthropy can literally make a life-saving difference. The scale of the problem should not deter private funds: current and promised future funding from international governments, though apparently large, will take some years to be disbursed and is actually inadequate to meet the crisis.
- **The statistics on the AIDS pandemic are horrifying. South Africa has more people with HIV or full-blown AIDS than any other country in the world.** Almost five million people, over 11% of the population, are HIV positive. There are already more than half a million orphans and projections show the number rising to one million by 2005. Prevalence is concentrated among certain groups and there is evidence of South African society being "hollowed out" by the disease, affecting the education system, health services, communities, families and children. The effects on individuals, infected and affected, are appalling.
- **The South African government is considering action through a national antiretroviral treatment programme,** but the details of this remain unclear and it will not solve the enormous problems over any reasonable timescale. Meanwhile, people are dying and grass roots organisations have received little benefit.
- **The social and clinical life cycle of the virus can be intercepted at various points.** Initiatives to prevent HIV spreading further, treatment and care for those infected, care for families bereaved and children orphaned all make an invaluable contribution to the war on HIV/AIDS. Often interventions tackling one aspect can assist with other issues at the same time: those caring for infected people can help to educate communities as well as assisting those left behind.
- **Funders have a range of options.** There are antiretroviral drug treatments; there are simple, inexpensive and community based techniques to help people with AIDS in rural areas as well as townships; there are organisations concerned with the welfare of children affected by the pandemic; other projects focus on prevention and education.
- **NPC assesses the outcomes of each intervention for the immediate individual and for those connected with that individual.** This has implications for our cost analysis: avoided infections save the lives of future partners; antiretroviral drug therapy arrests orphanhood; registration of orphans leverages government funding.
- **The research in this report is based on a survey of the subject together with examination of organisations working on the ground.** A separate series of detailed reports on some of the individual organisations is available to grant-makers and donors.
- **NPC seeks to encourage higher levels of funding for outstanding projects;** we help donors to develop their grant-making strategies and propose specific grant-making recommendations through presentations to donors.



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# Introduction

## The purpose of this report

This report aims to provide a guide for donors who wish to fund projects to help those affected by HIV/AIDS in South Africa. Its purpose is to provide the detailed contextual information and analysis required to understand the extent of the pandemic, resulting social needs, types of response in operation, and the outcomes generated by such interventions.

The donors to whom this report is addressed will range from private individuals to grant-makers with extensive experience in this area. While the report aims to help all in this spectrum, it should be recognised that parts of the report have been written for the benefit of newcomers to the subject. When we refer to "donors" we include grant-makers, private individuals, companies or anyone else wishing to donate funds or provide grants.

Funding this complex and rapidly changing issue, at considerable geographical distance from the donor, can be far from straightforward. Few foundations or private individuals are in a position to dedicate in-country resources to support their grant-making.

This guide puts the case for combating the effects of the pandemic, analyses the delivery mechanisms, and advises on how donors can target their resources most effectively. A supplementary report takes this process a step further, by making specific project recommendations. NPC is in a position to help with grant-making to these recommended projects.

## The content of this report

The report is based on research carried out through extensive meetings with organisations, researchers, policy makers, analyses of charity accounts and activities and reading of research materials. Two visits to South Africa formed an integral part of the research. In South Africa many projects were visited in the field and meetings were held with experts, project workers and beneficiaries.

There is an enormous need for organisations and individuals to tackle HIV/AIDS in South Africa, as the crisis far exceeds the reach of organisations active on the ground. However, it would be impossible to cover all the organisations operating in the field in a research project such as this. Rather, the research for this report has analysed a range of organisations, covering different areas in South Africa and tackling HIV/AIDS through different means. This we hope will provide a practical guide to the field. Although details of example organisations are provided in Section VI of the report, it should be noted that organisations mentioned in the text are not necessarily recommended by NPC and equally omission does not imply a negative assessment.

The report is divided into sections covering NPC's standard need, delivery and outcome approach. Section I describes the aggregate picture of HIV/AIDS prevalence in South Africa. Section II discusses the response from South African and overseas governments in an attempt to clear the fog of confusion often shrouding discussions of their respective positions. A brief assessment of the non-governmental response is provided in Section III.

Sections I-III serve therefore as background material for donors and puts the case for action. This half of the report is likely to be of use to a range of donors, but with particular relevance to donors without extensive research resources. The second half of the report, Sections IV-VI, provides information about the practical methods of intervention and their results. Readers already convinced of the case for action and the role of private funding might wish to concentrate on these sections and to consider specific projects and funding opportunities.

The key question for donors convinced of the need to take action is: what intervention methods are available? Section IV address this subject and signposts the range of activities undertaken by HIV/AIDS projects. Section V considers the outcomes from different interventions and, by implication, different organisations. Tentative costings of outcomes can provide useful inputs to the decisions of donors and are provided in this section. Section VI lists a wide range of organisations active in HIV/AIDS in South Africa, breaking these down by their major activities. The list is not comprehensive. The precise recommendations on individual projects are contained in a supplementary report.

There an Appendix following the Conclusion (Section VII). The Appendix contains a detailed series of answers to frequently asked questions about the role of antiretroviral drugs in the treatment of people with HIV and AIDS.

## Section I: The need

**The number of people in South Africa affected by AIDS is huge: 4.8 million currently infected leading to a projected orphan population of one million by 2005. Those affected are frequently poor and lack the resources to access medicines or combat the opportunistic infections caused by HIV and AIDS. The effects on individuals, communities and the economy are profound.**

### Prevalence of HIV

South Africa has a population of 42.7 million<sup>1</sup> of which 14.7 million are children under 15.<sup>2</sup> The HIV prevalence is 11.4% in the total population, with some estimates placing it as high as 20% among adults. This means that at least 4.8 million people (including 860,000 children under 15)<sup>3</sup> are infected with HIV and will eventually develop AIDS. There are certain demographic bulges within the prevalence data: amongst young adults, amongst women, in townships and in some provinces. Putting these demographic bulges together, a young African woman in a KwaZulu Natal township probably has a 1 in 3 chance of being HIV positive, indeed a level as high as 52% has been recorded in an antenatal clinic in a semi-rural area of KwaZulu Natal.<sup>4</sup> Equally there are areas, such as Northern Cape, and segments of the community, Asians for example, which currently have relatively low prevalence.

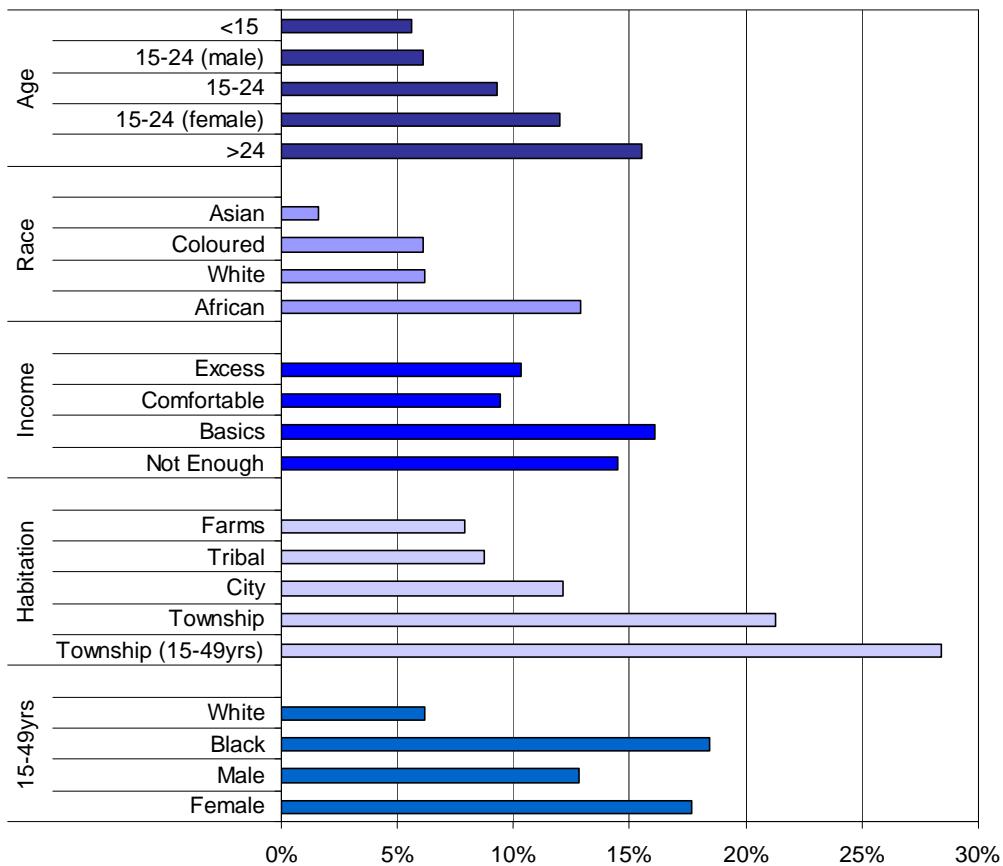
**HIV:** the Human ImmunoDeficiency Virus destroys the immune system itself. A person can live a normal healthy life while HIV positive, until the destruction is so far advanced that the immune system can no longer fight off infections.

**AIDS:** Acquired ImmunoDeficiency Syndrome is diagnosed when a person's immune system has been seriously damaged by HIV and they are attacked by "opportunistic infections", such as tuberculosis (TB) or common flu, against which they no longer have a sufficient defence. At this point, which happens on average around 10 years after infection with HIV, the patient becomes extremely sick and antiretroviral drug treatment is needed.

**The HIV prevalence in South Africa is estimated to be between 11.4% and 20%; young women being the group most at risk.**

The 11.4% quoted above comes from a benchmark study by the Human Sciences Research Council (HSRC) published at the end of 2002.<sup>5</sup> The study breaks the prevalence down into many categories, some of which are shown on Chart 1. The figures should be treated with caution because it is very difficult to measure prevalence. First, there are no physical indications of infection until AIDS is manifest and, even then, a blood test is needed to distinguish a case of AIDS from a "normal" disease. Second, there is still a huge stigma attached to being HIV positive, and so attempts to estimate prevalence by sampling are frustrated by people refusing to be tested. The HSRC study visited 13,518 individuals, 34.6% of whom refused to have an HIV test. If there is any correlation between refusing to be tested for HIV and a lifestyle with a high risk of contracting HIV, then studies of HIV prevalence based on such samples underestimate.<sup>6</sup> Virologist Professor Lynne Webber from Pretoria suspects there is an overall prevalence of 15% and notes that some insurance companies even use a figure of 20% in their projections.<sup>7</sup>

Chart 1 highlights the extremely high prevalence in townships. Euphemistically called "informal urban areas", townships are a legacy of apartheid. Large numbers of non-whites were moved to areas far from their original settlements and far from the centres of economic activity. This resulted in millions of people being socially dislocated from their original communities and crowded together in poor conditions with extremely high levels of unemployment (up to 46%).<sup>8</sup>

**Chart 1: HIV Prevalence by categories**

Precise statistics on prevalence are difficult to calculate: testing is not universal and the largest and most detailed study encountered resistance.

The white population has not been subject to the social dislocation of the blacks, which is one of the major reasons for the lower prevalence in Chart 1. Women, and particularly young women, have high prevalence because the virus transmits more readily from male to female than visa versa. Furthermore it is culturally difficult for girls and young women to refuse sex and many are forced into sex work because of poverty. This is most clear in Chart 2 which shows the age distribution of new infections. Teenage girls are the group most at risk by a huge margin.

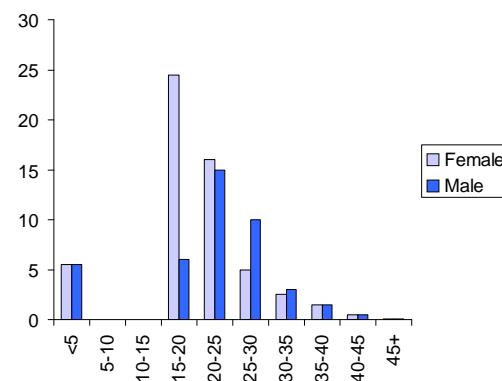
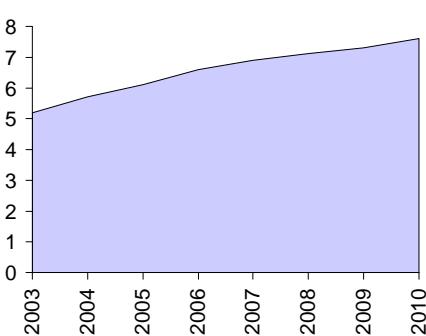
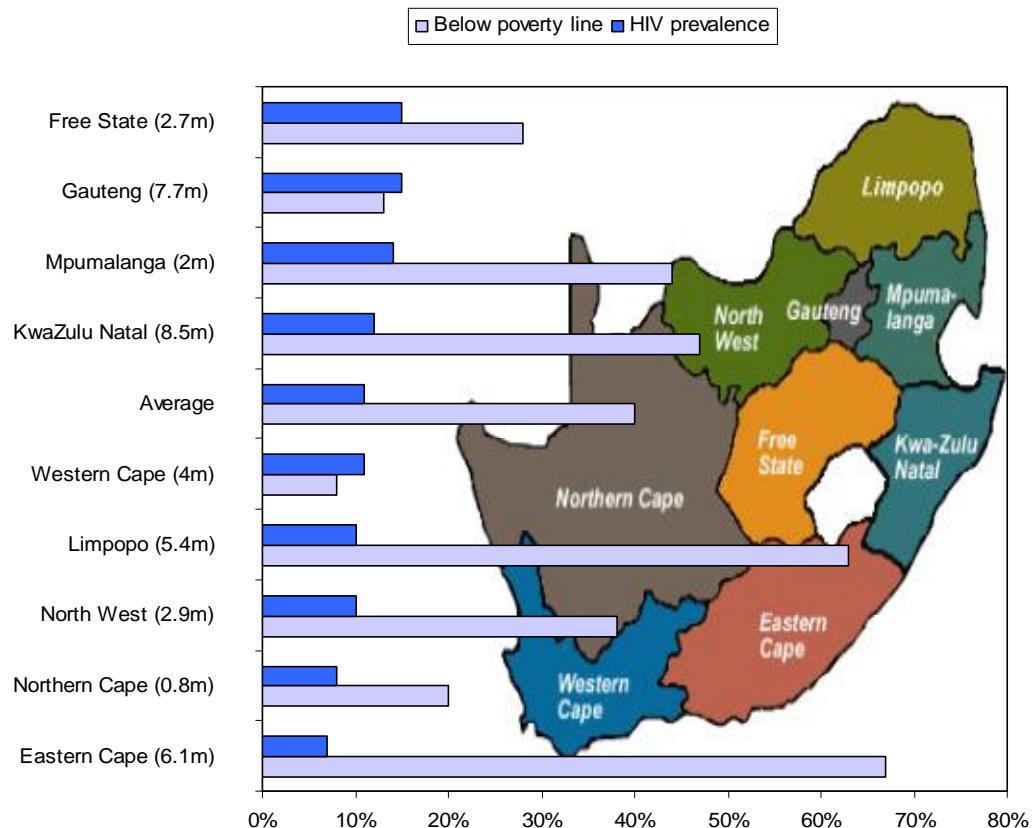
**Chart 2: Age of infection  
(% first infected by age)****Chart 3: Projected spread of HIV  
(millions of infections)**

Chart 3 shows the projected spread of HIV, which rises to almost 8 million infections in 2010.<sup>9</sup> Prevalence data can also be broken up by province revealing a dramatic variation across the country.<sup>10</sup> Free State, for example, has over twice the prevalence of Eastern Cape.

The high level of HIV prevalence among the black population in townships can be partly attributed to the legacy of apartheid.

**Chart 4: Prevalence of HIV and poverty in provinces (with population)**

**Although some provinces record low prevalence overall, they may contain pockets of high prevalence.**

Poverty varies greatly across the provinces. Eastern Cape has almost ten times as many people living below the poverty line as Western Cape.<sup>11</sup> Focusing on provincial data can obscure the fact that there are pockets within each province with much higher than average rates of both HIV and poverty, so it would be wrong to conclude that the wealthier states have no need for philanthropy.

Is there a link between poverty and HIV prevalence? Chart 1 shows that people in the lower income categories are five percentage points more likely to have HIV than the higher income categories, however the relationship is not a neat positive correlation. It would be interesting to see the data split out into genders because a wealthy man is likely to have access to more partners than a poor man, and hence would be more likely to contract HIV, while a poor woman may need to engage in sex to make ends meet. People on the ground say that the problems of poverty exacerbate both the spread of HIV and the impact of AIDS.

On a provincial level there is no obvious correlation between poverty and HIV prevalence. However the poorest provinces have the least resources to tackle the current and future infection levels. Moreover, malnutrition tends to accelerate the progression to AIDS and so poor people are likely to succumb more quickly to the opportunistic infections which are the hallmark of full blown AIDS. Since the epidemiological characteristics of the spread of HIV is similar in most of the provinces, those provinces with lower prevalence levels at the moment will deteriorate towards the high levels of Free State and Gauteng, and the poorer provinces will be least able to deal with the pandemic at either an individual or societal level.<sup>12</sup>

**HIV/AIDS is exacerbated by poverty: the fact that the poorest provinces lack the resources to combat HIV/AIDS aggravates the situation.**

## Sex and the spread of the epidemic

*"We're just beginning to understand that where AIDS is concerned, gender inequality is lethal. It requires a campaign, across the continent and the world, to enshrine gender equality in the family, in the laws, in the institutions and in the apparatus of the State."*<sup>13</sup>

Understanding the nature of sexuality in Africa, its intimate connection with self-esteem and the taboos surrounding its discussion helps to overcome obstacles in implementing prevention strategies, reducing stigma and enabling people to seek treatment, or to protect themselves against the virus.

South Africa has suffered a brutal history in the twentieth century, leading to social dislocation and violent experience. Apartheid broke down many of the societal norms which, together with migrant working, erosion of family life, poor education and poverty, has had a detrimental effect on many aspects of behaviour, including sexual relationships.

As in other parts of the world, a man's success may be measured by the number of women to whom he has access.<sup>14</sup> At the same time women are expected to submit to men (without being obviously promiscuous)<sup>15</sup> and in reality enjoy few rights of refusal particularly if their self-esteem is low. The "sugar-daddy syndrome" ranging from presents for girlfriends to sex-trading for cash or groceries, is clearly visible in HIV prevalence statistics, highlighting the vulnerability of young women. In a zone of acute poverty sex often presents itself as a route to a square meal for oneself and one's family.<sup>16</sup> AIDS develops slowly: the risk of death from a disease which will manifest itself in the distant future seems less of a hazard than the immediate need for food. The use of sex-workers by men working far from their families is another well-documented hazard.

The brutalisation of South African society in the 20<sup>th</sup> century is now manifesting itself in sexual violence which is common and not restricted to adults: adolescents, children and even babies are subject to such abuse<sup>17</sup> – over 21,000 cases against under 18's were reported in 2000.<sup>18</sup> The arrest and conviction of perpetrators is extremely rare and communities are generally reluctant to expose such abuse. One of the challenges facing organisations coping with vulnerable children and the effects of abuse is to address the problem of tacit acceptance of sexual violence.

The use of condoms has not been optimal despite the fact that the government distributes free condoms through public health facilities and on trucking routes; negotiation for the use of condoms by girls is seen as a sign of their promiscuity, or lack of trust,<sup>19</sup> and represents yet another barrier for education initiatives to overcome.

With high levels of unprotected, risky sexual activity comes a concomitant prevalence of sexually transmitted infections ("STIs"). When STIs go untreated, they become a perfect conduit for HIV: lesions associated with STIs, coupled with the increased immunological activity at the infection site provide entry points and favourable environments for HIV. Poor nutrition, chronic infections and parasites also increase human susceptibility.<sup>20</sup>

## Effect of AIDS

**Attitudes to sex among the South African population create a barrier to the reduction of the spread of HIV.**

The HIV prevalence data is a forward indicator of the scale that the AIDS pandemic will reach in the coming years. There is a lag time, which may be as long as a decade, between a person being infected with HIV and developing full-blown AIDS, the state at which their immune system is barely functioning and they are suffering from opportunistic infections.

Already AIDS is taking an immense death toll amongst those who contracted HIV some years ago. It has been estimated that 360,000 people died from AIDS in South Africa in 2001 alone.<sup>21</sup> A portion of these deaths, from infections such as TB, would have happened anyway without HIV/AIDS, but the vast majority are additional mortalities resulting from AIDS weakened immune systems, robbing victims of the ability to fight life threatening infections.

**360,000 people died from AIDS in South Africa in 2001:  
AIDS has reduced the average life expectancy for a South African born in 2010-15 to 42, down from 70.**

## Life and Death

For many South Africans, either being unaware of the benefits of knowing their HIV status (planning, protection of self and partners, access to help and support for healthy living), or living without access to treatment or care, it is sometimes preferable not to know you are HIV positive. A diagnosis of HIV is like a death sentence: you know you will die (you have watched others doing so). You know that as the disease progresses through the stages you will become weaker and less and less able to work. If you cannot work, your income will drop and it will be difficult to find money to feed yourself and your family. There can be enormous stigma surrounding HIV: if you are a woman and your partner finds out you are HIV positive he may beat you or leave you, your family may throw you out. Neighbours may shun you as a "bad woman": there are cases of HIV positive women having been stoned to death and, perversely, gang raped. What will become of your children as you sicken and die?

When the disease reaches the final stages, the symptoms of your decay are foul: you will probably have chronic diarrhoea in an environment where sanitation facilities are limited. You will be wasting away. Your skin is flaky and may well have sores all over it from various infections and herpes. Candida (thrush) in the mouth, gut and genital areas will be tormenting you: the ulcers in your throat and mouth will make swallowing impossible, you may be having difficulty with your digestion because of infections. You will probably have TB and may well have passed this on to family members.

Life in the "informally settled" areas of townships (shanties and shacks) is difficult enough without suffering from AIDS. It is overcrowded, the cardboard roofs leak, there are "bucket" toilets provided by the council but they are not emptied often enough. Your extended family will be up-country somewhere eking out a living in a remote area where there are no jobs, access to water is difficult, and distances to services far. Life is no better for your country cousins, which is why you moved to the shack settlement to look for work in the first place.

One of the features of the AIDS pandemic is the children left as orphans, many of whom may be HIV positive themselves. By the end of 2001 there were 660,000 children who had lost either mother or father to AIDS.<sup>22</sup> By 2005 it is expected that there will be over a million full orphans, about 7% of all children in South Africa.

A dramatic indicator of the effect of AIDS is its effect on expected life spans. Without AIDS the average life expectancy for a South African born in 2010-15 would have been 70; with AIDS it will fall dramatically to just 42 – a decrease of 28 years.<sup>23</sup> After a hundred years of continually increasing life spans in almost every country in the world, AIDS is turning the clock back instead of forward.

AIDS will be a significant drain on the South African economy, affecting the demographics of the population and draining public and private resources to treat those affected. Actuarial models predict that the labour force in 2015 may be 21% lower than it would be without AIDS.<sup>24</sup> Absenteeism will increase, not just by those suffering from AIDS but also for those caring for relatives or attending funerals. Overall GDP growth is predicted to be 0.5% lower per annum and inflation about 2.3% higher.<sup>25</sup>

A recent World Bank report<sup>26</sup> warns that AIDS causes far greater long-term economic damage, since macroeconomic models have overlooked the impact of AIDS on human capital (people's accumulated skills, knowledge and life experiences). AIDS destroys human capital directly by killing young adults and it weakens human capital formation because orphans are deprived of love and guidance and spend much less time in school. The poor education of children today translates into low adult productivity a generation later. "South Africa could face progressive economic collapse within several generations unless it combats its AIDS epidemic more urgently."<sup>27</sup>

If orphaned children are not given adequate care and education, there will be increasing inequality among the next generation of adults and the families they form. Social customs of adoption and fostering may not be able to cope with the scale of the problem generated by the sharp increase in adult mortality, thereby shifting the onus onto the government. The government, however, will be less able to finance this because its tax base is being weakened as adults are killed by AIDS. Co-author Clive Bell stresses that "keeping infected people alive and well, especially parents, so they can continue to live productive lives and take care of the next generation, is not only the compassionate thing to do, but it is also vital for a country's long-term economic future."<sup>28</sup>

**Falling life expectancy, rising number of orphans, and damage to the economy are just some of the detrimental effects of AIDS in South Africa.**

## Section II: Governmental responses

**South African government policy has historically sought “African” solutions.**

*The South African government’s response has tended to get bogged down in ideology rather than meeting immediate needs, and this has led to slow decision making on a number of key policies. At the time of writing, a decision finally appears to have been made to provide antiretroviral drug treatment, but the details and timescale are unclear. The current budget for AIDS (equivalent to £55 per infected person) is clearly not adequate. Neither is the estimated contribution from foreign donors adequate (£10 per infected person), although whether this is due to lack of foreign generosity or South African governmental reticence is not clear. From a global perspective however foreign governments are committing too little to AIDS: the efforts of the Global Fund together with \$15bn promised from Bush to AIDS is a good start, but will be spread over several years and many countries. The impact will not be felt on the ground for some time.*

An exchange rate of £1 = 12.44 Rands (average for May 2003) is used throughout this report. Similarly £1 = \$1.61 is used.

### The South African government

After the long struggle against apartheid, the South African government faced many challenges to heal old scars and build a prosperous and equitable society. Unfortunately the fledgling government was too busy to handle a crisis on such a huge scale as HIV/AIDS and balked at touching on the deep social taboos surrounding sex. The responses it has made have been heavily criticised and have caused considerable controversy. However, in response to intense pressure from civil society, the government has just announced plans for an enhanced treatment programme.

President Mbeki has been personally associated with many of the ups and downs of the AIDS policy. He launched the Partnership for AIDS strategy in 1998 while Deputy-President, but has been distracted by controversies since then. There is a theme running through the related controversies discussed here: the desire to tackle AIDS using African resources rather than relying on expensive imported drugs.

(1) Virodene was a locally developed treatment which Dr Nkossana Zuma (then Health Minister) tried to fast-track past standard safety tests procedures. The appeal of Virodene was that it was a cheaper local treatment that sidestepped foreign pharmaceutical companies. However it transpired that the drug contained a dangerous industrial solvent.

(2) In 1998 the government refused to treat pregnant women with the antiretroviral drug AZT to reduce the risk of HIV transmission from mother to child. The reason given was the cost and toxicity of AZT. The drug is indeed toxic, and a short course of AZT was more expensive in 1998, before drug companies cut their prices and before Nevirapine was introduced as an alternative treatment for preventing transmission. Preventing children being born with HIV should have been a priority notwithstanding these problems, and – after much campaigning by AIDS groups – Prevention of Mother-to-Child-Transmission (PMTCT) became part of health policy, although the speed of roll out varied significantly across the country and in some provinces appeared not to be being rolled out at all. At the end of July 2003, the Medicine Control Council announced that it was considering withdrawing its approval of Nevirapine, which would turn back the clock on PMTCT, unless the manufacturers can “prove” its safety within 90 days.

(3) The most serious of the controversies has been Mbeki’s analysis of the causes of AIDS. His main point, that poverty is a critical causal factor in the spread of AIDS and in the morbidity rate of those inflicted with the syndrome, is correct and important. It draws attention to the desperate need to address poverty as much as AIDS itself.

Different sexual practices and social relationships are certainly part of the reason for the occurrence of an AIDS pandemic in Africa but not the West. However malnutrition, poor health care and social collapse – the results of poverty – are also significant co-factors. A malnourished person has less defence against infection; a poor health care system has hampered prevention and treatment initiatives; social collapse has facilitated high levels of risky sex. Mbeki muddied this clear message by flirting with the ideas of Peter Duesberg, a Californian biochemist who argues that HIV does not cause AIDS. However, the vilification Mbeki has received for merely considering Duesberg’s ideas has been out of proportion to the extent of his flirtation and the actual effect it has had on government AIDS policy. This is demonstrated by the long and diplomatically costly battle that Mbeki has fought with

**The government is right to highlight the importance of poverty as well as HIV: over 50% population live on less than £150 per annum.**

pharmaceutical companies to ensure affordable access to antiretroviral drugs – a treatment which combats AIDS precisely by attacking HIV.

### Resource allocation choices

**Antiretroviral treatment would cost about £1bn per annum, but the government must balance this against other budgetary needs.**

The issue of antiretroviral drugs is at the heart of the policy debate in South Africa. Journalists often portray Mbeki as anti-antiretroviral drugs because of his interest in Duesberg, but the truth is probably more complicated. 22m people, over half the population, live on less than £150 per year.<sup>29</sup> The government has the difficult job of allocating limited resources to tackle poverty while fulfilling all the other functions of a nation. This fiscal conundrum can be illustrated by considering one possible mechanism for addressing poverty, a Basic Income Grant (BIG) for all citizens.

It would cost around R66bn (£5.3bn) per annum to provide a BIG of R130 (£10.45) per month to every citizen. Universal antiretroviral drug treatment for AIDS patients, even with the 90% fall in drugs prices since 2000, would cost around £1bn.<sup>30</sup> By way of comparison, the current health budget is R39.1bn (£3.1bn) and the social security budget is R42bn (£3.4bn), even with the 2003 budget's dramatic increase of 12% and 15% respectively. South Africa's GDP is a little over R1.1tr (£88bn) and government spending accounts for about 30% of this, meaning that the cost of a BIG and universal antiretroviral drug treatment might require close to a one third increase in government spending before considering savings elsewhere in the budget.

### Social services provision:

The key departments in the provision of social services are:

- i) Home Affairs Office – controls the issue of birth, marriage and death certificates, the former and latter being absolutely crucial to obtaining any support for orphans and vulnerable children. The Home Affairs Office is generally under-resourced and the issue of certification is a bottleneck in the provision of support and protection to children.
- ii) Social Development Office (also known as Social Welfare) – controls the issue of grants. The relevant grants for orphans and vulnerable children are<sup>31</sup>:

Grant Type	Amount per month	
Old age	R700	£56
Disability	R700	£56
Foster care	R500	£40
Care dependency	R700	£56
Child support	R160	£13

R1000 (£80) per month is the amount usually claimed for children in institutions.

- iii) Courts – in order to claim a foster grant the child has to be legally fostered (even if it is by a relative).

As at May 2002 an estimated five million children under seven lived in conditions of poverty sufficiently low to qualify for a Child Support Grant, yet only 1.9 million children were receiving it. The highest rates of child poverty are in KwaZulu Natal, Eastern Cape and Northern Province, where 65% of children live below the poverty line. In these same three provinces, there are nearly 2.5 million children eligible for the grant but in Eastern Cape and Northern Province, only 25-30% of children are accessing them. KwaZulu Natal is little better at 46%. Lack of identity documents necessary to access the grants are a key problem: only 51% of all children have birth certificates (most likely to be in the section of society which is not in poverty).<sup>32</sup>

The foster grant is similarly difficult to access. There is concern among some quarters that in the absence of a Basic Income Grant to address the acute poverty issues in South Africa, the foster grant is being used by families for general income purposes and that this may be commoditising children.

**Although some social service provision is available, many families lack the documents that are necessary to access the available grants.**

**48% of South Africans believe the government has not allocated sufficient resources to AIDS and 95% want the government to provide antiretroviral drugs.**

**On 8<sup>th</sup> August 2003 the government made a dramatic U-turn. It appears to have approved an antiretroviral treatment program, although the details of this are not yet clear.**

It appears to some that the government faces a choice between tackling poverty, through a BIG or some other means, or funding antiretroviral treatment. Interestingly, the strongest advocate for universal antiretroviral drug treatment – the Treatment Action Campaign (TAC) – also supports the concept of BIG because it would provide a social safety net for families ravaged by AIDS. The net additional cost of the BIG would, in fact, be less than R66bn (£5.3bn) because it would replace some existing benefits. Evidence from Brazil, which has been providing universal antiretroviral drugs since 1996 (currently treating over 100,000 people), is that the net cost of antiretroviral drugs is small – in fact they may even result in a net saving by reducing hospitalisation costs for dying AIDS patients. However the hospitalisation cost savings achieved in Brazil (possibly £476 per patient per year<sup>33</sup>) may not be replicated in South Africa where the health service is heavily rationed.<sup>34</sup> Even without net savings it might be possible, with large sacrifices elsewhere in budget or with an increase in taxation, to pay for both initiatives, but so far the government has not come out clearly in favour of either let alone both.

### Latest developments

On the 8<sup>th</sup> August 2003, as this report goes to press, the Cabinet issued a surprise statement which appears to be a complete U-turn in policy on antiretroviral treatment. This may turn out to be a historic development, however it needs to be treated with caution for the time being and set in context.

The National Economic Development and Labour Council (NEDLAC) negotiates agreements on key policy issues between business, labour, government and civil society. Last October a NEDLAC task force began drafting a plan for a national antiretroviral drug treatment program, initiated by TAC. In parallel, the Departments of Finance and Health set up a research committee to investigate the costs of antiretroviral drug treatment. The intention was to approve the NEDLAC plan, though with treatment targets delayed until the research committee's investigation was complete, in time for World AIDS Day on 1st December. However, at the last minute, the government negotiators indicated that they needed longer to consider the plan before signing. Then, according to TAC, they "became uncontactable" and the NEDLAC process broke down. In response TAC launched a program of civil disobedience in early 2003. The research committee's report on treatment costs was expected have been presented to the Cabinet in February, however this was continually delayed.

The HSRC study reported that 68% of the population believed that the government was committed to tackling AIDS, however only 48% believed that it had committed sufficient resources. An overwhelming 95% said they would like to see the government providing an antiretroviral treatment programme.

The 2003 Budget included R3.3bn (£265m) over three years for AIDS, which TAC said would be sufficient to rollout PMTCT, post-exposure prophylaxis for rape survivors and to begin a small antiretroviral drug programme. Notes to the Budget mentioned that "investigations on the introduction of a national antiretroviral drug programme are far advanced, and recommendations are close to finalisation." While the Treasury had apparently recognised the need for an antiretroviral drug programme, The Department of Health had not made its position clear, while Health Minister Manto Tshabalala-Msimang has very publicly stressed diet as an alternative to treatment.

At the start of August the government appeared to be seriously back-tracking on PMTCT and prophylaxis for rape survivors. Then, out of the blue, the Cabinet finally met to discuss the "Report of Joint Health and Treasury Task Team charged with examining treatment options to supplement comprehensive care for HIV/AIDS in the public health sector" (Joint Report).<sup>35</sup> The Cabinet issued a statement that "antiretroviral drugs do help improve the quality of life"<sup>36</sup> of AIDS patients and instructed the Department of Health to develop a detailed operational plan for a treatment programme, by the end of September. This statement has been generally taken to be a pledge to roll out a national treatment programme. A Summary of the Joint Report is publicly available at the time of going to press.

The Summary of the Joint Report is generally extremely positive. It carefully contextualises the role of antiretroviral treatment within other HIV/AIDS interventions, considers the practicalities of treatment roll out and firmly asserts the need for equitable distribution. This last point is laudable, but may well result in some frustrations since the provincial governments have differing capabilities to deliver antiretrovirals, and it would be a pity if the provinces such as Western Cape which are already experienced in delivering treatment are required to proceed at the pace of the slowest.

The report investigates cost implication scenarios including provision of antiretrovirals to 20%, 50% and 100% of eligible patients by 2008. Interestingly the 20% figure is dropped in later parts of the report. In reality the 100% scenario is most likely, particularly given the government's concern not to discriminate in any way, for example by providing better treatment in cities than in rural areas or in some provinces than others.

The report talks about 4.7m HIV positive South Africans and 400-500,000 with clinical AIDS. These certainly seem conservative figures. The costings of treatment are similar to the figures we have used. The current annual cost of treatment per patient - including drugs, monitoring and service delivery costs – is given as R11,705 (£1,030) but with an aim or achieving the best international cost of R7,611 (£700). These figures seem to imply a non-drug cost of around £400 per patient. The total cost for 100% provision in 2008 is said to be in the range R6.7-8.9bn (£590-783m). One of the headline figure in the report is that universal treatment would defer 1,721,000 deaths until after 2010. Based on a (very) conservative estimate that treatment saves 3.6-4.4 years of illness-free life, the program would save 5m life years at a cost of R8,825 (£777) per life year saved and defer the point at which 860,000 children are orphaned.

The report is not clear as to precisely how many patients are expected to go onto treatment in which year under the various scenarios. Assuming the 100% option is chosen in October, then a timeline, based on the report's own figures would imply that the first patients would start receiving medication around July 2004 and by the end of 2005 up to 200,000 patients would be receiving treatment.

Implementation is to be subject to a "detailed operational plan" provided by the Department of Health in the Autumn. It will be clearer then the extent to which the government will actually follow the recommendations of the Joint Report.

## Foreign governments

**South Africa receives donations from British, Canadian, Dutch, Irish and Japanese governments. Aid from the US will rise significantly next year.**

Overall, South Africa receives about \$450m (\$11 per capita) in overseas aid.<sup>37</sup> Only part of this goes to AIDS projects, perhaps no more than \$80m,<sup>38</sup> mainly to large scale national programs.

South Africa is a light user of multilateral agencies: it has not borrowed from the World Bank, African Development Bank or Japan, and the UN agency activities are "small".<sup>39</sup>

### Europe

The UK, Dutch and Irish governments are particularly active donors because of their historical links with South Africa; all fund portfolios of largely public sector projects. All three fund the influential Soul City HIV education initiative. Although the UK Department for International Development is providing £46m per annum to South Africa (including £16m via the EU) it is not clear that much of it goes to HIV/AIDS.<sup>40</sup> Other donors make modest contributions, for example Canada contributed \$0.5m to a "Sustainable Livelihoods" initiative for children with HIV.<sup>41</sup> Japan has contributed \$1m to a United Nations Development Programme prevention project in KwaZulu Natal.<sup>42</sup> The European Commission funded €25m into the Partnerships for the Delivery of Primary Health Care (including HIV/AIDS) in 2002, and in 2003 is funding €10m into a Regional HIV/AIDS awareness and education programme.<sup>43</sup> Sweden, Norway and the Netherlands also contribute unilaterally to South Africa in general, although again it is not clear how much of this is allocated to AIDS.

### US

The US government is a major donor, currently funding projects such as the Nelson Mandela Goelama community care programme for orphans. In 2002 USAID spent \$15m on HIV in South Africa,<sup>44</sup> about 3% of its \$510m global HIV spending. The NIH (US National Institute of Health) is also contributing \$32m over five years to the South African participants in a collaborative known as CIPRA (Comprehensive International Programme of Research on AIDS).<sup>45</sup> Unfortunately NIH funds are not available to pay for drugs, so the CIPRA money is for capacity building and research. The US contribution is likely to increase following President Bush's pledge in the State of the Union speech this year to increase spending on AIDS to \$15bn in the five years 2004-8. The White House claims that this financing will prevent seven million new infections (60% of the projected 12 million new infections in the 14 target countries); provide antiretroviral drugs for two million HIV-infected people; and care for ten million HIV-infected individuals and AIDS orphans.<sup>46</sup> The \$15bn will go into treatment (55%), prevention (20%), care for the dying (15%) and protection of orphans (10%). If the money is distributed similarly to 2002 spending, then the US will spend

an average of \$90m per annum in South Africa. This would be a significant contribution if it materialises and if it is well directed. Large amounts of aid can be difficult to digest however and, when the administration costs of implementation are taken into account, impact on the ground is sometimes diluted. It must also be noted that the Bush administration's budget for the 2004 fiscal year only recommends \$1.7bn for the initiative, rather than the \$3bn implied by the pledge and corresponding Bill. Nevertheless this initiative from the US does give hope that the international community is beginning to take the pandemic seriously.

### Global Fund

**The Global Fund is heavily under-funded. Bush's pledge to allocate US\$15bn will take time to materialise – but it shows that the world's biggest economy takes the pandemic seriously.**

Another sign of hope is that Kofi Annan's proposal of a Global Fund for AIDS, TB and Malaria was unanimously endorsed in June 2001 at the first UN General Assembly Special Session on AIDS. The Fund has been welcomed by AIDS groups as a more independent and informed grant maker than bilateral governmental aid. The Global Fund distributes funds as applications are received, but states that "the highest priority will be given to proposals from countries and regions with the greatest need, based on highest burden of disease and the least ability to bring the required additional financial resources to address these health problems".<sup>47</sup> So far 61% of funds have been allocated to the Sub-Saharan region. As of January 2003 \$2.15bn had been pledged and more than 90% of that sum had actually been received. This is a significant pot of money, however it falls far short of the \$10bn per annum which Kofi Annan had said was needed.<sup>48</sup> The Fund had requested \$2.5bn in 2003 and \$3.5bn in 2004 from the US. President Bush has offered only to contribute a third of funding up to a maximum of \$1bn each year (announced at Evian G8 summit, previously the US had only committed \$200m per annum). The Fund has disbursed \$1.5bn to 160 programmes in 85 countries in its first and second round of grants, however it is already facing a budget shortfall of \$1.6bn to meet anticipated needs in the third round of grants this October. The Fund has approved applications totalling \$190m over five years for South Africa in the first two rounds of grants.<sup>49</sup> \$118m is for national initiatives of the Department of Health such as the media campaigns of LoveLife and Soul City (described later) and \$72m is for a programme in KwaZulu Natal including antiretroviral drugs.

There are about 40m people infected with HIV worldwide.<sup>50</sup> If we assume the Global Fund resources are distributed according to prevalence and optimistically that \$2bn per annum is available for AIDS on an ongoing basis, then South Africa could expect to receive around \$250m pa from this source, although, to date, the total approved is only \$190m over five years. If the predicted \$250m does materialise, and if it is all directed to antiretrovirals, then it could meet about 15% of the cost of a national antiretroviral programme. In reality the pot will almost certainly be smaller.

## Section III: Non-governmental responses

*At first glance, the South African voluntary sector is vibrant with a large number of local initiatives near economic centres such as Cape Town, Johannesburg and Durban. However, the sector is quite small in economic terms. Contributions from foreign non-governmental organisations (NGOs) are not huge either. Neither local nor foreign efforts are anywhere close to meeting needs. This presents opportunities to donors.*

### South African voluntary sector

**The relatively small but active voluntary sector in South Africa is complemented by an informal network of community initiatives.**

South Africa's voluntary sector is tiny compared to the UK, both in absolute and relative terms, mainly due to the much smaller involvement of the government in the sector but also because the economic circumstances of South Africa are very different. A rough estimate of the voluntary sector spending on AIDS is £435m, of which about £136m comes from local donations, with the remainder from fees, the government and foreign aid and philanthropy.<sup>51</sup> The level of local donations should be considered in the context of over 40% of the population living in poverty.

#### How wealthy is South Africa?

Average GDP per capita is \$2,768 (2000) which is a tenth of the UK level of \$26,002 (2002). The "Gini coefficient" measures income distribution. A Gini of 0 would mean perfect distribution, a Gini of 1 would mean a single person has all the income. South Africa has a Gini of 0.635 (up from 0.596 in 1995) which ranks it as one of the most financially unequal countries on the planet.

The voluntary sector in South Africa is fragmented and, although some NGOs have been successful in collaborating and forming networks, lack of co-ordination is a real problem in many areas. Regions close to economic centres appear to be much better served than some of the poorer regions where gaps in the provision can be severe. However, there is a paucity of reliable data on numbers of organisations, activities, location and coverage so targeting of underserved areas is difficult except by anecdote. There are opportunities for philanthropists to support collaborative initiatives to minimise overlap in resource starved environments.

There are just over 100,000<sup>52</sup> voluntary sector organisations in South Africa falling into a number of categories. Some of the largest South African NGOs are small by UK standards: under £1m income per annum and with only 200-300 employees. Only 1,300 roughly have more than 50 employees. Substantial (in local terms) NGOs enjoy funding of less than £300,000 per annum. Most of the voluntary sector organisations are smaller still, with less than ten or so employees. The most organised groups form themselves into not-for-profit organisations (NPOs) which can attract tax benefits. Other groups are often offshoots of churches or community groups, responding to local needs. In addition there is an informal network, which is much harder to quantify, of family and community care for victims of AIDS and the resulting orphans and widows. These last two categories are generally referred to as community based organisations (CBOs).

At a local level there is evidence of a very active Rotarian network and the national lottery also supports local initiatives. Local corporates are often involved in initiatives as well, or fund community chests which distribute funds to local causes.

There are some influential AIDS advocacy groups in South Africa, of which the most visible is the Treatment Action Campaign. These groups have long been lobbying government to increase resources to tackling AIDS, as well as advocating particular strategies such as universal provision of mother-to-child-transmission treatment.

An exciting recent initiative is the foundation of the Southern African HIV/AIDS Intermediary Grant-makers Collaborative (SAHIC). This group was formed in July 2002 at a meeting convened by the Synergos Institute, and five of the eight founding members are South African, namely AMREF, INTERFUND, The Aids Foundation, The Nelson Mandela Children's Fund and Social Change Assistance Trust. SAHIC is an action-orientated network of local grant-makers which aims to coordinate donors' efforts on a regional basis by sharing information and best practice. There is also the South African Grant-makers Association but their activities are general and not just AIDS specific.

**South Africa is not perceived as a country of acute need by many overseas donors.**

## Foreign NGOs and grant-making trusts

Foreign NGOs and grant-making trusts often have an agenda which is wider than just HIV/AIDS, and so direct spending on AIDS may not be as great as expected.

Development NGOs such as Oxfam, CAFOD, Christian Aid and World Vision are active, but as AIDS is now mainstreamed within their work it is hard to separate the specific AIDS component from more general community initiatives. Save the Children is present but, except for supporting two HIV/AIDS outreach projects, is mainly focused on research and advocacy. CARE focuses on general poverty alleviation and civil society building efforts, but also supports a programme involving sex-workers and migrant populations between South Africa and Lesotho. ActionAid has concentrated its efforts in other African countries. Médecins Sans Frontières operates an antiretroviral drug programme in the Khayelitsha township and is particularly active in lobbying the government for a public treatment programme. Red Cross operates several home based care initiatives at a cost of £300,000 per annum.

NPC's very rough estimate of total foreign grant-making (which does not include the development NGO spending) to AIDS projects is £23m per annum.<sup>53</sup> As comprehensive data on grant-making activity is not available, NPC's calculations are estimates only, but it would appear that the main givers are the big US Foundations. For instance, the Kaiser Family Foundation has been a substantial contributor to the national media AIDS awareness campaign, as well as funding research. They are committed to improving health inequalities, particularly as regards AIDS, and their total South African funding is US\$15m. Although its main focus is civil society, the Ford Foundation is funding AIDS programmes on the ground such as research into child abuse – a major cause of HIV infections amongst young people – and memory boxes at University of Cape Town. The Bill and Melinda Gates Foundation has funded a great deal of AIDS research elsewhere, including trying to develop microbicide prevention for the use of women, but is not particularly active in South Africa. It recently committed \$50m to a comprehensive prevention and care programme over the border in Botswana. Bristol Myers Squibb launched a \$100m "Secure the Future" fund in 1999 specifically for HIV/AIDS and related issues in South Africa, Namibia, Swaziland, Lesotho and Botswana.<sup>54</sup> By 2001/2 between \$3-4m had been committed to community outreach and medical research programmes in South Africa – consequently a large number of projects NPC contacted or visited in South Africa were benefiting from this funding source. The Rockefeller Brothers Fund has contributed \$2.8m to South Africa between 2001-2003, but only about 40% of this is directly AIDS related. Wellcome is funding a research programme out of the University of Natal.

From the UK, the Diana Memorial Fund committed approximately £1m to palliative care in Africa, a substantial proportion of which has benefited South Africa. We estimate that the Elton John AIDS Foundation is funding around £1m per annum into programmes ranging from a hospice in Soweto to orphan response programmes in KwaZulu Natal. From Europe, Association Francois-Xavier Bagnoud is also active. A newer and slightly unusual grant-maker is Starfish, which was launched in 2001 by South African expatriates in the UK. Starfish fundraises from individuals and companies and aims to inspire greater grassroots action across South Africa. To date Starfish has committed around \$1m in funding, principally to children's projects in KwaZulu Natal but has much larger ambitions.

## Overall shortfall

**Unfortunately, the combined sum of government funding and foreign aid are vastly inadequate.**

The scale of the HIV/AIDS pandemic – with almost five million people infected, and many more family members affected – means that the sum total of government action and foreign aid in the South African voluntary sector is still vastly inadequate. Fewer than 20,000<sup>55</sup> people out of government's own estimates of 470,000 clinically requiring antiretroviral therapy are currently receiving the treatment they need. These are mainly wealthy individuals or employees of large corporations with private health care. In areas of general care and support for bereaved families it is very difficult to ascertain the degree of coverage by existing agents. Anecdotally however NGOs are finding that their resources and capacity are inadequate: South Coast Hospice, together with one hospital and 29 clinics, apparently administer a catchment area of one million people. This implies that 11,000-15,000<sup>56</sup> people may be suffering acute AIDS, but South Coast is only ministering to 1,500 patients and they are the principal provider of home based care in the area. Elsewhere in rural KwaZulu Natal the Centocow Mission estimated they were reaching only 50% of their catchment of 20,000 people.<sup>57</sup> Beyond their catchment area it was not clear that there was anyone operating at all. Naledi Hospice in Bloemfontein estimates there are 10,000 people requiring their services but can only cover 3,500.<sup>58</sup> Overall NPC estimates that over half of people infected and affected do not receive any services, let alone ones which are adequate.

The existing activities of a few foreign NGOs and grant-makers in South Africa demonstrates that there is scope for a range of interventions. The rest of this report outlines which kind of interventions are most effective and how donors can practically give to specific HIV/AIDS projects. Private funders have the freedom to act with much greater speed and flexibility than governments and can pioneer interventions which will guide future governmental spending and maximise social benefit to a people being ravaged by AIDS. Other advantages are that donors' money is their own: they can take risks, support areas of unfashionable need, without being answerable to political constituents such as tax payers.

## Section IV: Ways to combat AIDS

***There is much that can be done to help those infected and affected by HIV/AIDS. Interventions can be large or small scale. The grant-maker or donor need not be daunted as even relatively small sums can go far in transforming the lives of individuals and helping communities to recover. This section deals with the three principal parts of the epidemic cycle and how to intervene at each stage.***

### The lonely hut

You are an eight-year-old girl in South Africa. Last week you attended the funeral of your last remaining aunt and recent carer: your mother died two years ago and you haven't seen your father since 1998 when he went to work in Durban. The deaths of your mother and aunt were slow and horrible: diarrhoea, terrible sores, chronic thrush leading to grave difficulty in eating, your aunt even became increasingly demented before finally succumbing to TB. During the period of your mother's illness you were not sure what was going on – by the time your aunt died you knew better what to expect, but still felt helpless as you had no idea what to do to help. You did not like to touch her sores with your hands but if you had to move her it was not possible to avoid this. Trips to take her to the hospital (50km away) were degrading. The neighbours did not come to help because of the sickness of your aunt – people said she was a bad woman.

Since your aunt died you and your five brothers, sisters and cousins have moved into your granny's smaller hut because it was impossible to maintain the roof on your aunt's hut which is almost falling down. Your granny is grief stricken and depressed since she now has no children, only grandchildren. What little savings she accumulated has been spent on medication and the funerals of her family. Granny looks old but is in fact only 45 and you are not sure whether she is sick or not. She is too young to get a pension, and you heard her talk about some money from the government for orphans but she couldn't find the papers she needed and had no money for transport to go to the social services office near the hospital.

Your older sister is very sad and stopped playing with you when she had to help Granny nurse your mother and aunt. She used to go to school, but doesn't any more. In fact no-one in the family goes to school any more, neither your cousins nor your brothers and sisters, and you miss your friends. There is very little to eat. When you are hungry and there is no food it is best to go to sleep. There is a garden, but the crops are poor this year because the rains came at the wrong time, water is far away and in any case you are not very good at gardening and granny has been too busy with your aunt to look after the garden. You have to get the water from the bottom of the hill which is very long and steep.

You help your sister to look after your younger brother, but he is sick and very weak. There is not enough money for the medicine and extra food he requires. You are very lonely and all your family are lonely because they don't know what to do. Everyone worries all the time.

Your older sister is visited by a man who sometimes gives a small amount of food when he leaves. He sometimes hurts her and you fear him and are worried that he has seen you and wants to touch you.

**The spread of AIDS has disastrous consequences, and not just on the health of the population: there will be one million orphans in South Africa by 2005.**

**The cycle of the HIV/AIDS pandemic is complex and interventions at any point are linked to earlier as well as later points in the cycle.**

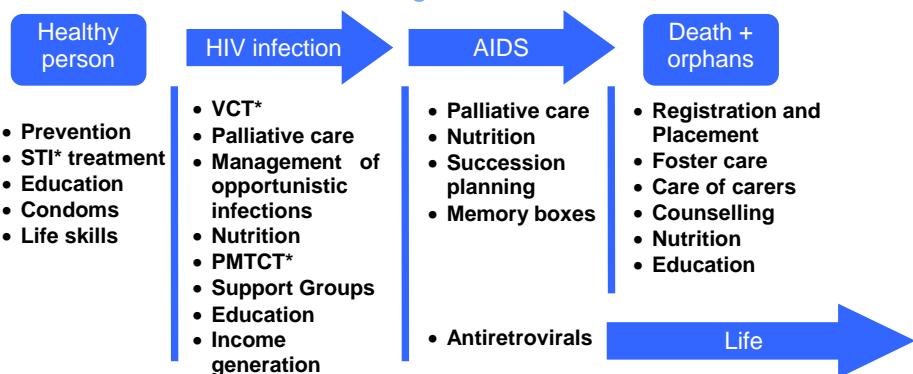
### Introduction

The war against AIDS is complex and multi-pronged, but broadly speaking is being waged on the following three fronts:

- a) prevention and education;
- b) people with HIV/AIDS: treatment and care;
- c) people affected by HIV/AIDS.<sup>59</sup>

These three are by no means mutually exclusive, and projects often involve two or more of these approaches. Favoured methodologies of combating AIDS are increasingly holistic. In addition, in a continent where transport and access, particularly in rural areas, can be a major obstacle to the delivery of services, it may be appropriate to offer more than one service once an infrastructure is set up to access a particular community.

### Chart 5: Interventions at different stages of life



\*VCT (voluntary counselling and testing); STI (sexually transmitted infections); PMTCT (prevention of mother to child transmission)

Chart 5 shows a person's progression from being healthy and HIV negative to becoming HIV positive with AIDS. It illustrates the various interventions at points during the progression to try to prevent or alleviate events.

Where data on South Africa's experience is absent, interesting data is often available from East Africa which is further ahead on the epidemiological curve. Lessons can be learned from this region and applied in South Africa.

This section gives some examples of projects tackling AIDS. There are many other organisations also doing good work but there is not space to mention them all in this report.

### Prevention and education

Infections avoided through prevention represent lives saved.

*"The mainstay of prevention programmes involves changing behaviour, improving access to condoms and decreased [clinical] vulnerability of HIV. Extensive research has shown that all prevention strategies need to take into consideration and address: poverty, discrimination, gender inequality, unemployment, illiteracy and cultural practices all of which enhance vulnerability to HIV infection".<sup>60</sup>*

*"....there is evidence that ....prevention of mother to child transmission programmes, and the management of sexually transmitted diseases, are cost effective."<sup>61</sup>*

There is a clear demographic opportunity for South Africa in that HIV prevalence for those under 20 is currently 6%.<sup>62</sup> Between ages 20 and 24 the prevalence rises to 13%, and between 25 and 29 it more than doubles again to 28%. If the prevalence among those now under 20 can be maintained at levels below 10% as they emerge into their twenties, then the menace of HIV may recede in the same way as it has in Uganda. However, teenagers are at very high risk of contracting the virus, and orphans and vulnerable children are generally regarded as being higher risk than others.

#### Uganda: further ahead on the epidemic curve

*"Uganda continues to present proof that the epidemic does yield to human intervention. Recent HIV infections appear to be on the decline in several parts of the country—as shown by the steady drop in HIV prevalence among 15–19-year-old pregnant women."<sup>63</sup>*

Uganda is often hailed as a success story in combating AIDS; witness the drop in HIV prevalence between 1992 (15-30%) and 2000/1 (9.5%), with a fall in the capital city Kampala from 29% to 11%. This could be misleading as it is estimated that up to 800,000 people have died since the inception of the epidemic<sup>64</sup> and this would inevitably lead to a drop in prevalence if death rates exceed incidences of new infection.

However, incidence has halved in some areas (e.g. Masaka)<sup>65</sup>, and this is a much more important indicator. Despite some conflicting evidence, the improvements appear to be a result of:

- changes in sexual behaviour and increased condom use;
- treatment and reduction of sexually transmitted infections (STIs).

It is essential to promote awareness of the dangers of AIDS and explain ways of preventing HIV, as well as to encourage behaviour change.

President Museveni was first alerted to the seriousness of the epidemic by the Cuban government who tested a cohort of Ugandan troop secondees in the 1980's. Early in the epidemic the Ugandan government faced the AIDS crisis head on, and with the help of international donors encouraged multi-faceted initiatives to tackle the epidemic. Advertising campaigns promoting "abstinence, faithfulness, condoms" have been clear on behavioural risks. Local (village) councils have been involved in forming local committees to promote prevention and address stigma. AIDS education is to be introduced into primary schools.

In addition to the interventions above, it is also likely that the sheer level of mortality has shocked the population into protecting themselves.<sup>66</sup>

### Education and behaviour change

AIDS education is important in order to protect this generation. A grasp of biological facts taught within school would be a helpful start, but in order to change behaviour more complex cultural issues need to be well understood. Who do young people listen to in matters of sex? Is it the church? Is it the local leaders, parents or carers or even "sangomas" (traditional healers)? Is it the media? Peer education has enjoyed considerable success in Tanzania, for example.<sup>67</sup> How are gender issues addressed? In addition, it has been argued that risky sexual behaviour does not necessarily stem from an ignorance of biological facts but a failure to "internalise" risk; in other words to understand the implications of such behaviour and to appreciate that it affects oneself – not just everyone else.

The role of the education system in prevention is an important but difficult issue, not helped by the fact that teachers continue to be badly affected and infected by the disease, and more teachers are dying each year than are completing their teacher training. However, the education system can help to reinforce improvements in behaviours in successive generations. As we have seen in the UK with increases in sexually transmitted diseases among the under 25's, lower risk behaviours in one generation are not automatically passed to future generations. Messages have to be reinforced repeatedly and successively. Education also has a role to play in teaching children how to care for those with AIDS, with teachers often performing vital support functions for children who are bereaved or having to care for a sick parent. **Naledi Hospice** is working with the Department of Education in Free State to train teachers in AIDS issues.

South Africa, with substantial sums from the Global Fund (\$40m to date), has embarked on a national campaign (outside the education system) to promote awareness and to encourage behaviour change among youth. Among NGOs, **Soul City** has produced a soap opera covering a wide range of HIV issues through the storyline and characters. **LoveLife** combines media advertisements, a provocative and controversial billboard campaign and work with youth groups to try to influence adolescent behaviour. It claims success in reaching all environments, though in rural areas the success was questioned on the ground. This may be because television is widespread in townships but less so in deep rural areas such that youth in these areas are unlikely to benefit from a branding strategy.

AIDS education also needs to be reinforced at a more intimate level among younger children, particularly as they may be in contact with AIDS patients. Younger children are also at risk from sexual abuse. Gender issues, specifically the right and ability of girls and women to say no or negotiate safe sex needs to be addressed early.<sup>68</sup>

Abstention may not be realistic. The success of an education programme will be undone if there are not services available to children and teenagers providing:

- access to condoms;
- treatment of sexually transmitted diseases;
- counselling and advice on voluntary testing for HIV;
- encouragement of disclosure of HIV status if tested;
- support and protection against stigmatisation if HIV positive.

The national awareness efforts are complemented by the work of NGOs, both specialist and general, who are trying to increase awareness and promote behaviour change at the community level. As examples:-

**LoveLife** and **Soul City** not only have substantial media campaigns but also offer helplines (10,000 calls per month) and adolescent "Y" clinics where counselling and condoms are

Media campaigns, help lines, and specialist educational schemes are important steps to raising awareness and encouraging behaviour change.

**Local education initiatives are also important.**

available. Behavioural questionnaires suggest considerable success from these interventions, but at present there is no data showing the impact on the epidemic.

**Student Partnership Worldwide (SPW)** has piloted a peer education scheme in rural Eastern Cape. SPW identifies young people themselves, not teachers, as the key to influencing behaviour. SPW recruits student volunteers from both Africa and the West who, in pairs, will tackle a primary and a high school in a particular area. The SPW volunteers help to identify “peer leaders” within a school and then support them in running their own health and HIV discussions and education sessions. The volunteers also get involved with community projects (such as water sanitation) to strengthen links and reinforce messages. They have just over 40 volunteers, covering around 16,000 children in Eastern Cape.

**Ubuntu Community Fund** works in a similar, if less intensive, way in urban Eastern Cape where unemployment can be as high as 90%. Ubuntu has trained 24 matriculators and each covers 24 primary and secondary schools. The matriculators teach for two hours on an eight day cycle and the teaching includes issues of self-esteem and general health as well as HIV/AIDS. Each matriculator covers about 1,000 children per week. Ubuntu is also opening counselling centres for abused and traumatised children. This programme is likely to be replicated in other areas by other NGOs.

The first biological study involving **AMREF** and London School of Hygiene and Tropical Medicine, based around Mwanza in Tanzania testing the efficacy of primary school peer education, is due for release this year. This should help to provide harder outcome data as to the effectiveness of an education strategy among the very young.

These projects aim to engage both sexes in behaviour modification: targeting men (and in these cases boys who will become men) is very important in breaking the cycle of gender inequality in sexual relations.

There remains much to be done to stimulate changes in the social attitudes of adults to support such initiatives amongst the young. **ActionAid** is specifically developing programmes in other parts of Africa to engage adult men in debates on sexuality and relationships. An initiative in Zimbabwe against sexual violence is gaining support amongst local chiefs. Traditional leaders in KwaZulu Natal have put together a proposal for the Global Fund part of which addresses the problem of women's sexual vulnerability.

### **Voluntary counselling and testing (VCT)**

Most medical interventions directed at AIDS include voluntary counselling and testing (“VCT”) as a very helpful component. Early detection of HIV improves medical and psycho-social support for individuals, and if counselling persuades individuals to disclose their status then this is an added benefit. Significant reductions in risky behaviour were noted among positive tested individuals in 35 recent studies<sup>69</sup> and where the effectiveness of VCT programmes have been measured in East Africa it is estimated that one HIV infection is averted for every 10 people accessing VCT programmes.<sup>70</sup> Individuals testing negative are given a reason to modify behaviour and protect themselves. In South Africa VCT is most likely to be successful when people have a strong incentive to get tested: e.g. pregnant mothers needing to ascertain whether a Nevirapine dose is required or people seeking access to one of the limited antiretroviral drug programmes. VCT is rarely successful when offered in isolation: but offered as a component of a programme addressing issues of care, socio-economic needs and stigma it is very helpful. It also needs to be offered continuously: it should not be a one-off test but a test which those testing negatively take at regular intervals to reconfirm their status and reinforce long term beneficial behaviours.

### **Treatment of sexually transmitted infections (“STIs”)**

Transmission of HIV during heterosexual sex is not automatic, particularly between healthy individuals. Sexually transmitted infections, however, are the perfect vector for HIV. Ulcers and rashes provide HIV with easy entry points during intercourse. In addition, infections reduce natural immunity to the virus.

It is difficult to measure the difference in transmission probabilities between people with or without STIs because of “co-factors” associated with these groupings. In the absence of STIs, HIV male to female transmission probability is 0.2% per sexual contact. In the presence of STIs including ulcers one study indicated that this probability increases to 6%.<sup>71</sup> Although this implies a thirtyfold increase in risk per sexual contact, because of other correlating factors (e.g. behaviour) within the test group the actual increase in risk per sexual contact is more likely to be tenfold.<sup>72</sup>

**Treating sexually transmitted infections reduces the spread of HIV effectively.**

Part of **LoveLife**'s strategy is to address the problem of STIs through education, counselling and treatment; more generally, prevention strategies cannot ignore the issue of STIs. Part of USAID's funding at the government level is for treatment of STIs.

### Prevention of mother to child transmission of HIV (PMTCT)

One of the most heartbreaking forms of transmission of HIV is from mother to child in utero, during birth and during breastfeeding.

In utero infection is rare, but the most vulnerable moment of the child is during birth, where transmission rates are approximately 30%. A single dose of the drug Nevirapine during labour each to mother and to child halves the risk of transmission to 15%, and costs only a few dollars. A full highly active antiretroviral drug (HAART) regime in the final trimester of pregnancy and during labour can almost eliminate transmission risk to under 1% but requires clinical supervision similar to a normal antiretroviral drug programme.

The South African government appeared to have committed to rolling out Nevirapine in maternity and obstetrics units across the country until the Medicines Control Council suspended Nevirapine's licence in July 2003. In any case roll out had been patchy with some provincial governments refusing to make it available whilst others, such as Western Cape, were greatly in favour and aiming to roll out the full HAART regime. At the time of writing it is not clear how the government's stance will affect Nevirapine provision in all the provinces.

The **Perinatal HIV Research Unit** at Chris Hani Baragwanath Hospital was established ten years ago and was a pioneer of PMTCT in Johannesburg, particularly Soweto, and is treating 8,000 mothers in respect of PMTCT. It has grown into a comprehensive AIDS research unit which, in conjunction with **HIVSA**, provides numerous clinical and psychosocial support services to AIDS sufferers in addition to PMTCT.

**Mothers to mothers to be** is an NGO based in Cape Town which aims to improve the delivery of PMTCT to mothers as well as providing psycho-social support to pregnant and recently delivered mothers at an extremely vulnerable time. **Mothers to mothers to be** is piloting the use of triple therapy HAART on pregnant mothers. The results are likely to be taken into consideration by the provincial government when debating whether to include HAART as part of its future PMTCT strategy. Breastfeeding is a difficult issue as the use of formula milk by a mother in a community clearly identifies her as HIV positive. **Mothers to mothers to be** is starting to test HAART on lactating mothers to see if this reduces transmission during breastfeeding and whether HAART would be an alternative to using formula milk.

It is a cruel irony that successful PMTCT programmes may exacerbate the orphan problem as children become more likely to survive their parents. Ideally it is desirable for PMTCT programmes to include family planning so that further pregnancies (and the concomitant risk of accelerating the onset of AIDS and the problem of future orphans) are avoided.

### People with HIV/AIDS

The better the care of people with HIV and AIDS, the longer they live and the better the quality of life. Such care indirectly benefits those around the patient – parents live longer, delaying the onset of orphanhood; patients live better, thereby requiring less attention from their own children or parent, and may even be able to sustain employment or income generation. Children of people with AIDS who are well-cared for can continue their education. It is also important that the stigma surrounding people with AIDS is addressed through care: people with AIDS may be thrown out of homes and communities but if organisations can support patients and educate communities through their programmes stigma and exclusion can be reduced.

Nutrition, treatment of opportunistic infections and basic palliative care methods can extend quality of life and life expectancy. Antiretroviral drugs go a step further and treat the virus in a way that can in most cases achieve substantial increases in longevity and allow people to lead near normal lives. Nutrition, good health care and access to palliative care is still appropriate even after starting antiretroviral treatment.

### Antiretroviral drugs

Antiretroviral drug treatment (or therapy) uses a combination of drugs to inhibit the replication of the HIV virus and boosting the patient's immune system. Antiretroviral drug treatment does not cure the condition, but it does bring very substantial clinical benefits to the patient. Once on an antiretroviral drug regime, which involves three drugs taken twice a

**Nevirapine halves the risk of mother to child transmission from 30% to 15%; however it is still not universally available.**

**Antiretroviral drugs prevent the collapse of an AIDS sufferer's immune system, however the treatment raises a number of practical issues.**

day, it must be adhered to rigidly: non-adherence reduces benefits and increases the likelihood of antiretroviral drug resistant virus strains developing. Furthermore, a degree of clinical sophistication is needed to determine the drug regime for a given patient. Antiretroviral drug treatment is complex, and this section is only a brief overview, the Appendix explains it in more detail.

Antiretroviral drug treatment is generally applied at Stage 4 of the disease's progression. Stage 4 involves a complicated clinical diagnosis, but generally refers to the final stage of HIV/AIDS and the point at which a person's "CD4" count drops to below 200 although it can drop to this level in earlier stages. In practice some practitioners start treatment earlier than Stage 4 (although generally using the CD4 count as the test) so as to avoid the problems associated with the morbidity due to tuberculosis found in many Stage 4 patients. A more detailed explanation of the biology of antiretroviral drugs can be found in the Appendix. Antiretroviral drugs have been described as having a "Lazarus effect" in bringing AIDS sufferers back to life from the brink of immune system collapse, though some patients develop resistance to the drugs and others (about 6%) have such extreme side effects that the antiretroviral drug regime is suspended. Over the last six years, however, the introduction of antiretroviral drugs in Europe and the US has helped cut AIDS deaths by over 70%. In Brazil, AIDS mortality fell by 51% between 1996-1999 when antiretroviral treatment became universal. The development of resistant strains, though, is gradually reducing the effectiveness of antiretroviral drug programmes in some countries and some medical scientists fear the development of resistant strains through ill-applied treatment programmes resulting in "treatment anarchy". In South Africa the extent of resistant strains is not yet known, and whether indeed strains will emerge under treatment programmes. Physicians consulted in South Africa are pleased overall with the results of antiretroviral drug programmes, but the problem of treatment anarchy emphasises the need for coherence and co-operation.

**Antiretroviral drug treatment is not yet available from the state, and NGOs are playing a vital role in demonstrating the efficacy of treatment and building capacity within the medical sector in anticipation of future rollout.**

The provision of antiretroviral drugs raises some practical considerations:

- **Patient selection:** who gets priority when resources are finite? If one's objective is to delay or prevent orphaning, then mothers may be favoured over other members of society, possibly leading to unforeseen social consequences.
- **Nutrition:** reasonable nutrition levels are a crucial component of the antiretroviral drug regime and access to income-generating activities (sometimes part of a programme) is helpful in this regard.
- **Adherence:** this is key to the success of antiretroviral drug treatment and there are several successful methodologies to promote good adherence levels in patients being piloted in South Africa.
- **Counselling and support:** this is essential to manage patient expectations and to promote adherence to the drug regime and responsible behaviour with sexual partners.
- **Support groups:** these encourage adherence and help patients and families avoid stigmatisation.<sup>73</sup>
- **Clinical supervision:** the administration of treatment is extremely labour-intensive during the initial months and the training of doctors and nurses to administer the programme is crucial. Primary health clinics and even tertiary hospitals show a poor record of administration of antibiotics to TB patients,<sup>74</sup> so enormous capacity building would be required should the government roll out antiretroviral drugs.
- **Access to laboratory testing:** this is necessary to keep track of progress.
- **Treatment of opportunistic infections:** access to ordinary medicines for infections and ailments, together with timely delivery of antiretroviral drugs to outlets is essential. Again, primary health clinics are frequently under stocked with basic medicines.

There is probably insufficient infrastructure at present to introduce widespread antiretroviral drugs responsibly and effectively. In well-managed programmes the adherence of patients is extremely encouraging. However, the medical profession as a whole in South Africa is not experienced in antiretroviral provision and unless this capacity is developed, it is difficult to foresee how patients will be able to adhere to the most appropriate regimes. In addition the laboratory testing of patient bloods which is a necessary part of a treatment programme is not available in all parts of the country. On the other hand, once capacity is developed and programmes developed, the clinician's life may be simplified as the need to treat a range of complex opportunistic infections is reduced. In some respects the epidemic represents an opportunity to develop health systems.

The Joint Report (of the health and treasury task team, described earlier) does not mention how NGOs and the voluntary sector might play a role in developing South Africa's nationwide antiretroviral programme. Now that the Cabinet has endorsed the principle of

providing antiretroviral treatment through the public health service and has requested the Department of Health to develop a detailed operational plan, it will be essential for NGOs to collaborate with provincial authorities in developing programmes. This will be important not only in developing infrastructure efficiently and effectively, but also for planning an exit for private funders.

Currently there is an urgent need for seed funding to develop infrastructure and a training platform in anticipation of the future governmental funding. Medical NGOs and philanthropists can therefore play a vital role in:

- Developing models and evidence-based protocols which could realistically be rolled out to wider audiences;
- Building capacity within the government health system to cope with antiretroviral drugs and related health issues, particularly in the rapid training of medical and related personnel in antiretroviral therapy;
- Offering a bridgehead service whilst provincial governments and national government develops operational plans and mobilise funding;
- Saving lives while policy is debated and programmes are developed.

Concomitant social and cultural observation on the effect of antiretroviral intervention methods is very helpful in determining for the future what will work best. This would be in line with the Joint Report in determining if antiretroviral therapy is epidemiologically beneficial or not.

There is a potential risk or ethical dilemma for private funders relating to the longevity of antiretroviral drug provision. Whilst medically possible, in reality it is extremely difficult (and ethically questionable) to cease treatment of patients with antiretroviral drugs once started (apart from treatment in connection with PMTCT efforts). The effects of treatment cessation on development of drug resistance is not yet clear: medical opinion appears divided. Programmes can be started in expectation that more substantial funders will step in at a later date, but ultimately if this does not occur private funders will have to face the possibility of continued funding or cessation of programmes.

The international NGO **Medecins Sans Frontiers ("MSF")** has an ambitious programme treating 600 patients in Khayelitsha, the biggest township in Cape Town. MSF uses three local clinics for delivery and some key medical personnel have been brought in from MSF overseas. Clinical supervision of adherence is intensive, and selection of patients involves a community-based committee. The programme includes an extensive education programme, and training for local medical personnel. MSF is able to import generic drugs from Brazil. Having demonstrated effectiveness in an urban environment, MSF is piloting a programme in a rural area of Eastern Cape which would be a more challenging prospect.

**Crusaid**, a UK-based NGO, has funded a smaller programme based in Guguletu, another large township in Cape Town. It has been developed and managed by local South African doctors using community infrastructure. Crusaid has provided funding, but the expertise is local. Funding is secured for 180 patient spaces, but the optimal number for the infrastructure now in place would be 300. The Guguletu project relies more on trained lay counsellors who are themselves HIV infected to provide adherence supervision as a pilot for other programmes. The project buys non-generic drugs locally at prices which are starting to become comparable to imported generics. Crusaid are wanting to develop this site into a centre of excellence and training facility for antiretroviral therapy clinicians. In the light of the recent government announcement this would be very helpful.

The **Perinatal HIV Research Unit** at Chris Hani Baragwanath Hospital in Johannesburg is running several antiretroviral programmes, some access programmes, some current and past (but with treatment continuing) pharmaceutical trials. They estimate that they have 500 patients being treated (200 of whom are children) but that there are 2,000 known patients which could be rolled into the access programme. Most of the patients are on drug trials.

**Pangaea Foundation** (born of the San Francisco AIDS Foundation) is supporting small "seed" antiretroviral drug programmes using local infrastructures in four sites: Durban (St Mary's Hospital), Guguletu (the Crusaid project), Masiphumele in Western Cape (to be managed by the Guguletu team) and Soweto (Perinatal HIV Research Unit at Chris Hani Baragwanath Hospital). It is planning to develop sites in other provinces and have identified another three to five possibilities. Any of these programmes could be expanded in terms of patient slots and time.

**The co-operation between private funders and local authorities is extremely important: many NGOs use community infrastructure to implement projects.**

**ARVs are not widely available and many projects providing drugs have not reached sufficient scale.**

At the time of writing, **ARK**, a UK based funder, was negotiating an antiretroviral drug provision project for the Cape Flats townships with the provincial administration of Western Cape, which, if approved would be the largest such project to date.

Since 2000 **Treatment Action Campaign** has been active in increasing the treatment literacy of clinicians, carers and volunteers with regard to care and antiretroviral therapy,

### ***Antiretroviral drugs to children***

This presents a terrible humanitarian dilemma. In a resource-poor environment where treatment is rationed, very young children are neither carers nor bread-winners. The preservation of children at the expense of adults can ironically increase levels of orphanhood by keeping children alive to become orphans on the one hand, whilst allowing adults who might care for children to perish.

In practice, antiretroviral drugs programmes increasingly favour treating whole families where possible. This reduces tensions within families: mothers are unlikely to accept treatment themselves whilst watching the demise of a child, and a treated child is less of a burden on family economics, emotions and care logistics.

**Kidzpositive**, based at Groote Schuur, one of the main Cape Town hospitals, provides antiretroviral drugs to an estimated 175 children and is extending its treatment to the mothers of children in its care. It also provides comprehensive health care for affected families, counselling, nutritional support, help accessing social welfare grants and an income generating project.

### ***General care and support***

Good care in terms of nutrition, prevention of opportunistic infections (through education for instance), and treatment of opportunistic infections can delay the onset of AIDS and the need for antiretroviral drugs. This delay saves resources and should be viewed as an integral part of treating any cohort of patients. General counselling and support can contribute to all these objectives and the need for such care, including palliative care, continues once antiretroviral treatment has begun. Although the government is considering nationwide provision of antiretroviral drugs, it is unlikely that the treatment will become available quickly to many sufferers. In any case there will always be patients who do not have access to drugs for clinical, social or geographic reasons. They may not be appropriate candidates because of resistance and side effects or may live in areas beyond the reach of coherent antiretroviral delivery. There are also those who are HIV positive and have AIDS who have not yet reached the stage at which antiretroviral drug treatment is appropriate requiring support and treatment.

**HIVSA** and the **Perinatal HIV Research Unit** (operating together in Gauteng) take “wellness” particularly seriously and are involving primary healthcare nurses/lay counsellors in Soweto to help manage 1,000 patients in the pre Stage 4 development of the disease.

Access to clean water is an issue for people with HIV and AIDS, whether on antiretroviral treatment or not. There is no easy answer to this given that the provision of clean water, particularly in rural areas, is expensive. NGOs in KwaZulu Natal are vociferous in objections to local government charging high connection fees. Home based care programmes should include education on water hygiene.

### ***Nutrition***

Although there appear to be no clinical studies comparing malnourished control groups with well-nourished patients, medical practitioners agree that nutrition is a crucial component in the treatment of AIDS<sup>75</sup> particularly as AIDS patients require increased levels of protein, vitamins, minerals and calories. Malnutrition is often a key problem associated with AIDS patients resulting in a vicious downward spiral of reduced energy, increased sickness and reduced ability to generate income, thereby further reducing nutritional intake. It is unfortunate that the southern African diet has become less healthy during the last century due to shifts in cultivation patterns. A reversion to more varied foods would boost immune systems and improve the health of people with HIV and AIDS.<sup>76</sup> Some projects are trying to encourage and improve cultivation activities in both rural areas and also townships where small plots and even used car tyres can provide opportunities to grow nutritious foodstuffs. Alternatively “EPAP” is a specially developed food based on mealie meal (the staple maize porridge diet of many South Africans) with added nutritional supplements which can provide 90% of an adult AIDS patient’s nutritional requirements for a cost of R60 (under £5) per

**Nutrition and palliative care massively improve the quality of life for AIDS sufferers.**

month. EPAP is applauded by many clinicians and is a valuable component of many treatment programmes.<sup>77</sup>

### **General medical and palliative care**

The prevention and treatment of opportunistic infections, such as thrush (oral as well as genital), is crucial to maintaining patients' well-being. As an example, patients suffering from oral thrush are often unable to eat.<sup>78</sup> TB and forms of the herpes virus also commonly afflict AIDS patients in debilitating and painful ways. Diarrhoea is a regular problem, and untreated diarrhoeal infections further exacerbate nutrition difficulties and accelerate the progress of AIDS.

*"Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount."*<sup>79</sup>

Palliative care is important because it is not only humane, but also give patients dignity and provides families with support and sense of value: its benefits are discussed in more detail below. The driving force behind palliative care appears to be the **Hospice Palliative Care Association of South Africa (HPCASA)** which has been developing palliative care protocols and curricula. During 1999/2000 they piloted the Integrated Community-based Home Care (ICHC) model that was developed by **South Coast Hospice** in 1996. The ICHC model has now been officially adopted by the Department of Health as one of the recommended models.

### **Integrated community homebased care (ICHC)**

The **Hospice Palliative Care Association of South Africa (HPCASA)** in conjunction with the University of Natal piloted the ICHC model in seven hospices and found that it was effective in a variety of settings from rural to metropolitan. **Naledi Hospice** in Bloemfontein was selected as an urban hospice. ICHC reduces hospital admissions and average length of stay in hospital. This focus on the home environment reflects the strategy of the hospice and palliative movement in the UK which also favours the home as the preferred place for treating terminally ill patients. **HPCASA** has 56 hospice members and 38 outreach members, with ICHC being rolled out by the membership.

In the ICHC model, hospices act as "centres of excellence" training "caregivers" as well as health professionals. ICHC links hospices, primary health care clinics and hospitals as well as caregivers in developing a care plan for patients. Caregivers work in teams with nursing and medical supervision, social workers and bereavement counsellors who then go into the community to train and support carers of AIDS patients in the home. The patient's carers at home are shown how to nurse the patient, how to avoid patient to carer transmission of the disease, how to alleviate symptoms using local remedies and basic medication, and are given advice on nutrition. Families are regularly visited by caregivers who provide support and may supply gloves, basic medication and other equipment if available. A home's access to basic items and commodities (such as paper or plastic bags) has to be taken into account when deciding how to care for the patient. If more complex care is required, or an opportunistic infection needs treatment, the caregiver can call upon a qualified nurse to provide stronger drugs, or advise on whether to admit the patient to hospital or involve the local Primary Health Care Clinic. The caregivers themselves receive support to prevent burn-out which is otherwise common.

After the patient is admitted to hospital and treated, the hospital is better able to discharge the patient in confidence that the patient will receive adequate care back in the home and community.

ICHC also provides psycho-social and spiritual support to patients and the bereaved. There is anecdotal evidence from operators in the field that the psychological well-being of patients has a bearing on longevity and quality of life, helping to combat the isolation and depression frequently associated with AIDS. Such intervention also mitigates the trauma for children watching the passage of life of a loved one through sickness to death, and reduces the feelings of helplessness among family members.

Bereavement support is part of this process. Interventions are crucial if the child is to recover sufficiently to control their own lives (for example saying no to sex), make the best of education, and eventually become independent adults. Memory Boxes or Memory Books are now being used to help this process (see below).

**The Integrated Community Home based Care model enables communities to be part of the medical response to the crisis.**

**Humane care for the sick and dying helps the bereavement process for those left behind, including children.**

The advantage of ICHC is that it uses caregivers who are embedded in the community and know the families concerned and are always on the look out for new cases. It also provides an entrée to the family when providing other services such as bereavement counselling, help with placement planning of children, placement and registration once the children are orphaned.

Families often contain more than one patient, in which case ICHC can treat and support both patients via the same intervention. ICHC is not expensive (£250 for the last year of a patient's life) and can benefit large numbers of people. Below are some examples of projects providing the need for such care.

**South Coast Hospice** covers 1,517<sup>80</sup> patients in an area consisting of 1,000 sq kms of coastal strip and hinterland centred around Port Shepstone in KwaZulu Natal through its ICHC programme. There are 8,000 known HIV positive people in the catchment area, although with up to one million people in the area this surely represents only the tip of the iceberg, as the antenatal and voluntary counselling testing clinics in the area are recording 52% infection rates. The hospice has only seven beds but also has a training centre attached where nurses and caregivers can be trained. There is a satellite bedded unit in the rural area. South Coast also offers psycho-social support to patient's families, including services to orphans. The most recent ICHC team is based at a clinic 65 kms from Port Shepstone.

**Naledi Hospice**, based in Bloemfontein, Free State, is a similar model to South Coast: two small hospices (one paediatric 15-bed unit, one seven-bed adult unit) which are centres of excellence where ICHC teams are trained and developed to service local needs. The area covered by Naledi is estimated to encompass one million people and includes Botshabelo, a rural town 50kms outside Bloemfontein. The Free State claims some of the highest infection rates in the country (26%<sup>81</sup>) and Naledi estimates there are 10,000 patients within its range although they actually treat about 3,500 adults and children in any one year. Like South Coast it also extends its services to orphans and vulnerable children which is the largest part of their programme. Naledi has up to 600 paediatric patients at any one time.

**Community AIDS Response** (CARe) in Johannesburg is not a hospice but works closely with HPCASA providing care to 10,000 patients. CARe works on a system of graduating volunteers (volunteers proceeding through a step process eventually becoming full staff). There are roughly 40 volunteers and stipended field workers as well as 14 fully paid staff. Each volunteer covers about 270 patients out of four satellite offices near health clinics. CARe offers a package of care, support, counselling and education to people with AIDS and their caregivers. Nutrition is an important aspect of their work, and CARe helped to develop EPAP, described earlier.

### *Support groups*

Mutual support and contact are essential to ensure psychological comfort and improved quality of life.

The psychological well-being of patients' effect on life expectancy should not be underestimated. Interviews with HIV positive mothers in support groups emphasise the importance of mutual support and contact – without the support groups they would have lost the will to live. Support groups are less expensive than one-to-one counselling, and can reduce and even replace the need for one-to-one counselling. They are easy to establish, and many projects offering support either to children or to patients have support groups as part of their activities. **Cape Town Child Welfare** has support groups as an essential part of its intervention. **Pine Town Child Welfare** has set up successful support groups attended by sixty-five women. At **Moretele Hospice** the weekly support group has caught on more strongly: one hundred patients (well over half) attend. The support groups are often combined with self-sufficiency projects, e.g. income generation or gardening. Not only is income improved (and by implication nutrition), but self-esteem is also improved and group income projects provide social opportunities as well. **MSF** co-ordinate over 40 support groups in Khayelitsha and are likely to publish findings on good practice and their social work is regarded as an important auxiliary service to antiretroviral drug provision.

There is enormous stigma associated with having HIV/AIDS. Even in a society where death is commonplace from other causes, few people want to associate with AIDS patients: investing social or other energy in someone who is dying is viewed as wasted effort. An HIV positive woman for instance is seen as unclean, potentially polluting the men in her community.<sup>82</sup> Support groups for people with AIDS, coupled with community education, can help to overcome stigma within communities and reduce the isolation experienced by AIDS sufferers.

Support groups are also important in helping to prevent abandonment of children by HIV positive mothers who expect their children to be positive too and cannot face caring for a

sick child. **Mothers to Mothers to Be** help support mothers through this extremely vulnerable time.

### **Children with AIDS needing palliative care**

NPC estimates that there are 800,000 children who are HIV positive. Adult palliative care initiatives generally include care for children as part of their programme. Day care centres are increasingly being developed as a solution for carers of sick HIV positive children who need to work (or go to school themselves). **Naledi Hospice** offers this service in several sites in Botshabelo.

## **People affected by HIV/AIDS**

*"Orphanhood is a process that starts long before the death of the child's caregiver."<sup>83</sup>*

There are many many people, especially children, within the circle of a person with HIV/AIDS who are badly affected by the consequences of the disease. Children are probably worst hit, but also affected are the parents of sufferers, siblings, relatives, and the wider community who are left to pick up the pieces left behind by bereavement and trauma.

Services to children include:

- **Registration and grant access:** registration of birth certificates and death certificates is necessary in order to obtain grants available from the Social Development office.
- **Placement of orphaned children:** either with their own extended families or with foster parents.
- **Nutrition:** whilst carers are very sick or grants are being processed, children may need basic nutrition.
- **Education:** and will also need funds for education (fees and school uniforms) and younger children should ideally attend early education centres.
- **Psychosocial support:** bereavement counselling and support groups.
- **Shelter:** emergency shelter and longer term shelter for those without any families.

These services are provided by a range of organisations, for instance hospices will provide some services to orphans, e.g. registration and bereavement counselling which will start before the parent or caregiver has died. Child welfare organisations will provide registration and bereavement counselling services, and also material support for emergency cases, shelters, foster care services, carer support groups and income generating schemes.

When helping orphans and vulnerable children it is important not to discriminate positively in favour of those orphaned by AIDS over those orphaned for other reasons. Such discrimination has a divisive effect in communities as well as being inequitable.

HIV positive children are more likely to be abandoned than their negative counterparts as mothers feel unable to cope with the prospect of caring for a sick child. In turn these children are more difficult to foster.

### **Orphan registration**

There is a social services system in South Africa which varies from province to province in terms of efficacy and in providing child support grants, foster grants, old age pensions, disability benefits and other support. A box in Section I describes the main components of this system.

Carers of orphans are entitled to receive a state foster grant of R450 (£36) per month. In some provinces there is ambiguity as to whether orphans placed with grandparents or near relatives qualify, but broad consensus is being reached that any orphan with any relatives can receive the grant.

In order to receive this grant, which is generous relative to the minimum adult wage of R1,000 (£80) per month, the orphan must have a quantity of paperwork in order:

- Correct birth certificate
- Parent(s) ID
- Parent(s) death certificate(s) and, in some areas, their birth certificates.

**Complex access procedures and the need to have the correct paperwork prevent many orphans from accessing grants available from the state.**

Once grants are accessed, the child's carer is able obtain nutrition and education for the child – but there is often an interim period of acute risk.

Certificates are provided by the Home Affairs Office which often experiences application bottlenecks. The application for a foster grant can then be made to the Department of Social Development but the process includes a court hearing by the Justice Department formally to "place" the child with its new carers.

This process can take up to 18 months in some areas (Kwazulu Natal), and in extreme cases fails entirely due to mis-processing. Well-resourced centres (Bloemfontein) can achieve the processing in three months.

During the registration period the orphan is at acute risk – he or she has no parents and no income. Relatives and neighbours are often unable to support orphans without the foster grant. Orphans generally have no idea as to their entitlements or how to access them. Literate adults are required to negotiate the complex access procedures.

Interventions which assist in orphan registration provide an invaluable service in enabling and accelerating placement and grant access. Once the child is placed and income being received, his or her life (in the most basic sense) can "restart". Other interventions can then be brought to bear.

**Acess** (Alliance for Children's Entitlement to Social Security) is addressing orphan support through advocacy. Hospices and child welfare organisations are active in helping with this type of orphan support.

### Memory boxes, bags and books

A Memory Box is created for the child by its parents or by the child itself (lovingly and beautifully hand-decorated) and ideally should contain<sup>84</sup>:

- **Documentation:** birth certificate, parent's ID, space for parent's death certificate.
- **Family album:** stories, photographs, drawings connected to the child's life with its parents.
- **Family tree:** means of identifying relatives and potentially tracing them at later dates.
- **Will:** desired placement of child with trusted relative, inheritance of possessions.
- **Letters for child:** these will be for the child throughout its life providing guidance, hopes, sentiments.
- **Treasured objects.**

A Memory Box project provides a conduit through which people can confront AIDS and its implications. It is a useful tool to place at the heart of the bereavement process.

Paperwork and placement issues are therefore tackled sensitively prior to the death of the parent, which helps the registration process.

Some projects favour the child creating the Memory Box as a crucial part of the therapy and preparation for the parent's death. Some projects use Memory Box projects to support the terminally ill parent and may develop them as part of a support group. Some projects have Memory Boxes as part of their family counselling sessions.

A child's own sense of identity is crucial in order to mitigate trauma and sense of loss.

**South Coast** offers services to 453 orphans and vulnerable children through their work with memory boxes and they have a social work team undertaking registration and placement of orphans.

Like South Coast, **Naledi** offers bereavement services to 930 orphans and vulnerable children but is more heavily involved with the provision of material support, and also supports six day care centres for children with food parcels and transport.

The **Bambanani Happiness Box Project** run from the Aids and Society Research Unit at the University of Cape Town uses Memory Boxes and other types of art work not only as a therapeutic and counselling tool, but also to help with participatory research whereby individuals explore their own stories in transformative ways.

## Orphan placement and foster care

Proper placement is crucial to the emotional development of children. As mentioned before, registration is a vital part of this process. In some cases placement is possible with a member of an extended family or neighbour. However there are cases where no such adult exists: in townships families are often nuclear and the romantic ideal of the extended family is a myth. Increasingly foster care schemes are being developed to place orphans with women or couples whose children are grown up or who are unable to conceive. Between four and six children may be placed, although there are schemes which place more with families. Small family homes of larger numbers of children are also seen as a solution in the absence of better alternatives.

**Foster care is often the best option available to an orphan; the state foster grant has helped the foster movement to develop.**

The existence of the state foster grant has helped the foster movement to grow although there is a danger that orphans may become commoditised as sources of income. Given the precarious state of child protection the vetting of potential foster parents is difficult, but in general foster placement offers better chances of protection than no placement at all.

**Pine Town Child Welfare** in Durban has 1,153 foster children and 800 foster parents on its books and provides screening and training of foster parents, supervision/follow up, registration and support groups (14).

**Johannesburg Child Welfare** has 1,333 foster children which are similarly supported. It also has an adoption case-load.

**Umtha Welanga** is a specialist foster care initiative in Cape Town. Currently the small team of five handles a caseload of 120 children but is aiming to quadruple in size in order to meet demand in Cape Town.

**Ikamva Labantu**, which is a large umbrella organisation in Cape Town offering a wide range of community services, also has a foster care programme covering 265 children on a slightly different model where larger numbers of children are placed in family care where there is one matriarch and supporting female relatives.

## Material support – nutrition

Money is often short while people are sick (being unable to earn a living but at the same time requiring expensive medication) and in the period after their death. Sick people are entitled to a disability grant of R620 (£50) per month, but only if they are sufficiently "disabled," which entails a subjective judgement. Sometimes weight is the benchmark used (50 kilograms for an adult), and in some provinces the grant has been suspended altogether because of fraudulent claims.

Consequently, nutrition levels witnessed in families with patients or recently dead carers are shocking and development levels in children retarded. Food parcels are often the only way to keep children adequately nourished. Families awaiting foster grant approvals often cannot afford to feed extra children and so reject them. It costs little to keep a child in nutrition if EPAP is distributed but infrastructure is required to provide nutrition to the neediest families. Many operators offering children's services automatically provide food parcels as part of the support.

## Material support – education

There are two types of education relevant here: minding very young children and preparing them for school, and education from primary school onwards where uniforms and school fees are the concern of those intervening.

Education of orphans is precarious unless a grant is accessed. Moreover, school is often the children's only square meal. Children cannot attend school without uniforms and payment of small "fees" and so they drop out unless assistance is provided. School fees vary depending on the school, but are typically between R50-300 (£4-24) per term. The total cost of education averages around R750 (£60) per annum.

Early education and care of very young children is not provided by the state but early education centres play an important role as places of safety for orphans and vulnerable children whilst carers go to work or school, or are too sick to look after very young children. They may also provide nutrition. **South Coast Hospice** has started a day care programme for rural pre-school children in collaboration with one of the KwaZulu Natal tribal authorities.

**The provision of food, counselling, shelter and items necessary for attending a school are important for helping families affected by AIDS.**

## Combined support

**Moretele Sunrise Hospice** in Gauteng supplies regular nutritional supplements to AIDS affected families and funds for school uniforms, books, fees for orphans in addition to facilitating registration with the local social services. **God's Golden Acre** provides similar support as part of its outreach programme. This is especially required as the local social services in rural KwaZulu Natal barely exist. In addition God's Golden Acre helps to repair homes as in rural areas mud structures literally fall down as sick and dying adults fail to maintain thatched roofs.

**Ikamva Labantu** supports 350 early education centres run by local women. Ikamva's vision is to use its connections with the early education centres to identify children at risk and provide additional services (social work, medical, counselling) from a network of Family Enrichment Centres which it is in the process of setting up. Its 350 early education centres cover around 17,000 children.

## Counselling for bereaved, care of carers

Bereavement is hard to bear particularly after witnessing long illnesses. It can sometimes be difficult to reach children who have suffered so much and lost their childhood. Self-esteem will be extremely low and in the worst cases children will have been abused by neighbours or relatives during the period of vulnerability.

It is difficult to gauge how these children will mature. Many people in the field fear that they may become alienated and excluded as a result of their experiences. Some children will express this by withdrawing, others by becoming angry and aggressive. Counselling can help children adjust to such extreme circumstances, and although it is difficult to quantify the success of counselling, hospices and child welfare societies, as well as other community based organisations, are particularly active in providing counselling services. Increasingly child welfare groups are using children's support groups as an effective (and cheap) counselling tool. Memory boxes (see above) are also a useful tool.

The requirements of a child who has been sexually abused by a relative or neighbour will be much more intensive than the norm. This is a specialism of **Johannesburg Child Welfare** which counsels over 1,000 abused children per annum and is pro-active in training professionals from all over South Africa.

Carers left with children of deceased parents benefit from support groups just as people with AIDS benefit from support groups. They provide social opportunities to people who may otherwise feel isolated as well as comfort during a grieving process. **Pine Town Child Welfare** offers support groups to carers; **Cape Town Child Welfare** takes this a step further by having support groups for the orphans themselves as well.

Carers of HIV positive children need particular support: **Naledi** and **South Coast Hospices** offers advice and guidance to such carers as part of the ICHC programme.

## Institutions and shelters

The problem of orphans is so large that in some communities the ideal models (placement with families) may not be achievable. So if a child has no-one to look after them, there may be no option but to place the child in institutional care, preferably within local communities. HIV positive children are particularly at risk of abandonment and less likely to attract fostering or adoption. Children who end up living on the street harden quickly and a street child requires intensive rehabilitation. Street children often come from disintegrating families split by poverty, which is why interventions keeping the remnants of the family together are so important. Good shelters will take trouble to trace communities and families as quickly as possible to try and re-place children back at home, but often there is no-one for them to go to.

**Temba Club** has a mission to eliminate the problem of street children in Margate, near South Coast and close to the border of Transkei, a particularly poverty-stricken homeland. Temba is already offering emergency shelter to 60 children and has a mobile unit covering cases at risk in the rural areas from which these children flow.

Shelters or institutions are expensive and sub-optimal options, but the state does provide statutory grants to children in sheltered accommodation of R1000 (£80) per month. The sector is poorly regulated, and so many shelters or institutions are not well run, although some do excellent work.

**Children who have been abused need specialist help. Those who are bereaved benefit from support groups.**

**Given the scale of the problem, shelters and institutions are sometimes necessary, but need to be well-managed.**

Small family homes offer an alternative, a solution offered by **Pine Town Child Welfare**. **God's Golden Acre** provides a cluster of small family homes within one compound.

**Cotlands** specialises in residential care and education for around 100 children a year including abandoned infected children and babies. It also has a satellite outreach operation in a remote area of KwaZulu Natal.

### Sustainability of interventions

**Community involvement is crucial for maximising efficacy and efficiency.**  
**Ideally communities and families acquire the skills of self-sufficiency.**

If a support group includes a *profitable* income generating scheme then so much the better. Self-esteem, independence and motivation are useful outcomes of such schemes as well as the importance of livelihoods in providing nutrition and access to transport. As poverty is linked to both the spread of AIDS and the problems of affected people, poverty alleviation is important. Many hospices, NGOs, and community based organisations have an income generation programme in their portfolio of activities, although not all income generating schemes are genuinely profitable and so such schemes need to be carefully assessed.

The production of cheap food for both nutrition and income purposes is important to many families but not all have the know-how or means to "garden". There are enterprising initiatives to teach such skills, such as the production of mulch and compost for gardens, and the planting of fruit trees which are less sensitive to rainfall. **Valley Trust** in KwaZulu Natal is working to improve production, particularly among AIDS affected families.

On a more macro level, it is clear that the more a community can marshal its own resources to cope with the crisis, the better: developing and supporting local philanthropists independent of outside resources is essential to developing civil society. Therefore, responses which include large numbers of volunteers and involve community based and grass roots organisations not only provide better cost per user results, but are also more likely to survive and take hold. Similarly it is important that external support does not undermine community initiative and motivation.

The role of people with AIDS in all interventions is important. As activists, educators, advocates, and advisers, people with AIDS can be very powerful in driving change. Nkosi Johnson, the 11 year old, born HIV positive, who won a legal battle to be admitted to primary school and spoke at the opening ceremony of the 13th International AIDS Conference in Durban, did an enormous amount to de-stigmatise AIDS. NGOs also report that people with AIDS can encourage peers to change behaviour.

This section has given an overview of specific interventions that are being made to combat AIDS in South Africa, as well as emphasising the multi-faceted methodologies favoured by most community-based NGOs. We now turn our attention to an analysis of the outcomes generated by such interventions in the lives of the beneficiaries. The outcomes achieved differ according to interventions and these, in turn, vary by cost. Any grant-maker or donor supporting organisations tackling AIDS in South Africa must consider the balance of benefits and costs when deciding which projects to support.

**Any grant-maker or donor must consider the balance of costs and benefits when deciding which projects to support.**

## Section V: Outcomes from interventions

**The resources available to tackle HIV/AIDS fall far short of the need. It is therefore desirable that private giving is targeted to interventions which have demonstrably effective outcomes. Fortunately, many giving opportunities in South Africa have proven outcomes and it is difficult to spend money without doing some good. However, unlike governments, which may choose interventions which are politically uncontroversial and popular, donors have the freedom to focus on the interventions which are most effective.**

### Introduction

The outcomes available from the different interventions discussed in Section IV are:

- Preventing HIV from spreading to adults or children;
- Treating those with HIV/AIDS to extend their life;
- Caring for those dying of AIDS to improve the quality of their final years and support families trying to cope
- Protecting orphans and children who are at risk of losing their caregiver to AIDS.

Some interventions will have outcomes fitting a number of these categories, some will fit just one. When assessing outcomes it is often useful to distinguish between the cost per user and the cost per successful user. All charitable activities are targeted towards achieving positive outcomes. But some are more successful than others. An intervention which succeeds in only 10% of interventions has a cost per successful user ten times higher than its cost per user. As intervention methods vary in their success rates, these two measures of unit cost are often considerably different and both are of interest to donors.

The effectiveness of each intervention can be assessed on three levels:

- (1) Raw output, e.g. the number of condoms distributed by a safe sex project or the number of patients receiving antiretroviral drugs.
- (2) Direct outcomes, e.g. the increase in condom use or the number of patients whose immune systems recover as a result of the drugs.
- (3) Quantified impact, e.g. the number of HIV infections prevented, the years of life gained by patients, adjusted for quality, or the economic benefit to society.

The output (1) is by far the easiest of these to measure, and is therefore the level of assessment most frequently quoted by charities, but is not very useful in making comparisons. Considerable information gathering is needed to measure the outcomes (2) reliably, but these figures are much more useful in assessing the effectiveness of interventions and allocating resources. Comparable data on the impact (3) is the most useful measure of effectiveness and enables funders to make clearly informed choices between different kinds of intervention. Unfortunately, complex calculations, involving assumptions on issues such as the epidemiological spread of HIV and the expected life span of a person without HIV, are needed to move from the direct outcome data to a good estimate of impact.

Ideally good level (3) information would be available for all the different interventions. This could then be compared to the cost of each intervention to estimate cost-effectiveness. This would enable a comparison of the cost of funding one sort of intervention versus another. Where possible this section quotes level (3) cost-effectiveness data; although this data often comes from other African countries, their circumstances are sufficiently similar to South Africa to ensure relevance. Unfortunately the information available is not as broad or reliable as one might hope.

Measuring outcomes is an activity fraught with problems. There are considerable difficulties both in defining success and in costing projects aimed at success. There is also the problem of longevity of success in projects trying to achieve long term societal changes which are not measurable within a two-three year time scale.

Nevertheless, grappling with these difficulties is a useful exercise, because some understanding of what constitutes success and the cost effectiveness of the interventions is better than none. Because of the difficulties, the discussion which follows should not be regarded as conclusive but is aimed at helping donors interested in directing funding to AIDS projects in South Africa.

**Private donors are free to choose the most effective interventions.**

**Understanding the outcomes is an important part of the assessment process.**

## Outcomes of prevention

The best place to tackle any virus is at the point of infection. The effects and impact of averting infections are far-reaching: numerous economic and social costs (the cost of treating sick people, lost earnings capacity and productivity, loss of skills and knowledge, social ills associated with loss of carers of children) are avoided if infections are avoided. In addition, the avoidance of infection among sexually active adults and adolescents also results in added protection for their partners and their partners' partners and so forth. For children, the avoidance of infection represents an opportunity for a healthy life.

From an epidemiological perspective the focus of intervention should be stopping the most infections for the minimum cost, and therefore a useful outcome measure is the cost "per infection prevented" (pip), this is analogous to the cost per successful user. It should be noted, however that the only conclusive way of preventing infection would be a vaccine, and the interventions discussed below may merely delay when an individual is infected, rather than preventing them from ever being infected. Nonetheless, although these prevention initiatives do not make individuals immune from HIV, they do slow the rate of infection through the population.

## Education and behaviour change

Condoms are one of the principal methods of preventing adult infections. There appears to be surprisingly little recent or satisfactory data on the cost-effectiveness of male condom distribution. A study in Kenya of prostitutes being given access to male condoms and treatment for sexually transmitted diseases showed that this intervention was extremely cost effective at £8-12 pip.<sup>85</sup> However it is difficult to determine how consistently they are used in the long term, and to what extent other factors in a distribution programme (e.g. general health education, treatment for sexually transmitted diseases) might be affecting transmission rates. In Kenya a study on female condom distribution showed a range of costs depending on whether the group targeted were sex workers (£193 pip) or medium risk women (£1,532 pip).<sup>86</sup> This extremely wide range reflects the number of occasions a woman is exposed to the virus and, therefore, the probability of being infected. Generally it seems that in populations where prevalence is low and still most noticeably present in high risk groups (commercial sex workers, truck drivers) and that targeting a particular group is a cost effective containment measure but that it must include education and general health. Equally, education programmes targeting the general population are assisted by the availability of condoms from user-friendly sources.

For youth education programmes in Eastern Cape the cost per user is £10-20. Reliable data on the pip cost of education programmes is not yet readily available, although it is hoped that a study by AMREF in Tanzania will be available later this year. However, we can say that providing people with prevention education provides them with opportunities to make more choices regarding self-protection than would otherwise have been the case.

## Voluntary Counselling and Testing

Voluntary Counselling and Testing (VCT) is a prevention tool because of its beneficial effect on behaviour. Evidence from Tanzania and Kenya from 2000 shows around £307 pip.<sup>87</sup> VCT has a low hit rate in terms of infections prevented though it costs just £15-18 for each user. An additional outcome is that any user testing negative has the benefit of choosing to protect themselves, assuming they are in a position to negotiate safe sex. Some studies suggest that users testing positive are just as likely to modify behaviour and that counselling couples jointly has been found to be the most effective methodology.<sup>88</sup> A further benefit is the opportunity for counsellors to advise HIV positive people on healthy living and nutrition.

## Treatment of sexually transmitted infections

Since sexually transmitted infections generally increase the likelihood of HIV transmission, possibly tenfold (see Section IV), treating them is an important method of AIDS prevention. A study of STI control programs in Tanzania in 1997 showed costs of £135 pip (at 1993 prices – approximately £200 at today's).<sup>89</sup> The aforementioned Kenyan study even estimated that a combined STI treatment and condom distribution program for sex workers in Kenya cost only £10 pip.<sup>90</sup> It is unclear whether such incredible cost-effectiveness can be replicated today when prevalence is much higher. However, STI treatment is undoubtedly useful and interventions which have a medical component should emphasise the importance of managing sexually transmitted infections.

A qualitative outcome of prevention programmes is that individuals are introduced to the possibility of risk reduction and empowered to make choices. There is also an epidemiological multiplier effect: each time an infection is averted, future infections from the would-be carrier are also averted. In addition, each averted infection has a positive impact on a family who then benefits from a healthy caregiver.

It is important to note that prevention initiatives, particularly those relating to behaviour change, work best when conducted in an environment where care (be it medical, psychosocial, economic) is available for people with AIDS and where communities address issues of stigma. Any prevention initiative undertaken in isolation is unlikely to be successful.

### **Prevention of mother-to-child transmission**

The standard method for preventing mother-to-child transmission at birth is a dose of Nevirapine to the mother at the start of labour and then to the newborn. The drug cost is only about \$4.<sup>91</sup> The total cost varies according to whether the infrastructure to deliver the drugs already exists. Because of such uncertainties and because of debate over the probabilities of transmission with and without Nevirapine, (although the most quoted probabilities are 30% risk without Nevirapine, halved to 15% with) studies outside of South Africa show a wide range of costs per infection prevented, ranging from £14 to £216.<sup>92</sup> The South African government has, in principle, agreed to shoulder the responsibility of this intervention using the existing antenatal infrastructure. Consequently, the cost should be relatively low at around £33 pip, as shown in Table 1. The provision of highly active antiretroviral therapy (HAART) to the mother in the final trimester of pregnancy reduces the risk of transmission to 1% and would cost roughly £200.<sup>93</sup> The pip cost is therefore £690.<sup>94</sup>

Formula milk feeding is much less cost effective because the transmission risks through breastfeeding is low at 10% and a six month regime of formula milk costs around £48. Therefore, many babies provided with formula milk would not have contracted HIV anyway. This implies a cost of £480 pip (one South African study estimated costs as high as £4,449 pip).<sup>95</sup>

Some people argue that the risks to the child's health from the absence of breast milk may be more dangerous than the risk of contracting HIV from the milk (because of the nutritional deficiencies of bottle milk relative to breast milk and the danger of powdered milk being mixed with unclean water). This is a controversial subject. In any case, provision of formula milk provides a mother with the opportunity to ensure absolutely that her baby does not contract the virus. It is worth stressing that the outcomes for mother-to-child transmission prevention interventions are rather hollow if the mother is subsequently left to sicken and die early in a child's life. There is the added complication that formula breast feeding may create stigma for the family.

### **Outcomes of treatment and care**

#### **Antiretroviral treatment**

Antiretroviral treatment keeps most users alive and if the user is a parent then there is the added benefit to their children. However, antiretroviral treatment is expensive, in both drug and delivery costs, even given the 90% cut in drug prices since 2000. Although the need is huge, and ultimately governments need to play the major role, there are substantial opportunities for private donors to make an impact. Privately funded projects today can trail blaze and build the capacity which will hasten and facilitate future publicly funded projects.

Current projects considered by NPC appear to be able to deliver antiretroviral drug treatment to patients for around £790 per annum. This includes drugs, medical infrastructure and laboratory testing costs. The net cost to society is significantly less than this, since people receiving antiretroviral drugs will make less use of hospitals than untreated AIDS patients. As noted in Section II, Brazil found that it saved £476 in hospital costs per patient per year during the first four years of its universal antiretroviral drug program.<sup>96</sup> A tentative estimate for AIDS hospitalisation costs in South Africa is £460, which is similar to Brazil.<sup>97</sup>

The hidden cost of AIDS in terms of lost productivity, staff replacement and skills loss has led a number of large corporations to provide antiretroviral treatment for their employees for economic as well as humanitarian reasons. Economically antiretroviral drugs not only save the state hospitalisation and general treatment costs, but also the cost of disability benefit and, after death, the cost of foster grants for the children. All in all NPC estimates that antiretroviral drugs have a net benefit to the state despite their high cost.

**The role of breast feeding in transmission and how to overcome this is a controversial subject.**

**The impact of antiretroviral drugs on a family is transformational: children are not orphaned and the value to a child of having a living mother is not quantifiable.**

The impact of antiretroviral drugs on a family is transformational: children are not orphaned and are relieved of the burden of care for their parent, thereby allowing them to attend school (antiretroviral drug provision to one mother of four not only impacts her life, but four others as well); mothers do not spend their days having to care for sick children and instead can work; partners are less likely to infect one another with variant HIV strains. Similarly the impact of an antiretroviral drug programme on a particular community is substantial, albeit at considerable cost. Communities are more likely to participate in VCT programmes if treatment is available; education and prevention opportunities are increased. Confidence of communities is improved and the future risk of delinquency amongst youth is greatly reduced.

In Table 1 we report an annual estimate of £790 as the cost of antiretroviral drug treatment (including infrastructure). This comes from the Guguletu HIV/AIDS Programme funded by UK-based charity Crusaid. It is important to note that this cost of antiretroviral drug treatment is a per annum cost and must be repeated indefinitely, in contrast to many of the interventions in Table 1 which are one-offs. High levels of financial commitment are therefore required unless funders are happy to run the political risk of future funding to take over programmes will not be forthcoming.

On the negative side antiretroviral drugs have side effects such as vomiting, rashes, headaches and insomnia, sometimes of such severity that people drop out of the programs. There is also the problem of drug resistant forms of HIV developing, feared by a number of medical scientists, which increases when adherence to antiretroviral drug regimes is poor. Good nutrition reduces the likelihood of poor adherence due to nausea and poor drug absorption.

Considerable uncertainty exists about the impact of antiretroviral drug treatment on sexual behaviour and transmission. On the one hand, there is some evidence from the US and Europe that patients receiving antiretroviral drug treatment become more sexually active, engaging in unprotected sex, thereby increasing the likelihood of transmission. On the other hand, evidence to the contrary exists and, furthermore, the viral load of someone who is receiving antiretroviral drugs declines, making them less infectious to any sexual partners.<sup>98</sup>

On balance the benefits of providing antiretroviral drugs largely outweigh the costs and risks. There needs to be sufficient infrastructure for delivery in place - clinical supervision, patient support, counselling and education - to make an antiretroviral treatment project work well. To enjoy economies of scale and to benefit a community rather than isolated individuals (envy can be disruptive if only a few are treated), antiretroviral drug programmes have to be of a reasonable size. A reasonable starting point is 300 patients and 1,000 patients makes more sense, though even this is inadequate to meet the long term needs of most communities in South Africa. Currently the government estimates that around 470,000 people (10% of those infected) would be eligible for treatment. Estimates by operators in the field of those who had already extremely sick were sometimes higher, and if a figure of 20% (NPC's estimate) were taken then up to one million people might be clinically eligible for treatment.<sup>99</sup> Either way, 500 - 1,000 projects of this scale (c£800,000 each per annum) are needed to meet the existing need for antiretroviral treatment. In any case, numbers based on current prevalence are a matter of when those infected will become eligible, not how many.

The recent government announcement to consider providing antiretroviral drug treatment to people with AIDS may enable donors to leverage government funding if donors assist with the training and capacity building of medical and related personnel.

### General care and support

As explained earlier, HIV patients are not generally suitable for antiretroviral drug treatment until the disease progresses to AIDS. Good prevention and management of opportunistic infections, nutrition and "healthy living" can delay the onset of AIDS and save valuable antiretroviral drug treatment resources for patients further advanced. This also avoids patients experiencing drug induced side effects.

Furthermore, when there are insufficient resources to pay for antiretroviral drug treatment, or when a person has an antiretroviral drug resistant HIV strain or suffers extreme side effects from the drugs, it is important to provide them with a dignified way of spending their final years. Live-in hospices are too expensive to be a widespread solution and not always suited to African lifestyle. Community based home care programmes can, however, be very effective in improving the quality of life for AIDS sufferers and their families and, perhaps also, extending life. An integrated community based home care programme in South Africa costs around £247 during the last year of a patient's life<sup>100</sup> and less than £100 pa in previous years.<sup>101</sup> Depending on intensity of care, some hospice outreach programmes are able to

**The expense of antiretroviral drugs and complexity of their administration require the availability of alternative strategies which are cheap and beneficial.**

achieve an average of £85 per patient per annum through networks of volunteer community caregivers.

One key aspect of a care programme is provision of good basic nutrition, which can have an enormous impact and costs only R60 (less than £5) per month to boost a patient's energy level (for work or childcare), health and sense of well-being. Another aspect is support groups which are a very easy way of enhancing quality of life. HIV positive sufferers can gather together to discuss problems, learn about "living positively" and plan for their children. The effects on behaviour were described in section IV. They are qualitative benefits but valuable in giving a sense of worth to the beneficiaries and their families.

Caregivers report frequent opportunities to improve AIDS education in the immediate family and community, and therefore there may be hidden prevention outcomes from care programs. Caregivers have also found (and this is also the experience of hospice provision in the UK) that the quality of care provided to patients prior to their death has a direct impact on the ability of family members to come to terms with the loss.

Day care facilities provided by hospices and similar organisations help to keep patients within their families and communities whilst giving respite to the primary carer.

## Outcomes of support of children and families affected by AIDS

For a child the preferable outcomes, in order, are:

- (1) **Remain within the family** in the community in which he or she has been brought up. Registration helps to achieve this if there is a family available. Assuming there is no abuse or neglect within the family, remaining within the family (even in a child-headed household) results in the least possible trauma for children. Transfer to an unknown extended family in an unfamiliar place is not particularly desirable and difficult to follow up to monitor potential abuse or neglect;
- (2) **Remain within the community** through foster care or placement in small family homes so that children remain close to their roots. Again, trauma may be reduced if a child remains in familiar surroundings and this also encourages the community to participate in the response.
- (3) **Fostering or placement with a good family** in a new community.
- (4) **Institutionalisation.** A temporary or permanent stay in an orphanage may be unavoidable (e.g. for abandoned babies, street children etc.). Institutionalisation is preferable to a life on the street but is not ideal for child development.

Aside from (4), all of the above are relatively low cost (see Table 1). For under £250 an orphan can be helped through the registration or fostering process. (It is assumed that emergency material support is a constituent part of this where possible to ensure continued physical and mental development.) Large numbers of children's lives can be radically improved with modest expenditure, particularly because, once tapped into, the government's grant system pays for children's needs. The vast number of black and coloured South Africans living in homelands and townships are heavily dependent on state subsidy for survival: relatives with any type of grant are expected to share this income with the extended family and real economic activity is very limited in the poor areas. Institutionalisation in orphanages is a less positive outcome than other solutions and is therefore left off Table 1. Orphanages are, in any case, considerably more expensive than other interventions, at around £964 per annum per child<sup>102</sup>. Day care centres (such as early education centres for pre-school children and centres for sick children) are very helpful adjuncts to initiatives, providing respite for the carers and places of safety, development and nutrition to the children.

The future for children who do not receive any intervention is extremely bleak. Anecdotally it is clear that orphans left to their own devices do extremely badly and one can assume very negative outcomes (including high risk of eventual HIV status) for unattended orphans. If large numbers lack benefits, then the outlook for future social development of communities is grim: unattended children will quickly grow into disaffected adolescents and young adults who turn to crime and delinquency as a way of life.

**The community based care of people with AIDS is linked to opportunities to provide education about prevention and, also, preparation for orphanhood.**

**Small sums of money can enormously affect the path of an orphan's life.**

## Cost analysis

The table below gives a summary of costs of the various interventions. Quantitative statistics should not be read in isolation however, and the efficacy of the NGO providing the intervention (including characteristics such as local participation, capacity building, social impact) should be considered in tandem.

**Table 1: Interventions and outcomes**<sup>103</sup>

Intervention	Prevents infection	Improve or extend life	Protects children	Cost per user, £	Cost per success, £
<b>Prevention</b>					
Education / awareness	ü	ü	ü	10-20	–
Voluntary counselling and testing	ü	ü	ü	15-18	180-200
Condoms/STI treatment for sex workers	ü	ü	ü	6	135
Treatment of STIs	ü	ü	ü	12	200 <sup>104</sup>
PMTCT <sup>105</sup> – Nevirapine	ü	ü	ü	5	33
PMTCT - HAART	ü	ü	ü	200	690
PMTCT – formula milk	ü	ü	ü	48 (6mths)	480
<b>Treatment and care</b>					
Antiretroviral drugs	?	üü	ü	790 pa	c 8,000
Antiretroviral drugs – impact on children	ü	ü	ü	158 pa per child	c1,600 <sup>106</sup>
Community based care	?	ü	ü	70-240 pa	–
<b>Services to children</b>					
Fostering	ü	ü	ü	220	–
Registration	ü	ü	ü	100	–
Education	ü	ü	ü	40-270 pa	–
Nutrition	ü	ü	ü	58 pa	–

Table 1 includes estimates, where sufficient data is available, of the cost of each intervention per user and, when it is measurably different, the cost per successful intervention. These outcomes highlight difficult choices for donors in terms of resource allocation. Often the choice is between helping large numbers of people (e.g. registration, palliative care) versus helping fewer numbers of people (e.g. antiretroviral drugs – although with antiretroviral drugs there is a ripple effect upon the family) but in a more profound way. The choices are also influenced by what programmes are available, or feasible to develop in the immediate future, and how much money a grant-maker or donor is willing to spend.

For illustrative purposes, and bearing in mind that it is very difficult to isolate interventions, we can use these figures to estimate of the social value of grants of £100,000:

- 250-500 avoided infections (and therefore saved lives) through combined voluntary counselling and testing, condom availability and treatment of sexually transmitted diseases. It must be stressed that although a particular infection is avoided, that individual may still be infected on another occasion. Voluntary counselling and testing and condom distribution is frequently a routine part of other initiatives; Education programmes may also be an effective means of prevention though hard data on this is not available.
- 145 avoided transmissions of the virus to children through the use of highly active antiretroviral drug therapy (HAART) and an excellent reduction in risk: the same financial investment in Nevirapine saves even more infections (because it is less expensive) but the risk profile is less good. In any case the government is gradually rolling this out itself. However unless the long term future of the child is resolved the value of these purchases may be eroded at a future date;
- 40-50 patients (possibly more) antiretroviral treatment for three years with the additional benefit this may confer on the patients' families (this could amount to more than 200 people). Only 8-10 patients would be covered for a treatment period of 10-15 years;

**Not all outcomes can be financially calculated and there are substantial differences in qualitative outcomes.**

- 500 patients benefiting from home based palliative care;
- registration of 1,000 orphans, or the fostering with non-relatives of 450 orphans;
- 1,700 children or AIDS patients with a years' good nutrition (EPAP) thereby improving development (children) or life expectancy (AIDS patients).

## Options

The earlier the intervention in the lifecycle of the disease the better the outcome, but this is not always possible. Large scale media initiatives tend to be the domain of big grant-makers, however local education efforts directed at youth have good potential outcomes for relatively low expenditure. Grants of £20,000 upwards can significantly contribute to efforts.

At the same time, there are acute needs which require immediate action, and which can be combined with less intensive education efforts. Antiretroviral drug treatment represents an excellent solution to several problems at once: the patient recovers, patient's children do not become orphans, HIV transmission risk is reduced. However, to be most effective as an intervention, antiretroviral drug programmes require reasonable scale and ongoing financial commitment. There are a limited number of programmes currently in development, and "exit" opportunities for private funders are highly dependent on political factors: will the government take on the burden of provision and, if so, when? Commitments of £200,000-£1m per annum for three to five years can transform communities.

More straightforward but still effective are those interventions which address the multiple problems of families and orphans in an comprehensive manner. Patients without access to current antiretroviral drug programmes should not be abandoned to suffer alone the indignities of AIDS. Palliative care and associated support initiatives are cheap and can improve the lives of large numbers of sufferers and their families. Either in conjunction with this support, or separately, there are opportunities to help with the registration of orphans (thereby leveraging state funding) or foster care where no family is available, which is a low one-off cost, together with inexpensive psycho-social and material support during the transition period. These interventions represent a world of difference to the children assisted and help to keep them safe. They are also frequently combined with efforts in HIV education. Grants in the £25-200,000 per annum range can be helpful in these areas. Ideally, these interventions would obviate the need for sheltered care.

There are also outcomes which are unquantifiable and intangible. Many of these interventions create hope, in addition to providing specific outcomes. They represent "beacons of possibility" to be emulated or replicated in an otherwise bleak human landscape. Although the effect of this on the psychology of a community or neighbouring communities is extremely hard to gauge. Many operators sense from their beneficiaries that hope, however intangible, brings real benefits to communities and wider society.

In an ideal world, money would be spent on preventing infections, but in reality high prevalence necessitates offering those infected and affected interventions at all points, which then provides further opportunities for preventing infection. NPC's recommendations based on outcomes would therefore be:-

- provision of antiretroviral drug treatment: either providing treatment including appropriate support (but in collaboration with provincial governments and local medical practitioners with a view to the health authorities taking over the project at maturity), or helping with the rapid training of medical and related professionals so that the government is better positioned to roll out universal antiretroviral drug therapy as soon as possible;
- support to families, ranging from home-based care for patients (if available) to registration of children for grants and foster placement (plus ancillary support);
- local prevention education and life skills initiatives, either dedicated or available as part of other interventions.

Other activities which support efforts above, e.g. early education/crèches for young children, and sustainable income generating projects also have very positive outcomes. NPC would also stress that the quality of project (level of community engagement, accountability, management) is equally important: the efficacy of the interventions identified above depend greatly on cost effectiveness on the ground and diligence in execution. A separate series of specific and detailed reports on some of the individual organisations is available to donors.

## Section VI: Examples of delivery

There are over 100,000 NGOs in South Africa many of whom are doing excellent work. Not all of these are doing AIDS specific work, but given the omnipresence of the problem many organisations are dealing with the epidemic in some way. During the course of its research, NPC visited eighteen projects on the ground in Western Cape, Gauteng, KwaZulu Natal, Free State. NPC has also had conversations with and obtained information on a number of others. However **this list is not comprehensive** and inclusion or exclusion in the text below does not necessarily mean a recommendation or rejection. Not all the projects below have been physically visited by NPC analysts. Funding in the table below means annual income in year to 2002 unless otherwise stated.

Project	Activities	Funding	Location
<b>Prevention initiatives: education</b>			
HIVSA at Baragwanath Hospital	Voluntary counselling and testing Support for people living with AIDS including education for families	n/k	Gauteng
LoveLife/Soul City	Media AIDS awareness campaign: TV, radio, posters, soap opera, youth work, youth clinics (inc condoms)	\$40m Global Fund (over several years)	Nationwide
Mindset, Liberty Foundation	Internet learning facility for schools including HIV/AIDS education	n/k	Nationwide
Parents for AIDS Action	Involvement of parents in de-stigmatising sex and AIDS thereby educating and protecting their children	n/k	Gauteng
Student Partnership Worldwide	AIDS education: peer education developed by local and overseas volunteers intensively	c£250,000	Eastern Cape
Ubuntu Community Fund	AIDS education: recent matriculates regularly visiting schools	c£225,000	Eastern Cape
Projects specialising in care of people with AIDS and also those providing services to children frequently have an education component to their work.			
<b>Prevention initiatives: mother to child transmission</b>			
Mothers-to-mothers-to-be, Cape Town	PMTCT, research into HAART during pregnancy and breastfeeding, and support networks for mothers and pregnant mothers who are HIV positive (550 mothers)	£112,500	Western Cape
Perinatal HIV Research Unit at Chris Hani Baragwanath Hospital	PMTCT and support networks for mothers and pregnant mothers who are HIV, also research into vertical transmission	c£3-4,000,000 pa	Gauteng
<b>Treatment and care: antiretroviral treatment programmes</b>			
Perinatal HIV Research Unit at Chris Hani Baragwanath Hospital	See above: in addition ARV pilot research projects covering approx 500 patients in total	See above	Gauteng
ARK (project being negotiated)	Proposal for provision of ARVs to mothers and in some cases families; 1,000 patients over three years	c£1,000,000 pa proposed	Western Cape
Guguletu HIV/AIDS programme/Crusaid, Cape Town	Provision of ARVs to families: Partnership with government; 180 patients	c£150,000 pa	Western Cape
KidzPositive	Provision of ARVs to 175 children and 50 mothers; counselling, nutrition, income-generating project	£120,000 pa	Western Cape
Medecins Sans Frontieres, Khayelitsha, Cape town	Provision of ARVs to adults: education programme; capacity building of local personnel; 400-600 patients	c£1,000,000 pa	Western Cape
Pangaea Foundation (out of San Francisco AIDS Foundation)	Support (clinical) and fundraising for ARV initiatives in S Africa including: St Mary's Hospital, Durban Guguletu and Masiphumelele Baragwanath Hospital, Soweto Aiming to cover seven provinces	£110,000 one-off to St. Mary's	KwaZulu Natal Western Cape Gauteng
Right to Care/ Wits Health Consortium	Wider access to ARVs	n/k	Gauteng

<b>Treatment and care: alternatives</b>			
Community AIDS Response	ICHIC programme; nutrition to patients and nutrition development; HIV education	£90,000+	Gauteng
HIVSA	Support groups, nutrition and HIV education (see above)	n/k	Gauteng
Moretele Hospice	ICHIC programme; Psychosocial and material support to orphans	£16,000	North West Province
Naledi Hospice	Core 7-bed hospice and paediatric unit; ICHC programme; Psychosocial and material support to families and orphans; Voluntary counselling and testing and HIV education	£170,000	Free State
South Coast Hospice	Core 7-bed hospice and rural satellite; ICHC programme; Psychosocial support to families and orphans; Training programmes; Voluntary counselling and testing and HIV education	£260,000	KwaZulu Natal
<b>Services to orphans and vulnerable children</b>			
Belgravia convent	Subsidised private education initiative for very underprivileged in poor inner city	n/k	Gauteng
Cape Town Child Welfare	Nine community centres providing child protection services; "Tembalabantwana" AIDS response programme including fostering using the nine centres	£800,000	Western Cape
Centocow mission	Rural outreach – material and psychosocial support to orphans and registration services	£15,000	KwaZulu Natal
Cotlands	Sanctuary for abandoned children; hospice for HIV positive children; early education for orphans Rural outreach	£550,000	Gauteng KwaZulu Natal
Gods Golden Acre	Small family homes; outreach in five valleys providing material support, nutrition, and housing, counselling	£80,000	KwaZulu Natal
Heartbeat	Rural outreach – supported by Save the Children	n/k	Gauteng
Helping Hands	Outreach to children: nutrition and care planning		North West Province
Hope and Homes for Children, HQ in UK	Four local NGOs supported: Moretele Hospice Centocow Mission Umtata Tembalatu Orphan registration services; material support (nutrition, education, housing repairs); Psycho-social support	£16,000 £15,000 £12,000 £10,000	North West; KwaZulu Natal; Eastern Cape; Mpumalanga
Hope HIV, HQ in UK	Grant-maker to local NGOs across sub-Saharan Africa including South Africa. Shelters for street children, and small family homes (including God's Golden Acre below), also lifeskills/outward bound, education often in collaboration with Salvation Army	c£100,000 in S Africa	UK based
Ikamva Labantu	Support of 350 early education centres; Fostering for 265 children; Also support for the blind and elderly; income generation	£185,000 net (£643,000 gross)	Western Cape
Johannesburg Child Welfare	Registration and psychosocial support for orphans; Shelter for orphans; foster care and adoption; Support for victims of child abuse (including sexual)	£1,200,000	Gauteng
Naledi Hospice	Registration, material support, memory books, day care, care for positive children	£170,000	Free State
Noah	Community response to orphan crisis – placement, income generation	n/a	KwaZulu Natal
Pine Town Child Welfare	Registration and psycho-social support to orphans; support groups for care givers; fostering and small family homes	£260,000	KwaZulu Natal
South Coast Hospice	Registration, psychosocial support, memory boxes, care for positive children	£260,000	KwaZulu Natal

Starfish, office in UK	Building portfolio of local NGOs (four so far) offering Orphan registration services; material support (nutrition, education, housing repairs); Psycho-social support	£500,000 since 2001	UK/S African partnership across five provinces
Temba Club	Emergency shelter for street children, rural outreach	£20,000	KwaZulu Natal
Thandanani	Orphan registration, placement, rescue of abandoned children via community committees	£175,000 budgeted	KwaZulu Natal
Umtha Welanga	Fostering for 120 children but aiming to expand	£21,000	Western Cape
Valley Trust	Education and health education, life skills, income generation and food gardening – partners other NGOs to educate families	c£800,000	KwaZulu Natal

**Research, advocacy, umbrella organisations**

ACESS – Alliance for Children's Entitlement to Social Security	Advocacy for children's rights to social services, grants, protection	Wants £700k over two years	Nationwide
AIDS Foundation of South Africa	Fundraising/grant making and capacity building for local NGOs and community based organisations	n/k c£2m pa?	KwaZulu Natal
AMREF (African Medical Research and Education Foundation), HQ in Nairobi, UK office	Developing community based responses to the crisis including education, behaviour change, voluntary counselling and testing	n/k	Eastern Cape, KwaZulu Natal, Mpumalanga
CADRE – Centre for Aids Development Research	Research and awareness campaigns	n/k	Nationwide
CINDI – Children in Distress	Network of NGOs collaborating to protect children	n/k	Mainly KwaZulu Natal
Save the Children, HQ in UK	Research, production of training materials, capacity building, advocacy, networking; Also supports Heartbeat and Naledi directly	n/k	Nationwide and Gauteng
Treatment Action Campaign	Lobbies energetically for universal antiretroviral treatment, affordable drugs pricing and other AIDS issues; Also active in promoting treatment literacy	£735,000	Nationwide

**University research**

Centre for Social Science Research, University of Cape Town	Research on sociological and economic implications of HIV/AIDS pandemic. Includes actual practical work involving memory boxes and other therapy (Bambanani)	n/k	Western Cape
Centre for the study of AIDS, University of Pretoria	Research and social science implications of HIV/AIDS pandemic	n/k	Gauteng
Children's Institute, University of Cape Town	Research, teaching, capacity building, advocacy specifically on children	n/k	Western Cape
RADAR – Rural AIDS Development Action Research	University of Witwatersrand and London School of Tropical Hygiene: clinical, social, VCT research	n/k	Limpopo
University of Natal/Africa Centre for Health and Population Studies	Medical, sociological, economic research and large database; Wellcome Trust involvement	n/k	KwaZulu Natal

## Section VII: Conclusion

HIV/AIDS is a blight on modern society. Communities are being decimated by the pandemic and the cost in terms of human misery is huge. The disease is largely confined to developing countries, who are the least resourced to cope with the scale of the problem.

On a world scale, the Global Fund remains under-funded, and in South Africa the speed of government action is slow and resources allocated to HIV/AIDS limited. President Bush's commitment of \$15bn to the war against HIV/AIDS is a step in the right direction, though the early evidence suggests that such a commitment is easier to make than deliver. Yet the exciting outcomes that are being created by a range of charitable projects in South Africa have illustrated that there is hope for AIDS sufferers and their families.

This presents opportunities for donors to fund initiatives to tackle the pandemic. Private philanthropists can provide capital to prove the validity of interventions, and subsequent governmental funding can leverage that initial capital many times over. The purpose of this report has been to analyse a range of interventions on the ground and to discuss the qualitative and quantitative outcomes created by these interventions. NPC's analysis is a tool to help donors effectively direct their funding.

The report has highlighted the effectiveness of three methodologies in particular:

- provision of antiretroviral drug treatment and related services to people with AIDS;
- support to families affected by AIDS, including support and care for those infected, as well as providing services to children and their carers;
- prevention education/life skills initiatives, either dedicated or as part of other interventions.

The efficacy of individual projects is not purely dependent on the means of intervention. The project itself needs to have a number of key characteristics: professional and committed management, integration with the local community it is serving, stability of future funding and prospects for growth. Innovation helps to evolve effective responses and support of any of the three methodologies above may be direct or through the development of local capacity. Above all, projects must be responding to critical local needs, and producing positive outcomes in the lives of their users. There is no one model that has proven better results over all others, and even if it were found, it would not fit all social environments.

NPC has visited a number of projects in South Africa which meet these criteria. Reports on these are available in a separate document, and provide detailed analysis of the intervention methods, the outcomes from the projects and their funding needs. There is sufficient infrastructure in the voluntary sector in South Africa for donors to be confident that their funds will be used effectively. Donors can choose between local initiatives (who we believe are able to account for money received and report on progress and outputs) or provide grants to intermediary NGOs based outside South Africa. Grants from £10,000 to £1m and more can generate outcomes for beneficiaries that will make a life-saving difference.

As well as efficacy, donors may have other strategic objectives:

- a desire to catalyse change, for instance in national policy or social behaviour, as well as benefiting confined local groups;
- innovation and support of new models or pilot projects with potential for replication;
- engagement of local philanthropists in order to leverage foreign funding and efforts;
- collaboration with other NGOs and where possible public/private partnerships to maximise local efficiencies;
- joint initiatives with other funders;
- initiatives in the wider context of sub-Saharan Africa.

NPC seeks to work with a variety of donors to enable them to intervene in any of these ways. The challenges of finding appropriate recipients, directing funds and monitoring and evaluating grants are not trivial, but NPC is confident that these challenges can be met.

This report began with a quotation from Nelson Mandela. It will close with further words from a speech he made in July 2003 in London. Mr Mandela referred to the "terrible and threatening scourge" of HIV/AIDS, but also described the disease as "no less than a war, a world war that affects all of us ultimately." NPC believes that the full spectrum of donors have the ability to make a vital and effective contribution to this war, and that this report provides a practical guide to enable them to do so.

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### Executive summary

Antiretroviral drug treatment uses drugs which inhibit the replication of HIV and thereby boost the patient's immune system. The treatment does not cure the condition, but it does bring very substantial clinical benefits to the patient. Different drug regimes suit different patients and so a degree of clinical sophistication is required in administering the drugs. Once on an ARV regime, which typically involves multiple drugs several times a day, the patient must adhere to it rigidly. Non-adherence negates the benefits and increases the likelihood of drug resistant virus strains developing.

In Africa, ARVs are generally applied at Stage 4 of the disease's progression. The clinical diagnosis of this is complicated, but generally it refers to the point at which a person's CD4 white blood cell count has dropped to around 200 per millilitre blood, and viral load has increased to around 30,000 particles per millilitre of blood, depending on the count methodology. Doctors have compared these measures to a train journey: if the train represents the disease and the journey its progression, then the CD4 count pinpoints the train's position on the map (and some would say also describes the condition of the train) while the viral load indicates the velocity of travel. Because of the prevalence of HIV related tuberculosis, some doctors are now applying antiretroviral treatment prior to stage 4 and the onset of tuberculosis.

The costs and benefits of providing ARVs can be summarised as follow:

Benefits and opportunities	Costs and risks
Massive improvement to quality of life and longevity for most patients	Side effects for some patients
Reduction of viral load and improvement in incidental STIs reduces transmittability of the virus <sup>107</sup>	Mutation resulting in ARV resistant virus strains; poor adherence will increase this problem
Knowledge of status together with treatment may reduce irresponsible sexual activity <sup>108</sup>	Improved vigour of patient may increase sexual attractiveness and activity
Reduction in cost to state in terms of disability benefits to patients and grants to orphans	High financial cost of providing drugs requires long term commitment from donors and/or government
Reduction in cost to state of the sociological consequences of orphans and community collapse	The need for effective and responsible delivery mechanisms
Huge improvement in the morale of patients and their family	"False hope" syndrome leading to psycho-social problems
Incentive to use Voluntary Testing and Counselling – an excellent prevention tool	

On balance the benefits of providing ARVs outweigh the costs and risks. The decision as to whether or not to provide ARVs should therefore generally be concerned with:

- Resource allocation: ARVs are expensive and require long term commitment by donors. Other interventions are much cheaper. Will governments eventually take up the responsibility of providing the drugs?
- Delivery: are clinical supervision, patient support, counselling and education up to scratch?

## 1. How much does ARV treatment cost in South Africa today?

The cost of an ARV regime varies considerably according to the drugs used, the prices offered by the pharmaceutical companies and the costs of administration.

Pounds/yr	Rand/yr	Source	Notes
<b>ARV Drug costs</b>			
£10,000	R12,440	THT	UK cost
£967	R12,024	Paul Roux	Uses patented drugs AZT+3TC (GSK) and Nevirapine (Boehringer). Includes 14% VAT.
£342	R4,260	MSF	AZT/3TC, Nevirapine generic imported from Brazil.
£501	R6,236	Crusaid	Implied cost of drugs in forecasts for new program in Western Cape.
£563	R7,000	TAC	Estimate from Dr.M.Cotton of Tygerberg Hospital.
£494	R6,144	Paul Roux	Using GSK patented drugs, because no generics available in suspension form for infants.
<b>Non-drug costs</b>			
£117	R1,454	TAC	Staff & monitoring costs assumed in forecasts
£392	R4,880	Crusaid	Administration and laboratory costs implied in forecasts

There are so few ARV programs currently running in South Africa that it is unclear what costs are realistically achievable. The main source of non-drug costs is the time of skilled medical professionals to treat and counsel patients and the costs associated with laboratory testing. It may be that if ARVs were rolled out widely across South Africa then scale efficiencies would reduce cost per patient below the £392 for the stand-alone Crusaid project. In some projects the medical professionals come from within the existing public health infrastructure and their costs are borne by the state. This is ideal because capacity building is achieved at the same time as costs are saved by the donor. Health professionals in South Africa are also hoping for reductions in laboratory costs.

There is a limit to the number of patients a doctor can reasonably treat or a counsellor support, and therefore this cost is less flexible than the cost of drugs. Crusaid indicated that their medical infrastructure (1 doctor, 1 nurse, 10 counsellors) could support 300 patients. The San Francisco AIDS Foundation reports that in the long term, as experience is accumulated, many more patients can be accommodated by such an infrastructure, up to 500 patients and above.

## 2. How does ARV treatment work?

Medical treatment of illness generally works by boosting the immune system's ability to combat invaders. This approach will not work with HIV because HIV attacks the immune system itself, preventing a key variety of white blood cells (CD4+ T-lymphocytes) from carrying out their natural function of directing the immune system, and turning them into HIV factories. Antiretrovirals prevent HIV from replicating and thereby limiting its spread. Drug resistance develops if HIV mutates such that the ARV chemicals can no longer recognise it. Side effects result when the ARVs also attack some of the body's own molecules. ARVs cannot completely eradicate the virus from someone's body, and therefore they must be taken regularly and indefinitely, which is why they are so costly to use.

Triple therapy: ARV drugs need to be given in combination in order to be most effective. Different combinations are most appropriate depending on the patient's clinical and social circumstances. Typically a patient begins a regime with at least two drugs from the class of drugs called nucleoside reverse transcriptase inhibitors (NRTIs) plus a third drug from other classes of drugs such as non-nucleoside reverse transcriptase inhibitors (NNRTIs) - thus the expression "triple therapy". Reverse transcriptase is a part of HIV required to infect cells in the body and make more virus. NRTIs and NNRTIs inhibit the workings of reverse transcriptase. Protease inhibitors, which inhibit HIV replication, may also be used depending on clinical circumstances.

In looking at choices for drugs in the African context two issues are key: how expensive is the drug to manufacture and how easy is the drug to take? Protease inhibitor class drugs are more expensive to manufacture than NRTIs or NNRTIs because the dosage is higher and the process more complex, but they have benefited from production efficiencies. Three-drugs-in-one pill products that only have to be taken twice a day are more likely to be adhered to than some protease inhibitors that involve many pills a day.

### 3. What effects does it have on patients?

ARVs have been described as having a “Lazarus effect” in bringing AIDS sufferers back to life from the brink of immune system collapse. However some patients develop resistance to the drugs and others (about 6% each year) have such serious side effects (e.g. changes in blood fats leading to heart disease) that the ARV regime is suspended. Over the last six years, the introduction of ARVs in Europe and the US has helped cut AIDS deaths by over 70%. In Brazil, AIDS mortality fell by 51% between 1996-1999 when ARV treatment became universal.<sup>109</sup> Nevertheless, the physicians we have consulted in South Africa are very pleased overall with the results of ARV programs. Clinically they have seen patients’ CD4 counts recover to near normal levels and viral loads reduce to 30-50 per millilitre.

### 4. When should it be used?

International consensus has developed to provide ARVs to people with CD4 below 200 or with stage 4 disease. There is some controversy over whether to start ART in people in less severe immune suppression because a balance must be struck between limiting viral replication and limiting the amount a time a person is exposed to ART – the longer the exposure the greater the risk of side effects and of resistance developing.

The British HIV Association recommends that treatment should not begin until the immune system has declined and the virus replicated to certain levels (technically: a CD4 count below 200 per millilitre or a viral load above 100,000<sup>110</sup> per millilitre), and the South African medical establishment takes a similar view depending on individual clinical circumstances. The reason for delaying treatment until this point (called Stage 4) is that people with HIV can often live healthily for 10 or 15 years without treatment, and it is better for the patient’s quality of life not to intervene during this period and risk ARV side effects. Furthermore ARV treatment during the patient’s healthy period would risk stimulating resistance development, rendering the patient helpless once full blown AIDS manifested. At the moment about 20-25%<sup>111</sup> of those who are HIV positive have reached the point at which it would be advisable to treat them with ARVs.

### 5. Can mother to child transmission of HIV be prevented?

Without intervention about 35% of children with HIV positive mothers contract the virus. 10% are infected in utero, 15% during labour and a further 10% are infected from breastfeeding.<sup>112</sup> The intervention to prevent transmission during labour involves a single inexpensive (c£6) shot of the ARV Nevirapine during labour and a single dose of Nevirapine to the newborn child, which halves the risk of transmission during labour. Bottle feeding can be used to avoid transmission from breastfeeding. However the bottle feeding program is the most costly part of preventing mother-to-child-transmission (MTCT) and has all the usual disadvantages of bottle feeding over breast feeding, particularly in areas lacking clean water to mix with the powdered milk formula. The mother herself gets no benefit from the Nevirapine, but runs the risk of developing resistance which would limit her ARV options in the future.

A full highly active antiretroviral drug (HAART) (triple drug) regime in the final trimester of pregnancy and during labour can almost eliminate transmission risk to under 1% but requires clinical supervision similar to a normal ARV programme.<sup>113</sup>

We are aware of two research programmes attempting to assess the real dangers of transmission during breastfeeding and how this may be addressed:

- Mothers-to-Mothers-to-be in Cape Town is planning to investigate whether HAART for mothers reduces the transmission risk of breastfeeding.
- In KwaZulu Natal a comparison is being made of unadulterated breast feeding versus a mix of bottle and breast feeding. There appears to be some indication that unadulterated breast feeding may have lower levels of risk than mixed breast and bottle feeding.

The South African government has finally committed to rolling out Nevirapine in maternity and obstetrics units across the country although in practical terms the coverage is patchy. Some provincial governments, such Western Cape, are more ambitious and want to roll out a full HAART programme.

## 6. How does a doctor decide which drugs to prescribe?

There are many different ARV drugs, and a doctor juggles a number of factors when deciding which cocktail to prescribe. Firstly the drugs must be effective on the patient's particular strain of HIV (which may be resistant to some ARVs). Secondly the potential side effects must be considered, and if the patient suffers very serious side effects from a certain regime then a different combination of drugs may be tried. Finally the ARV regime must fit sustainably into the patient's life. This last factor is very important for the poor, who may not be able to stick to a strict routine, or have privacy in which they can take their medication. Some ARV regimes require many pills to be taken at precise times. Missing just a few of the prescribed doses can seriously reduce the effectiveness and increase the risk of resistance developing. A drug regime which only requires a few pills a day may well be more effective for poor people with chaotic lives than a more potent, but more complex, regime with which the patient may not fully comply.

## 7. What medical advances are expected?

Research is underway to identify new chemical targets for ARVs to latch onto, particularly as HIV strains mutate and become resistant to existing drugs. A new range of drugs known as fusion inhibitors and entry inhibitors are also being developed that aim to prevent HIV from attaching to and infecting white blood cells. Other research is trying to discover ways of restoring the ability of damaged immune systems to fight HIV and the opportunistic illnesses that affect HIV-infected individuals.

The holy grail is a vaccine to enable the immune system to eradicate HIV as soon as infection occurs. Michael Gottlieb, the man who first identified AIDS in 1981, predicts that "by the year 2010 several of the most promising HIV vaccine candidates could be under study in controlled clinical trials... by 2021, one or more of these could have reached a level of effectiveness and safety that would allow its administration."<sup>114</sup> This is a very long way off. If HIV continues to spread at the rate epidemiologists predict, then long before a vaccine is ready, Asia may be facing a pandemic which dwarfs that currently underway in Africa. Microbicides (contained in vaginal gels) are an alternative prevention method to vaccines and condoms, and would give women more control over their own protection, and are being developed with the support of the Gates Foundation and the US National Institute of Health.

## 8. Who could pay for ARVs?

Universal ARV treatment for AIDS patients in South Africa, even with the 90% fall in drugs prices since 2000, would cost around £1bn per annum.<sup>115</sup> By way of comparison, the current health budget is R39.1bn (£3.1bn). Given that health is already 10% of government spending, external funding would be required to meet this need. A small number of wealthy HIV positive people could afford to pay for their own treatment, while others could receive treatment from their employers (such as Anglo American). Alternative sources of funding are the UN Global Fund for AIDS, bilateral aid (the US has promised \$8.25bn over five years to treat 2 million people worldwide) and private donors. Meanwhile employers such as Anglo American and De Beers are somewhat dismayed to find that ARV provision to their employees is regarded as a taxable benefit by the South African revenue.

The Global Fund itself has only received a small fraction of the intended £10bn/yr contributions while the US' pledge will take some time to materialise on the ground. So, for the time being, there is a huge gap in provision. Private donors might stimulate future governmental spending by funding pioneer programs which develop and demonstrate successful ARV methodologies.

## 9. How is the price likely to change in the future?

Competitive pressure from the generic producers, combined with public pressure on drug companies, has pushed down the prices of some branded drugs to around £700 and less, particularly if UNAIDS pricing is accessed. Some generics retail at half this price. MSF believes that, with expanded production, prices could fall to as low as £150. However the health professionals we have questioned in South Africa seem resigned to the price remaining relatively unchanged for the next few years.

Under the compulsory licensing provisions of the intellectual property rights provisions of the WTO's Doha Agreement, countries can manufacture generic drugs in the face of a health emergency. At the moment there is a crucial debate going on in the WTO about whether countries can also import generics from abroad (this is crucial because only a few developing countries such as Brazil and South Africa have the resources to manufacture their own generics). However, even in the best case scenario where all barriers are removed on generic production and import, it is unlikely that there will be another fall in ARV prices on the scale of the 90% drop since mid-2000, particularly as new drugs will be needed in the future to cope with resistant strains of the virus. It seems that £320/yr is a realistic sustainable target for ARVs, and therefore they are always going to look expensive compared to the per capita health spending of African countries, which may be as low as just a few dollars a year (even South Africa only spends £73pa<sup>116</sup>), and incomes (worldwide almost 3bn people live on less than \$2/day and 1bn on less than \$1).

## 10. What effect does treatment have on the spread of the disease?

ARVs reduce viral loads and incidents of sexually transmitted diseases. These two factors combined mean that the transmission of the virus through sexual acts is significantly reduced. Some commentators fear that this advantage would be lost if recipients of ARV treatment consider themselves cured and engage in risky sexual behaviour. Others argue that, because ARV treatment increases self-esteem and is a route to education, it actually results in more patients choosing to abstain from potentially infective sex. The jury is still out on this question, and the conclusion is likely to be mixed. What is essential is that all those receiving ARV treatment are taught that they still carry the virus and need to manage their sexual behaviour to avoid infecting new people. For women, who often have little power to refuse sex in South Africa, training programmes which improve their negotiating confidence in sex would help mitigate the risks of transmission.

## 11. What are the societal implications of ARV usage?

There are long term epidemiological effects of using ARVs which are extremely difficult to estimate. The question is whether keeping people alive with ARVs is likely to accelerate or control the spread of HIV. Some of the factors bearing on this are:

- ARVs reduce the viral load of the patient and consequently sexual transmissibility of the virus reduces;
- people with extended life spans have more time to infect others with HIV;
- ARV treatment may affect a patient's sexual behaviour for better or worse;
- non-compliance with ARV regimes will lead to resistant strains developing;
- treatment may be an incentive for testing, providing a boost to prevention efforts.

Another societal implication which must be included in any cost-benefit analysis of ARVs is the reduction in opportunistic infections resulting from strengthened immune systems. Brazil calculated that the first four years of its ARV program kept 358,000 people out of the hospital and saved \$1.1bn in health care.<sup>117</sup>

## 12. What are the issues regarding the treatment of children?

This topic presents a terrible humanitarian dilemma. Children are innocents in this pandemic and they respond very well to treatment. However, in a resource-poor environment where treatment is rationed, the preservation of children at the expense of adults can ironically increase levels of orphanhood.

In reality, ARV programmes increasingly favour treating whole families where possible. This reduces tensions within families: mothers are unlikely to accept treatment themselves whilst watching the demise of a child, and a treated child is less of a burden on family economics, emotions and care logistics.

## Glossary

- AIDS:** Acquired Immunodeficiency Syndrome
- AMREF:** African Medical Research and Education Foundation
- ARVs:** Antiretroviral drugs
- ART:** Antiretroviral drug treatment or therapy
- AZT:** Azidothymidine (chemical name), Zidovudine (generic name), Retrovir ® (brand name) - drug used as part of triple-therapy antiretroviral treatment
- CBO:** community based organisation
- CD4+ T-lymphocyte:** A type of white blood cell which is critical to the immune system. The normal count for a healthy person is 500-1600. A count below 200 is considered highly dangerous and is often the trigger for ARV treatment.
- Community Chests:** Local grant-makers funded by corporates and individuals.
- DfID:** Department for International Development, part of UK government responsible for overseas aid and development.
- Donors:** persons or organisations choosing to make a financial contribution to a project, charity or programme - covers a wide range from grant-makers to companies to private individuals.
- HPCASA:** Hospice Palliative Care Association of South Africa, also known as Hospice Association of South Africa or HASA
- HIV:** Human Immunodeficiency Virus
- HIV positive:** A positive diagnosis occurs if antibodies for HIV (not HIV itself) are detected.
- HAART:** Highly Active Antiretroviral Treatment or therapy, closely monitored treatment with triple-therapy ARVs. May also be referred to as ART.
- ICHC:** integrated community home based care
- Microbicide:** substance that can substantially reduce transmission of sexually transmitted infections (STIs) when applied either in the vagina or rectum.
- Morbidity:** incidence of sickness/disease, diseased/sick condition
- Mortality:** death rate, death
- MSF:** Médecins Sans Frontières (Doctors without Borders), a leading medical NGO.
- MTCT:** Mother to Child Transmission of AIDS, using ARVs to reduce the risk.
- Nevirapine:** Nevirapine (trade name Viramune) is one of a class of drugs called non-nucleoside reverse transcriptase inhibitors (NNRTIs) used in the treatment of HIV/AIDS.
- NGO:** non-governmental organisation
- Opportunistic Infections:** Diseases which attack, and may eventually kill, someone whose immune system has been weakened by AIDS.
- pip:** per infection prevented, a shorthand coined in the outcome section of this report.
- PMTCT:** prevention of mother to child transmission
- STI or STD:** sexually transmitted infection or disease
- TAC:** Treatment Action Campaign, lobbies for universal ARVs in South Africa.
- TB:** tuberculosis
- Viral load:** a measure of the density of HIV in body fluids.
- VCT:** Voluntary Counselling and Testing
- WHO:** World Health Organisation
- WTO:** World Trade Organisation

## Acknowledgements

This report would not have been possible without the tremendous support and encouragement of a wide range of professionals in the field in South Africa, in UK and elsewhere. People have been generous with their time and expertise and we would like to thank them for their valuable contributions. At the project level, the people giving their time and expertise are too numerous to mention, but their help is gratefully acknowledged.

NPC visited South Africa twice and enjoyed the time, help and hospitality of many people who have been extremely helpful in putting together this research. In particular we owe thanks to Kath and Mike Defilippi in Port Shepstone and to Liz and Gordon Hughes in Pretoria for providing roofs, transport and good advice. Kath especially has been a mine of information throughout the research process. Paul Roux has similarly been invaluable in patiently answering numerous questions and then rewarding the questioner with hospitality. Father Stanley and the brothers at the Catholic Mission at Centocow proffered a warm welcome and help during NPC's visit to KwaZulu Natal. Many thanks as well to Gerrit Ter Haar and Heather Reynolds for transport and education when visiting the valley of thousand hills. Helen Lieberman and Corinne Hudson, with their respective teams, have been particularly helpful in getting us around the townships of Cape Town safely and usefully.

These projects and the teams working there gave generously of time and assistance in South Africa:

Cape Town Child Welfare  
Centocow Mission  
Cotlands  
Gods Golden Acre  
Guguletu HIV/AIDS programme  
Ikamva Labantu  
Johannesburg Child Welfare  
Kidzpositive  
Medecins Sans Frontieres  
Moretele Hospice  
Naledi Hospice  
Nazareth House  
Pine Town Child Welfare  
South Coast Hospice  
Temba Club  
Tikkun Delft Community Centre  
Umtha Welanga  
Yabonga

In addition we met with a number of people in South Africa who were also very helpful in discussing issues and providing background:

Mitch Besser – Mothers to Mothers to Be  
Kevin Byrne – Save the Children  
Mary Crewe – Centre for Policy Aids Research  
Anthony Farr – Starfish  
Sonja Giese – Children's Institute  
Lauren Jankelowitz – Community Aids Response  
Debbie Matthew – Aids Foundation of South Africa  
Helen Meintjes – Children's Institute  
Jonathan Morgan – University of Cape Town  
Lynette Mudekunye – Save the Children  
Sue Peiser – Peiser & Associates  
Jonathan Schrire – Vrygrond Community Trust  
Mark Turpin – Care (South Africa)  
Penny Ward – Care (South Africa)

In the UK many people and organisations have been very helpful in developing our knowledge and debating the issues with us:

ActionAid – many people from the team contributed in many ways and ActionAid has been very helpful in including us in their symposia and education events.  
David Altschuler – One to One Children's Fund  
Anne Aslett – Elton John Aids Foundation  
Steve Beck – Geneva Global Trust

Jo Bexley – Diana Memorial Fund  
Care UK  
Jim Cogan – Student Partnership Worldwide  
Crusaid  
Russell Davies – Hope HIV  
Tabitha Elwes – consultant  
Laura Ferguson – AMREF  
Nathan Ford – Medecins Sans Frontieres  
Hope and Homes for Children  
Save the Children  
Andrew Tomkins – Centre for International Child Health

We have been fortunate in being able to correspond and talk to many others:

Selma Browde – Parents in Action  
Geoff Budlender – friend of TAC  
Rene Durazzo – Pangaea Foundation  
Glenda Gray – Perinatal HIV Research Unit  
Jacob Lief – Ubuntu Education Fund  
Leigh Johnson – University of Cape Town  
James McIntyre – Baragwanath Hospital and Perinatal HIV Research Unit  
Nancy Muirhead – Rockefeller Brothers Foundation  
Debbie Wason – University of Surrey  
Brent Woolff – Medical Research Council, Uganda

NPC is especially indebted to the panel of consultative readers who critiqued the report in its draft form. This was a time consuming task which the readers undertook cheerfully and thoroughly, making invaluable contributions to content and interpretation:

Teresa Albor – Absolute Return for Kids  
Kath Defilippi – South Coast Hospice and HPCASA  
Geoff Dyer – Financial Times  
Laura Ferguson – African Medical and Research Foundation  
Harry Hausler – London School of Hygiene and Tropical Medicine  
Lord Joffe  
Joan Marston – Naledi Hospice and HPCASA  
Jonathan Morgan – University of Cape Town  
Nicoli Nattrass – University of Cape Town  
Paul Roux – Groote Schuur Hospital and Kidzpositive  
Hakan Seckinelgin – London School of Economics

Lastly we would like to thank ARK, employees and trustees, for stimulating our quest in this vast area.

## Further reading

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<sup>2</sup> UNDP *Human Development Report 2002*  
<sup>3</sup> Estimate from multiplying the HSRC prevalence of 5.6% for 2-14yrs by UN population data of 14.75m children under 15yrs. The fact that children under 2yrs are not included in the HSRC data adds slightly to the uncertainty.  
<sup>4</sup> South Coast Hospice (2003)  
<sup>5</sup> Nelson Mandela/HSRC (2002) *South African National HIV Prevalence, Behavioural Risks and Mass Media*, Human Sciences Research Council  
<sup>6</sup> Statistically (ignoring the methodological problems just mentioned) the HSRC study gives 95% confidence that overall prevalence based on it's data is between 10% and 12.7% (11.4% is the mid point). Many of the figures for the prevalence of specific groups have much wider 95% confidence ranges because of small sample sizes, for example the range for Whites is 3.1%-9.2%. The upshot of this is that all the data should be treated with caution.  
<sup>7</sup> allafrica.com 10/12/2002  
<sup>8</sup> Wayne Ma, Daily Illini, 11/03/03  
<sup>9</sup> LoveLife / Kaiser Family Foundation (2000), *The Impending Catastrophe*  
<sup>10</sup> Nelson Mandela/HSRC (2002)  
<sup>11</sup> Bradshaw D, Steyn K (2002), *Poverty and Chronic Diseases in South Africa: Technical Report 2001*, Medical Research Council  
<sup>12</sup> LoveLife / Kaiser Family Foundation (2000), *The Impending Catastrophe*  
<sup>13</sup> Stephen Lewis, UN Secretary General's Special Envoy for HIV/AIDS in Africa, conference on HIV/AIDS and "next wave" countries Washington DC October 4<sup>th</sup> 2002  
<sup>14</sup> Leclerc Madlala (2002): *ibid* / Christine Varga (1997)  
<sup>15</sup> Leclerc Madlala (2002): *ibid*  
<sup>16</sup> Leclerc Madlala (2002): *ibid*  
<sup>17</sup> Dr Jewkes, Medical Research Council News Release, April 2002  
<sup>18</sup> Anthony LoBaido quoting police statistics, WorldNetDaily 2001  
<sup>19</sup> Donald Skinner (2001); *ibid*  
<sup>20</sup> Nicoli Nattrass, *Social Dynamics Vol 28 no 1 2002*, Centre for Social Science Research, University of Cape Town  
<sup>21</sup> UNAIDS, <http://www.unaids.org>  
<sup>22</sup> *ibid*  
<sup>23</sup> Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat (2003). *World Population Prospects: The 2002 Revision. Highlights*. New York: United Nations.  
<sup>24</sup> *The Macroeconomic impact of AIDS in South Africa* (2001), Stellenbosch University's Bureau for Economic Research  
<sup>25</sup> *ibid*.  
<sup>26</sup> Shanta Devarajan, Hans Gersbach, Clive Bell (2003) *Long-run Economic Costs of AIDS: Theory and an Application to South Africa*  
<sup>27</sup> World Bank press release (24/7/03)  
<sup>28</sup> *ibid*.  
<sup>29</sup> AIDS Consortium, <http://www.aidsconsortium.org.za/big/bighome.html> (3/6/03)  
<sup>30</sup> TAC (2003) *The Cost of HIV Prevention & Treatment Interventions in SA*. The £1bn takes their estimate of R7877 (£633) per person, assumes 1.2m need treatment (the Democratic Alliance proposed a universal ARV program in April 2002, which assumed that 20-25% of HIV positive need treatment now) and adds an extra 30% to cover administration of the universal program. The DA plan assumes that, after 5 years of gradual roll out, costs fall to R2400 (£193) for drugs and delivery costs fall to R1040 (£84). This seems very optimistic, but if achievable would mean the ARV program is affordable within the current health budget. The DA proposal would be means tested, with patients making a contribution to the costs.  
<sup>31</sup> Department of Social Development: <http://www.welfare.gov.za/>  
<sup>32</sup> Access' proposal for Global Fund 2003/4  
<sup>33</sup> NPC estimate. Brazil estimates that it saved \$1.1bn over 4 years and kept 358,000 patients out of hospital.  
<sup>34</sup> TAC estimates the hospitalisation cost of an AIDS patient at R18020 (£1449) which in 2000 should have cost R13.6bn (£1.1bn) overall, however the Department of Health estimates that it only cost R3.6bn (£289m) about 12.5% of its budget. If the Department of Health figure is correct then either TAC has overestimated costs or serious rationing of the health service is happening.  
<sup>35</sup> Summary Report of the joint health and treasury task team charged with examining treatment options to supplement comprehensive care for HIV/AIDS in the public health sector: 1<sup>st</sup> August 2003... Full report not publicly available  
<sup>36</sup> Statement on Special Cabinet Meeting on Enhanced programme against HIV & AIDS (8/8/03)  
<http://www.gov.za/>  
<sup>37</sup> UNDP HDR2002  
<sup>38</sup> Estimate based on the break down of private giving into the voluntary sector (see section 3.1). This estimate may even be on the high side since the US gave only \$15m and typically contributes around a third of international donations.  
<sup>39</sup> DfID website: 2002 Southern Africa Strategy Paper [www.dfid.gov.uk](http://www.dfid.gov.uk)  
<sup>40</sup> DfID website: 2002 Southern Africa Strategy Paper [www.dfid.gov.uk](http://www.dfid.gov.uk)  
<sup>41</sup> Canadian International Development Agency, <http://www.acdi-cida.gc.ca/>  
<sup>42</sup> Japanese MOFA, <http://www.mofa.go.jp/announce/announce/2003/3/0313.html>  
<sup>43</sup> EuropeAid, [http://europa.eu.int/comm/europeaid/projects/index\\_en.htm](http://europa.eu.int/comm/europeaid/projects/index_en.htm)  
<sup>44</sup> USAID, [http://www.usaid.gov/pop\\_health/AIDS/Funding/FactSheets/africa.html](http://www.usaid.gov/pop_health/AIDS/Funding/FactSheets/africa.html)  
<sup>45</sup> Perinatal HIV Research Unit at Chris Hani Baragwanath Hospital: James McIntyre July 2003  
<sup>46</sup> The White House, <http://www.whitehouse.gov/news/releases/2003/01/20030129-1.html>  
<sup>47</sup> Global Fund: [http://www.globalfundatm.org/faq\\_gfund.html](http://www.globalfundatm.org/faq_gfund.html)

- <sup>48</sup> Statement at G8 Summit (2001), <http://usinfo.state.gov/topical/econ/group8/summit01/www01072025.html>
- <sup>49</sup> AIDS Foundation of South Africa
- <sup>50</sup> UNAIDS
- <sup>51</sup> Russell, Bev & Swilling, Mark (2002) *The Size and Scope of the Non-profit Sector in South Africa*, School of Public & Development Management and the Centre for Civil Society. Figures increased by 32% to represent inflation over period 1998-2003. The figures quoted assume that 60% of the Health and Social Services sub-sectors' income relates to AIDS.
- <sup>52</sup> ibid
- <sup>53</sup> A survey of US Foundations estimated total giving to civil society in 1996 at \$42.9 m. S. Stacey and S. Aksartova (2001), *The foundations of democracy? US foundation support for civil society in South Africa*, Voluntas 12.4: International Journal of Voluntary and Nonprofit Organizations. Assuming R=\$0.23 (mid-price 1996), the estimate of R500m total foreign giving (Russell, Bev & Swilling, Mark (2002)) assumes that 37% of philanthropy is from the US foundations. Assuming 5% y-on-y increase in dollar giving and a depreciation of exchange rates to R=\$0.13, and using the 37% estimate, total philanthropy is about R1246m today. If we distribute this according to the distribution of local voluntary sector giving, R226m goes to health and R148m to social services. If we assume that 60% of the money donated to these combined sectors goes to AIDS, then we have R224m to AIDS, which is £18m. An additional £5m is added, representing half the Kaiser Family Foundation's giving, because of its particularly significant involvement with AIDS.
- <sup>54</sup> Bristol Myers Squibb <http://www.bms.com/>
- <sup>55</sup> South African Press Association (April 14, 2002) quotes the Democratic Alliance spokeswoman Sandy Kalyan who puts the figure then (a year ago) at 5-10,000.
- <sup>56</sup> South Coast own catchment figures: 1m x 11-15% (HSRC survey) prevalence x 10% AIDS
- <sup>57</sup> Centocow Mission (discussion)
- <sup>58</sup> Naledi Hospice (discussion)
- <sup>59</sup> The phrase "affected" is used to differentiate between people who are infected by HIV AIDS and those who are affected by the epidemic because family members are infected. People affected may also be infected, and vice versa.
- <sup>60</sup> AMREF HIV/AIDS study South Africa May 2002
- <sup>61</sup> ibid
- <sup>62</sup> Mandela/HSRC (2002)
- <sup>63</sup> UNAIDS
- <sup>64</sup> Agence France-Presse (05/10/00)
- <sup>65</sup> UNAIDS
- <sup>66</sup> Dr Brent Woolff
- <sup>67</sup> AMREF/London School of Hygiene and Tropical Medicine: MEMA Kwa Vijana Project, Tanzania, results not yet published, but likely to confirm behaviour change by biological study
- <sup>68</sup> A HIV educator in Free State reported a classroom of 14 yr old boys demanding that "sex is their right" when trying to introduce negotiating skills and rights of refusal to the girls.
- <sup>69</sup> Michael Sweat et al (July 2000) *The Lancet*
- <sup>70</sup> ibid
- <sup>71</sup> LF Johnson and R Dorrington (2002): *Study in Cameroon 1998*
- <sup>72</sup> Centre for Disease Control, <http://www.cdc.gov/>
- <sup>73</sup> Sonja Gielse – University of Cape Town 2003
- <sup>74</sup> AMREF South Africa 2003
- <sup>75</sup> Dr Robert Book: Medical Officer for Naledi Hospice; Dr Paul Roux, Groote Schuur Hospital
- <sup>76</sup> Dr Sam Page, 2001, *Promoting the survival of rural mothers with HIV*
- <sup>77</sup> Community AIDS Response, Johannesburg; Dr Robert Book; Helen Joseph Hospital; Entebbe Hospital
- <sup>78</sup> Dr Robert Book
- <sup>79</sup> WHO 1990
- <sup>80</sup> 2002 accounts: ICHC stats – to what extent do they overlap with inpatient unit?
- <sup>81</sup> HSCR/Nelson Mandela household survey 2002 (project claims 31% prevalence)
- <sup>82</sup> Christine Varga (1999), *Resistances to behavioural change to reduce HIV/AIDS/AIDS infection* / Jonathan Morag, Centre for Social Science Research, University of Cape Town
- <sup>83</sup> Sonja Giese, Children's Institute Cape Town
- <sup>84</sup> A Memory Box can sometimes be a Memory Bag or Memory Book with a pocket in the book sleeve.
- <sup>85</sup> Moses S, Plummer FA, Ngugi EN, Nagelkerke NJD, Anzala AO, Ndinya-Achola JO (1991), *Controlling HIV in Africa: effectiveness and cost of an intervention in a high-frequency STD transmitter core group*, AIDS 1991; 5: 407-11.
- <sup>86</sup> Creese A et al (Lancet 2002) *Cost-effectiveness of HIV/AIDS interventions in Africa: a systematic review of the evidence*
- <sup>87</sup> Sweat M, Gregorich S, Sangiwa G, et al. (2000), *Cost-effectiveness of voluntary HIV-1 counselling and testing in reducing sexual transmission of HIV-1 in Kenya and Tanzania*, *The Lancet* 2000; 356: 113-21.
- <sup>88</sup> ibid
- <sup>89</sup> Gilson L, Mkanje R, Grosskurth H, et al. (1997), *Cost-effectiveness of improved treatment services for sexually transmitted diseases in preventing HIV-1 infection in Mwanza Region, Tanzania*, *The Lancet* 1997; 350: 1805-09.
- <sup>90</sup> Hayes R, Wawer M (1997), *Randomised trials of STD treatment for HIV prevention*, *Genitourinary Medicine* 73(6): 432-43
- <sup>91</sup> Moses S, Plummer FA, Ngugi EN, Nagelkerke NJD, Anzala AO, Ndinya-Achola JO (1991), *Controlling HIV in Africa: effectiveness and cost of an intervention in a high-frequency STD transmitter core group*, AIDS 1991; 5: 407-11.
- <sup>92</sup> Peffer D, Nafissa O, Vaz P (2002), *PMTCT: Cost-benefit analysis of a program in Mozambique*.
- <sup>93</sup> Creese A, Floyd K, Alban A, Guinness L (2002) *Cost-effectiveness of HIV/AIDS interventions in Africa*, *The Lancet* 2002; 359: p1640. pip costs converted from \$ (2000) to £ (April 2003) using average FX rate of 1\$/£0.66 and inflation of 5.9% from June 2000 to April 2003
- <sup>94</sup> 3 months antiretroviral therapy = £790x3/12 rounded up
- <sup>95</sup> £200 \* 100/(29) = £690

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- <sup>95</sup> Soderlund N, Zwi A, Kinghorn A, Gray G. (1999), *Prevention of vertical transmission of HIV: analysis of cost effectiveness of options available in South Africa*, BMJ 1999; 318: 1650–56.
- <sup>96</sup> NPC estimate. Brazil estimates that it saved \$1.1bn over 4 years and kept 358,000 patients out of hospital.
- <sup>97</sup> The Department of Health estimates that 628,000 AIDS hospitalisations cost R3.6bn (£289m) in 2002, which is £460 each. The estimated number of Stage 4 AIDS cases is around 1.2m, double the quoted hospitalisations (which anyway probably include many repeat hospitalisations by the same individuals).
- <sup>98</sup> Moatti JP: Ivory Coast study
- <sup>99</sup> 4.7m people infected x 20-25% at Stage 4 of the disease
- <sup>100</sup> Leana Uys and Martin Hensher, *South African Medical Journal* 2002
- <sup>101</sup> South Coast Hospice data
- <sup>102</sup> This is the size of the state funding per child in an orphanage
- <sup>103</sup> **Source of figures in Table Section V:**
- Condoms: cost/user from Peffer D (2002 "Prevention of mother to child transmission cost benefit analysis of a programme in Mozambique page 13)
- Condoms: cost/success see 5.2 Creese et al 2002 and Moses et al.
- STIs: Gilson, Mkanje, Grosskurth et al (1997)
- Education/awareness Student Partnership Worldwide / NPC estimates;
- Voluntary counselling and testing: Michael Sweat et al (2000) (see above);
- ARVs: figures from Crusaid, Cost/success assumes 20% non adherence, resistance or drop out due to side effects over a 10-year period;
- community based care NPC estimates from South Coast Hospice and Hensher study;
- fostering NPC estimates from projects visited;
- registration NPC estimates from projects visited;
- education NPC estimates from projects visited: : low end of scale = school fees and uniforms, upper end of scale = early education support;
- nutrition = cost of Epap to adult or child per annum (R60 per month)
- <sup>104</sup> Original cost and calculations re-estimated at 2003 prices (4% inflation)
- <sup>105</sup> The PMCTC cost per success calculations are as follows: :
- Nevirapine: one shot per HIV positive mother reduces the risk of transmission from 30% to 15% (i.e. 15% improvement), £5 ÷15% = £33
- HAART: course per HIV positive mother reduces risk of transmission from 30% to 1% (i.e. 29% improvement), £200 ÷29% = £690
- Formula milk: assumes breastmilk transmission risk of 10% (estimated) , £48÷10% = £480
- <sup>106</sup> Assuming 10 years of treatment while children grow up
- <sup>107</sup> Leigh Johnson et al. (2002)
- <sup>108</sup> Prof J-P Moatti: Study Ivory Coast, found that patients treated with ARM had a greater adherence to preventative behaviour.
- <sup>109</sup> MSF, <http://www.accessmed-msf.org/campaign/faq.shtm> (7/6/03)
- <sup>110</sup> National AIDS Treatment Information Project in USA suggests 30,000-55,000 viral load (depending on count method) and CD4 200
- <sup>111</sup> South African Press Association (April 14, 2002) quotes the Democratic Alliance AIDS spokeswoman Sandy Kalyan who says they used 20-25% in their calculations for a universal ARV programme.
- <sup>112</sup> Many different probabilities are quoted, and it seems probabilities do vary from region to region. These figures from: <http://www.engenderhealth.org/res/onc/hiv/transmission/hiv3p4.html>
- <sup>113</sup> Conversation with Mitch Besser.
- <sup>114</sup> International Herald Tribune (6/6/01)
- <sup>115</sup> TAC (2003) *The Cost of HIV Prevention & Treatment Interventions in SA*. The £1bn takes their estimate of R7877 (£633) per person, assumes 1.2m need treatment (the Democratic Alliance proposed a universal ARV program in April 2002, which assumed that 20-25% of HIV positive need treatment now) and adds an extra 30% to cover administration of the universal program. The DA plan assumes that, after 5 years of gradual roll out, costs fall to R2400 (£193) for drugs and delivery costs fall to R1040 (£84). This seems very optimistic, but if achievable would mean the ARV program is affordable. The DA proposal would be means tested, with patients making a contribution to the costs.
- <sup>116</sup> £3.1bn ÷42.7m people
- <sup>117</sup> Christian Science Monitor (08/09/02)