

# Beyond the Targets

Ensuring children benefit from expanded access to HIV/AIDS treatment

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a world which respects and values each child  
a world which listens to children and learns  
a world where all children have hope and  
opportunity**

## **Mission**

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We deliver immediate and lasting  
improvements to children's lives worldwide**

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# Contents

Acknowledgements	iv
Abbreviations	v
Executive Summary	1
Introduction: A new landscape of opportunity?	3
1. Bringing children into view	6
2. Meeting the challenges	10
3. Shaping the future response	24
4. Recommendations	29
Endnotes	31

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# Abbreviations

AIDS	acquired immuno-deficiency syndrome
ARV	antiretroviral
ART	antiretroviral therapy
CBO	community-based organisation
CCM	Country Co-ordination Mechanism
DFID	Department for International Development (UK)
FBO	faith-based organisation
HBC	home-based care
HIV	human immuno-deficiency virus
MTCT	mother-to-child transmission of HIV
NGO	non-governmental organisation
OVC	orphans and other children made vulnerable by AIDS
PCR	polymerase chain reaction
PEFFAR	Presidential Emergency Fund for AIDS Relief
PLHA	person/people living with HIV/AIDS
PMTCT	prevention of mother-to-child transmission
STI	sexually transmitted infection
TRIPS	trade-related aspects of intellectual property rights
UN	United Nations
UNAIDS	Joint United Nations Programme on AIDS
UNCRC	United Nations Convention on the Rights of the Child
UNICEF	United Nations Children's Fund
VCT	voluntary counselling and testing
WHO	World Health Organization



# Executive Summary

*Beyond the Targets* draws together two parallel, and equally urgent, agendas – expanding support for the millions of people needing access to treatment for HIV/AIDS, and meeting the care and protection needs of millions of children affected by HIV/AIDS.

The aim of the World Health Organization and partners to reach three million people with antiretroviral therapy by the end of 2005, the ‘3 by 5’ initiative, is a recognition that HIV/AIDS is a global emergency. But the target will only be achieved if there is an unprecedented effort to mobilise resources and build up the healthcare systems in those countries most affected by the pandemic. With political will, the technical challenges are not insurmountable.

Children are the most affected by HIV/AIDS. Treating parents, especially mothers, benefits children in many different ways. First, it reduces the likelihood of children being infected with HIV through mother-to child transmission. Secondly, improving the length and quality of life of their mother is critical for the development of children and allows more time to prepare them for the illness and death of their parents. This increases their chances of inheriting property and assets, having a sense of family identity, and receiving appropriate care.

Achieving the 3 by 5 goal would mean millions fewer children losing their parents. And community-based, non-governmental and governmental organisations could be *pre-emptive* in supporting children who do become orphaned. For the first time, project and programme designers can look at preventing problems faced

by HIV/AIDS-affected families, rather than being locked in a mode of ‘impact mitigation’.

The world has agreed on what needs to be done to help children affected by HIV/AIDS. The UN Declaration of Commitment on HIV/AIDS (2001) and the Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV/AIDS (2004) clearly state the principles and responses required to ensure that the impact of AIDS on children is minimised. The obligations of the international community and national governments are defined but, so far, there has been little progress.

Despite recent increases in funding for HIV/AIDS, the lack of funding, including for the 3 by 5 initiative, is alarming. Global calls for resources have gone unheeded. The same is true of support for orphans and children made vulnerable by HIV/AIDS. Their problems have barely been recognised. The US Government is the only donor that has directly ear-marked funding for AIDS-affected children. However, as it will be hosting the EU and G8 in 2005, the UK Government now has an opportunity to take a leading role. The rhetorical link often made between tackling AIDS and tackling poverty must now be turned into substantive action.

*Beyond the Targets* explores these connections and aims to define the opportunities that increased access to care and treatment will present. HIV/AIDS is a global emergency, and we now have the opportunity to meet our collective responsibilities to the children, families and countries that are devastated by the pandemic.





# Introduction: A new landscape of opportunity?

The impact of HIV/AIDS has permeated the social, cultural and economic fabric of many nations. With no known cure, it is devastating those countries least able to cope. At the end of 2003, 40 million people were infected with the virus. HIV/AIDS is shortening lives, and destroying families, communities and national economies. In 2003, 4.2 million people became infected; 700,000 of these were children.<sup>1</sup> With the advent of antiretroviral therapy (ART), there is now a dramatic improvement in the survival rate and quality of life of people living with HIV/AIDS. This is only true, however, for those living in the developed world.

Without increased resources and action, at current infection rates it is estimated that by 2010 there will be an additional 45 million people living with HIV/AIDS, of which more than 3.4 million will be children under 15.<sup>2</sup> These figures represent an unacceptable and largely preventable pandemic. HIV/AIDS has eroded many of the hard won gains in lowering rates of infant and child illness and death, and in those areas hardest hit, a doubling in child mortality by 2010 is predicted.<sup>3</sup>

Many millions more children are facing a future without parents. In 2002, more than 13 million children under the age of 15 had lost one or both parents to HIV/AIDS, and by 2010 at current rates of HIV infection, it is predicted that this number will increase to more than 25 million. In the absence of significant change, by 2010, children orphaned by AIDS will make up almost one in four of the global total of orphans, rising

to 50 per cent of all orphans in sub-Saharan Africa. Although exact figures are unknown, it is predicted that by 2005 over one in five of all children under 15 in sub-Saharan Africa will have lost either one or both parents, the majority to AIDS.<sup>4</sup>

Efforts to address the pandemic in the developing world have focused primarily on prevention of sexual transmission, deemed the most feasible option where resources are limited, despite the existence of drugs to treat HIV. In developed countries the situation is different. There has been an impressive reduction in the rate of progression to AIDS and HIV-related death in adults, adolescents and children after the introduction of ART.<sup>5</sup>

For those who are able to adhere to treatments, ART suppresses HIV, maintains the integrity of the immune system and postpones development of opportunistic infections. Furthermore, from a public health perspective, the massive reduction in viral load due to ART reduces the likelihood of transmitting the virus to others. Ideally, treatment not only allows people to return to work and to care for their children, it decreases stigma, and increases the demand for testing, thereby strengthening ongoing prevention efforts.<sup>6</sup> In December 2003, the World Health Organization (WHO) and the Joint United Nations Programme on AIDS (UNAIDS) launched an emergency plan to scale up access to ART for those in resource poor countries. The goal of 'treating 3 million by 2005', combined with

amendments to the TRIPS (trade-related aspects of intellectual property rights) agreement agreed in August 2003 aimed at facilitating access to ART, has refocused attention on the need to scale up access to treatment for all people living with HIV/AIDS. The coming of the '3 by 5' initiative has signalled a new and potentially dramatic shift in the landscape of the pandemic.

**More adults being identified and treated for HIV/AIDS increases the possibility of more vulnerable children receiving essential support and services.** In June 2001, the UN Declaration of Commitment on HIV/AIDS that resulted from the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS represented a global political commitment to tackling the epidemic – recognising that care, support and treatment are crucial for an effective response. Articles 65, 66 and 67 recognise that children orphaned and made vulnerable by HIV/AIDS need special assistance. They call for the 'building and strengthening of governmental, family and community capacities to provide a supportive environment for orphans and other girls and boys infected and affected by HIV/AIDS by providing appropriate counselling and psycho-social support; ensuring their enrolment in school and access to shelter, good nutrition, health and social services on an equal basis with other children'.<sup>7</sup>

Given the growing emphasis among the international community on increasing access to treatment for people living with HIV/AIDS, it is important that principles of urgency, equity and sustainability are maintained throughout, and that discrimination, which lies as the root cause of so much of the pandemic, is not reinforced by efforts to treat those directly affected. It is equally

important to emphasise that the widescale introduction and use of ART is only one aspect of a successful care, support and treatment approach.

The emerging connection between access to care and treatment for adults and the support of orphans and children made vulnerable by HIV/AIDS is the core theme of this document. The links are clear, but currently absent from policy and programming discussions.

## **Aims of this report**

This report aims to examine the implications of expanded access to HIV/AIDS treatment, as exemplified by the 3 by 5 initiative, for prevention of HIV in children and young people, and expanding support and care for orphans and other children made vulnerable by HIV/AIDS.

Section One outlines the conceptual links between treatment of parents and child support, and in doing so demonstrates the myriad of opportunities that increased treatment brings. These benefits relate to increased prevention of HIV through perinatal transmission; the reduction in the number of children orphaned through keeping parents, especially mothers, alive longer; the improved treatment of paediatric HIV/AIDS; and finally the development of pre-emptive models of support for children in AIDS-affected families.

Section Two explores in more detail some of the interventions integral to an expanded response, notably the targeting of mothers for treatment, the development of treatment for paediatric AIDS within a 3 by 5 framework and the scaling up of

support services to children in AIDS-affected families. Examples of programme good practice illustrate the feasibility of developing effective treatment and care programmes.

Section Three outlines the critical political and co-ordination processes that will make expanded access to treatment possible and maximise

potential benefits to children and young people. The roles of the United Nations, donor governments, multilateral funding mechanisms, developing country governments and ultimately civil society are explored.

Section Four concludes with key findings and recommendations.

# I: Bringing children into view

Increasing access to care and treatment for adults and supporting children affected by HIV/AIDS are not conflicting goals. Yet articulating how expanded access to antiretroviral therapy (ART) represents a crucial gateway to supporting millions of affected children is rarely attempted. While this omission is not wilful, failing to widen the focus to the child when attempting to treat the parent can result in a myriad of opportunities for support being missed. The aim is not necessarily to have a clinical support service providing medical and social services for children, but to establish an entry point to a range of service providers within a coherent support network. In this report we attempt to define the possibilities and framework of this support network (see opposite).

Expanding access to care and treatment supports other human rights initiatives. For example, the international community has a responsibility to provide care to parents and children living with HIV/AIDS if it hopes to fulfil one of the fundamental rights of children as set out in the UN Convention on the Rights of the Child (UNCRC): that of a child's right to survival and development. Children whose parent(s) are HIV-positive are at risk of losing their right to survival and development for a number of reasons, including:

- losing one or both of their parents before reaching adulthood, or in many cases before adolescence, can have a significant impact on their physical and emotional development
- stigma and the loss of livelihood associated with HIV/AIDS reduces access to essential basic services such as healthcare and education

- increased pressures and demands on the family may require children to leave school and take up work to contribute to household incomes. Children engaging in work at an early age, often in the non-formal sector, are at risk of exploitation and increased vulnerability to HIV/AIDS.

Ensuring children's rights to survival and development by expanding access to care and treatment increases the likelihood that:

- the family unit is maintained, as well as its means of livelihood
- further parent-to-parent transmission is prevented
- costs of treating opportunistic infections are reduced or avoided, both for the family and the public sector
- children are less likely to be orphaned or, still significantly, orphaned when they are older
- there will be fewer child-headed households in need of external protection and support.

Providing care, support and treatment for people living with HIV/AIDS clearly goes far beyond simply providing ART. While ART is undoubtedly an essential element of a comprehensive care, support and treatment package, it is generally only necessary in the latter stages of HIV/AIDS. Care, support and treatment cannot be carried out in isolation from other HIV-related responses and form one element of a holistic approach to HIV/AIDS responses that should incorporate the entire continuum of care (see Figure 1, page 8).

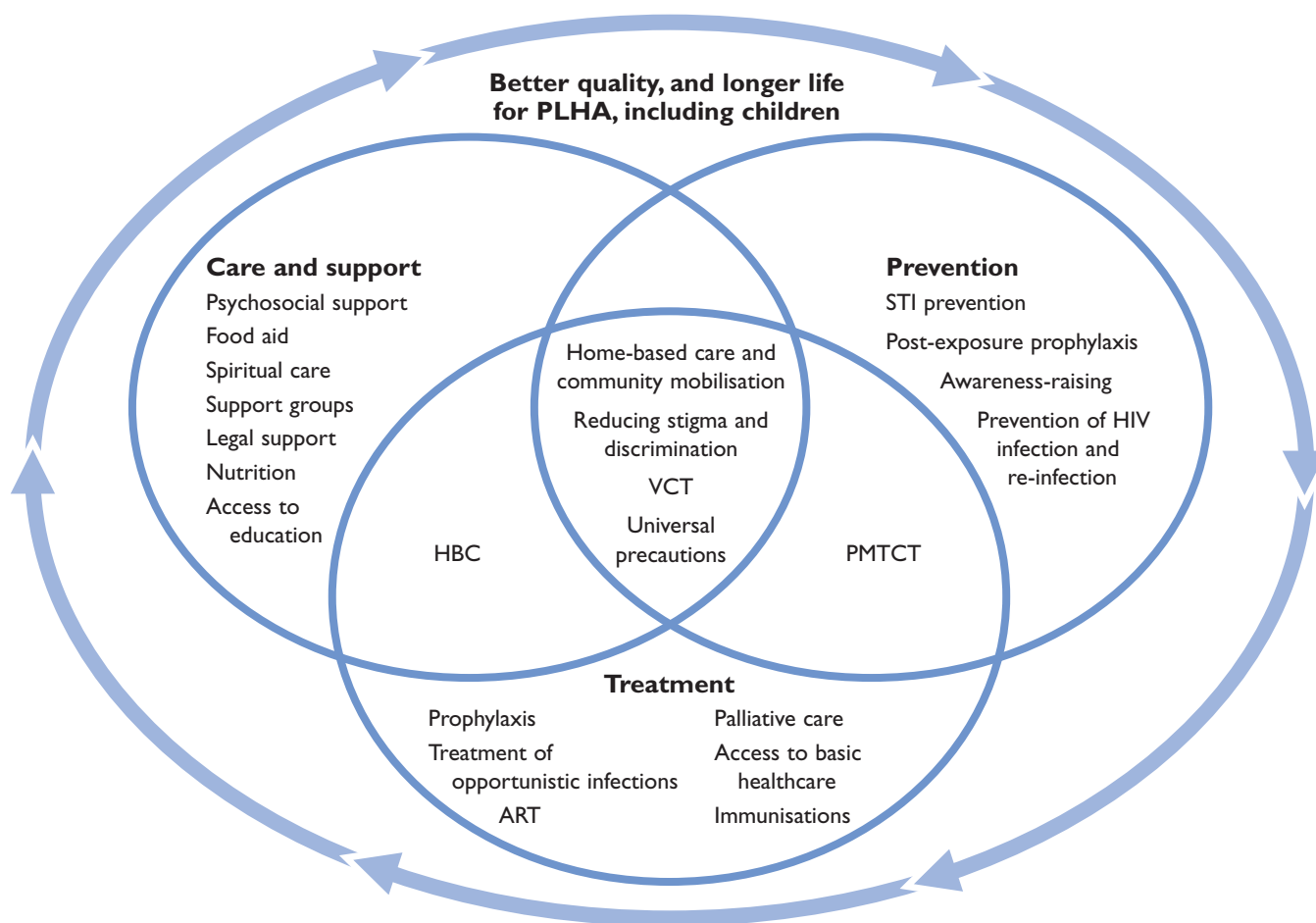
## Children missing out

For children living with HIV/AIDS, access to care, support and treatment is essential if their universal right to the highest quality standard of healthcare attainable is to be fulfilled. However, children living with HIV/AIDS in developing countries have limited access because:

- disease progression in children is not properly understood
- there are inadequate testing/healthcare facilities for children
- there is a lack of antiretroviral treatments suitable for children
- the needs of HIV-positive children are not prioritised by their families and/or communities
- families can't afford to obtain care, support and treatment for HIV-positive children.

## What children living with HIV/AIDS need

- psychosocial support
- support for their family (eg, advice on caring for them, psychosocial support, and advice on how to disclose the child's status)
- rehabilitation for those who are severely malnourished or traumatised, with longer-term nutrition and livelihood strategies
- medical care
- counselling
- adherence support
- spiritual care and support
- physiotherapy
- occupational therapy
- nutritional and dietary advice and support
- education
- support groups
- information on prevention and how to deal with disclosing their status.



**Figure 1: The interdependence of prevention, treatment and care, and support**

## Reaching children before they are affected by HIV/AIDS

The rapid expansion of treatment, which is primarily reaching adults, brings into view the millions of children living in HIV/AIDS-affected families. In the context of an overwhelming epidemic among adults, it is argued that many countries have opted to neglect the specific needs of HIV-positive children and young people. Treatment programmes appear to include them only as an afterthought.

Defining the ways in which children affected by HIV/AIDS are vulnerable compared to

other children, however, can be problematic. The current orphan definitions and estimates of the number of children orphaned by AIDS mask vulnerabilities other than parental death. Practical aims in the short term relate to reaching the unknown number of children who are living with parents suffering from HIV-related illnesses. More difficult will be reaching the millions, up to ten times greater in number, of additional children who are living with asymptomatic HIV-positive parents. The identification of these children will rely heavily on a rapid increase in the uptake of voluntary counselling and testing (VCT).

The early identification of HIV/AIDS-affected families, possibly before the onset of symptoms, allows service providers to be **pre-emptive** and **preventative** in their approach. This is a radical change in programming thinking, as responses with affected families so far have emphasised impact mitigation. Pre-emptive planning can avert many of the problems that characterise heavily affected communities at the present time.

Community health workers, home carers and social workers can track and monitor the appearance of the, often hidden, severe psychological consequences that children in AIDS-affected households experience. Psychosocial needs are frequently overlooked because many parents and service providers lack basic skills in recognising children's psychological or behavioural reactions. Patterns of psychological morbidity in children include showing signs of being unhappy, lonely and worried.

The loss of access to entitlements such as land, property and assets that many children experience when their parents die can be anticipated and averted. Practical interventions with communities, traditional leaders and law enforcement/welfare bodies can start once the parent's status has been disclosed, within pre-set lines of confidentiality if necessary. Succession and inheritance planning for AIDS-affected households is an area in need of an urgent and widescale response.

If the death of a parent is imminent, the possibility of placing the child with another family can be explored, preferably with the child's active involvement. Policy-makers should be aware that fostering could be appropriate even in cultures where it is deemed 'untraditional'. Conversely, fostering in situations where it is the norm does not necessarily mean that the

arrangement is in the child's best interests. The appropriateness of informal fostering hinges on questions of parental motivation and the likelihood of the placement being permanent. Crucially, there are no tools to assist programme designers and project workers arbitrating in such decisions, potentially allowing continued abuses and exploitation to flourish in areas of high adult mortality. As the demand for fostering planning increases, these support gaps must be filled, including support for child-headed households.

In addition, increasing adults' access to treatment will reduce the need for children to become responsible for the care of their sick parents, elderly relatives and/or younger siblings. In 7 per cent of a sample of AIDS-affected households in South Africa, a child was the primary caregiver for a sick adult.<sup>8</sup> Children who are required to care for younger siblings or to engage in extra domestic chores lack time to play or to interact socially with their peers. Over time, this leads to a restricted social circle and truncated relationships, which could prove crucial when the household experiences periods of extra stress and depends on outside assistance. In Malawi, orphans tend to form friendships with other orphans, which can isolate them and could result in social stratification rooted in patterns of stigma and discrimination.<sup>9</sup>

These few examples illustrate the potential ramifications for the well-being of children of expanding access to treatment of both adults and children. The shift to a preventative mode of response in relation to children affected by AIDS will be determined by the scale and success of increased access to safe and effective treatment. Section Two explores these possibilities in more detail.



## 2: Meeting the challenges

The increasing availability of antiretroviral treatment (ART) presents a host of challenges, not only in the delivery and management of the drugs with patients, but in ensuring the associated expansion of family and child-centred treatment and care. This section explores some of these challenges, namely: the '3 by 5' initiative, keeping parents, especially mothers, alive longer; the prevention of mother-to-child transmission (PMTCT); the scale-up of paediatric treatment and care; and the links to an expanded service network focused on supporting orphans and other children made vulnerable by HIV/AIDS.

### WHO, UNAIDS and the '3 by 5' initiative

"Lack of access to antiretroviral treatment is a global health emergency... To deliver antiretroviral treatment to the millions who need it, we must change the way we think and change the way we act."

Jong-wook Lee, Director General,  
World Health Organization<sup>10</sup>

The goal of 3 million people with HIV/AIDS receiving safe and effective ART by 2005 and beyond poses immense challenges. In the short term, just stating treatment as an aim is great political progress, and the mobilisation behind the desire for expanded access to care and treatment is a global imperative. The debate centres not on whether more people should receive treatment, but on how to ensure that access to treatment is safe, effective, equitable and sustainable. It is around the implementation of the overall strategy

that there are concerns, not the goal of 3 by 5 itself. It is imperative that the international community also looks at how, beyond 2005, it can gradually increase access to ART to all of those in need, and prolong lives for as long as possible. The 3 by 5 initiative must be seen as the first step in a much longer-term strategy, rather than a single end in itself.

Given the current capacity of drug delivery and health systems, less than one twentieth of those in need are receiving ART in sub-Saharan Africa, which has 70 per cent of the global caseload. Nigerian health services, for example, are currently reaching 15,000 people, compared to the 300,000 that would represent the 3 by 5 target.<sup>11</sup> Currently around 100,000 people in sub-Saharan Africa are on ART, contributing to a total of around 8 per cent of those in need in poor countries around the world.<sup>12</sup> The current coverage capacity of drug management systems, plus the fact that around 90 per cent of people do not know their HIV status, means that the target of three million by 2005 is almost certainly *not* going to be met.

Concern about not meeting the target could result in prioritising those most 'easy to reach', such as those in major urban centres. This, however, would *increase* inequity in access to care and treatment. Only an unprecedented expansion in supply and uptake of voluntary counselling and testing (VCT), combined with a massive increase in both public and private sector treatment capacities, will make the target even *theoretically* achievable.



## Challenges to meeting the '3 by 5' target

### ***Creating the demand for treatment***

- expansion of VCT services
- destigmatisation processes at all levels to encourage uptake of VCT
- instilling the belief that effective treatment is within reach, and creating supportive environments for use of comprehensive treatment.

### ***Strengthening the system infrastructure***

- increase in the scale of PMTCT+ programmes
- training for health staff
- upgrading of primary and secondary healthcare facilities
- identification and blockage of medicine 'leakage'
- setting up and monitoring of standards for both public and private sector practices
- training in opportunistic infection prevention and management
- identification and training in side-effect management
- widescale monitoring of viral resistance.

### ***Reducing costs***

- sustained reductions in drug prices
- removing trade and patent restrictions on supply and purchase of generic drugs
- reducing costs for CD4 (white blood cell) and viral load testing kits and equipment
- reducing costs for polymerase chain reaction (PCR) testing for infants and young children.

### ***Strengthening outreach to patients and their families***

- strengthening of home care structures to incorporate ART
- increasing support for disclosure and succession planning.

### ***Sufficient and effective resources***

- mobilising more resources
- co-ordinating efforts of UN, governmental, non-governmental, civil society and private sectors.

### ***Knowledge and experience in treating children and young people***

- sharing paediatric AIDS treatment experience
- research into the needs of HIV-positive children and young people in developing countries.

‘Success’ for such an ambitious initiative as 3 by 5 would mean more people accessing safe and effective treatment, without having future treatment compromised by experiencing a potentially dangerous, interrupted regimen. Ultimately, success would mean that all those who *want* ART (including children) can access treatment that conforms to rigorous standards for safety and effectiveness. Access is about more than just affordability: the location, quality of services, attitudes of health professionals, families and the wider community must also be considered. The UN regards access to life-extending treatment as a human right, so each individual on treatment represents a small success.

Paradoxically, there are potential *risks* involved in both meeting and not meeting the targets. Risks in meeting them relate to the danger of establishing short-term resources and drug distribution systems that cannot be maintained. This could lead to patients coming off or interrupting treatment, leading to accelerated viral resistance. As has been seen with vaccination coverage estimates,<sup>13</sup> pressure to meet targets can result in false reporting, fabrication or misleading alteration of data. Ultimate failure would entail the emergence and dominance of drug resistant strains of HIV.

Equally, however, there may be political risks for the World Health Organization (WHO), donors and activist organisations heavily backing the initiative if the target is not met. It could be argued, of course, that as with the Millennium Development Goals, literally reaching the target is not the point of the exercise. The process of target-setting has galvanised a political will to expand access to treatment. This is critical, and the more people who are able to access safe and

effective treatment, over the long term, the better. The process now has momentum, and the job is to maximise the benefits of the global drive, *without compromising quality for the sake of increased coverage.*

## Keeping parents alive longer

Because children are the most affected and the most marginalised in the fight against the HIV/AIDS pandemic, protecting them must be at the forefront of any treatment strategy. In countries where there are few resources, children of infected parents will almost certainly become orphans before reaching adulthood, which greatly reduces their own chances of survival. This is particularly true if they lose their mothers, as maternal death from any cause results in higher mortality rates in children.<sup>14</sup>

Focusing on mothers alone, however, would run the risk of neglecting the roles of other members of the household, and missing the interactions between household members. Fathers have an important wage-earning capacity, and any reduction in family income affects the child’s access to nutritious food and healthcare. Research conducted by Save the Children in Swaziland and Mozambique<sup>15</sup> indicates that disposable income in AIDS-affected communities is reduced by around 10 per cent, while the additional costs to the household of taking in an orphan represent around 7 per cent of household income in poorer households. When someone in the household is sick, the family risks losing assets, savings and income. This often leads to children, especially girls, being withdrawn from school. Targeting mothers should be the *beginning* of the expansion of care to other members of the family and community.

### Family-centred care

To date, although mothers are seen as a priority, most programmes targeting women in sub-Saharan Africa focus on prevention rather than care and treatment.<sup>16</sup> Many women lack decision-making power and control over income and are therefore unable to access fee-based healthcare.<sup>17</sup> There are further challenges for women who have lost their husbands and, as often happens to widows, their property.<sup>18</sup> This obviously has implications for children as well as mothers. Any scaling-up of treatment must ensure equity of access to healthcare for women and children.

This is more likely if family-centred treatment services are established. HIV-positive women identified through prevention of mother-to-child transmission (PMTCT) services can then be referred to these clinics. Specific clinics, and/or specific hours of practice that fit with women's other responsibilities, can provide a more supportive environment for women anxious about being judged by men within their community. This model can be extended to family-centred care, ensuring that partners and children who are infected/affected can also receive supportive and comprehensive care.

### Community-based care

Improving access to services for HIV-positive mothers will require tackling a range of barriers and taking a gender-sensitive approach. Low-cost community-based care needs to be expanded with healthcare workers who are trained in the diagnosis and treatment of HIV/AIDS-related infections, and equipped to refer the mother on to more advanced services should they be required. Interventions that empower women to make informed healthcare decisions and promote

women's health interests will simultaneously act in the interests of their children.

Many healthcare needs of HIV-positive people, particularly in the early stages of disease, require only basic infrastructure and can be treated by healthcare workers with limited training. Utilising home-based caring structures will reduce healthcare costs and improve local accessibility to services. Central to increasing access is the improvement of links and co-operation between local community-based organisations (CBOs), faith-based organisations (FBOs), non-governmental organisations (NGOs), schools and formal healthcare delivery structures. Home and community-based care has been used to respond to the care and support needs of people living with HIV/AIDS for many years and has proved that, with adequate support and training, it is possible for local communities to share the load with health professionals. Home and community-based care can be particularly useful for providing psychosocial support, helping people take and adhere to medication regimes, identifying opportunistic illnesses and providing referral services. However, research in Mozambique has shown that care is often offered in the early stages, and tends to drop off when the patient most needs care and support.<sup>19</sup>

### Palliative care

Palliative care improves the quality of life for patients and their families in the terminal stages of illness by integrating the physical, psychological and spiritual needs of the chronic and terminally ill, and providing support in the face of bereavement.<sup>20</sup> It is an essential component of a comprehensive care package for people living with HIV/AIDS. Relief of basic symptoms such as cough, nausea and fatigue can enhance day-to-day

life, and prevent unnecessary visits to hospitals and clinics, maximising resources available to the family.<sup>21</sup> There are limited services for terminal care in sub-Saharan Africa.<sup>22</sup> Many aspects of palliative care can be provided in the community through trained volunteer health workers, local NGOs and government services. Most care for the

dying takes place in the home and this is often what people prefer; training and support for the family maximises the care they are able to provide. Improved home care can also reduce community misconceptions regarding transmission of HIV between carers and patients, along with associated stigma.

## Caring for the chronically ill in Mozambique

Save the Children examined the impact of chronic illness on family members in Morrumbala Centre, Zambezia Province, Mozambique.

The study found that the immediate family carries the main responsibility in caring for a chronically ill individual. Although informal systems of support exist in the community – including churches, community leaders, community health activists and neighbours – community members have limited resources, and tend to support the chronically ill only at the *onset* of illness.

While most families have sufficient resources to treat illness in the initial stages, this is when they receive the most external support. As illness progresses, support declines. At the same time, agricultural production drops, basic necessities become scarce, and the family is often isolated and abandoned by the extended family out of fear, stigma or

exhaustion. Carer fatigue leads to the chronically ill being abandoned when they most need care and assistance.

Children were found to play a significant role in caring for a sick family member and assuming responsibility for domestic work. The children expressed worry and suffered stress and insecurity regarding their futures. One child said *“When my father became sick, I imagined he would die and we would suffer.”* Children often abandon school because they have too many responsibilities at home.

In conclusion, the study found that few families accessed the government services available to them. Although a small subsidy is available for the elderly and the chronically ill, it is rare for individuals to successfully navigate the complicated process to access this vital money.

Source: Save the Children UK, unpublished research

## Helping mothers plan for their children's futures in Uganda

In Uganda, the National Community of Women Living with AIDS (NACWOLA) and Save the Children developed the Memory Project. This project aimed to relieve the mental stress of children and to improve the coping mechanisms of families through increased family communication.

At the core of the project is the creation of memory books. Parents create a book for children to retain after their death containing memories of their lives, traditions and family history. The Memory Project has developed a training programme that has reached approximately 20 districts throughout Uganda.

The Memory Project involves far more than the creation of a scrapbook for children. It encourages parents to disclose their HIV status and opens up channels of communication between parents and children.

*“My father died when I was little and this book contains all the records we have and*

*memories of him,”* said one nine-year-old boy.

Creating the memory book also supports parents to make succession plans, including making a will, naming a guardian for their children and planning for their children's future.

*“I wouldn't have told the children without the memory book training. It was too hard. But now that I have done so, there is a big change. We have built confidence in each other. I encourage them. They encourage me. And we face life together.”* (An HIV-positive mother, Kasese)

Since its start in Arua district in 1999, 386 memory books have been completed. Most of these are by women, though some are by men. Most of those who completed books also disclosed their status, appointed guardians and drew up wills.

Source: *Memory Books and Succession Planning*, Save the Children UK Uganda Programme, 2004

Psychosocial support for HIV-positive parents throughout their illness is critical. Mothers face particular issues regarding pregnancy, disclosing their status to their children, and concerns over what will happen to their children after their death. Support groups for people living with HIV/AIDS can provide a forum for sharing strategies for prolonging health, overcoming stigma and coping with illness. Memory work with families increases communication and supports succession planning. Hope for the future can help mothers stay healthy longer, increase their confidence to access treatment and encourage them to adhere to the regimen.<sup>23</sup>

In south-east Asia, Save the Children has been providing holistic care and support to HIV-positive Burmese migrant women for several years, and plans to work with the government and other agencies to scale up this model into neighbouring China. In Cambodia, Save the Children has been working with Buddhist monks to reduce the stigma and discrimination attached to HIV/AIDS, and in Myanmar (Burma), efforts are being made to increase the provision of home and community-based care to families affected by HIV/AIDS.

### Reducing stigma

In sub-Saharan Africa, misconceptions and moral judgements related to assumptions about behavioural causes of infection have made HIV a highly stigmatising illness.<sup>24</sup> For women, the stigma surrounding HIV can be particularly great. This is often because HIV is first diagnosed in antenatal settings. As a consequence, women may be blamed for bringing HIV into the family. As more women are routinely screened through antenatal testing, this is an increasing challenge.

The effects of HIV-related stigma can be devastating. When a woman reveals her status, she may be at risk of violence from her husband<sup>25</sup> or ostracised by friends and family leaving her without traditional family support.<sup>26</sup> Mothers may therefore avoid accessing healthcare for fear it will reveal their status. When a woman knows she may infect her child, this increases the burden of blame and guilt; the term alone – mother-to-child transmission – suggests women are to blame for infecting their babies, regardless of how they themselves were infected.

### Access to treatment

ART, taken properly, prolongs the lives of those living with HIV/AIDS. Evidence from Brazil finds that, on average, life is extended by nearly five years.<sup>27</sup> The greatest obstacle, however, is that of access. Currently, most individuals living with HIV die from (preventable and) treatable opportunistic infections. Access to medications to combat these illnesses must be considered in tandem with ART provision. Treatment of minor infections and good nutrition from the early stages of diagnosis can sustain general health and prevent the immune system from deteriorating. Many infections can be managed simply and inexpensively at a community level through the use of antibiotics.<sup>28</sup> Treatment programmes must include a mix of prophylaxis, treatment of opportunistic infections and sexually transmitted infections, ART and palliative care.

Tuberculosis (TB) is one of the most significant opportunistic infections. In sub-Saharan Africa, three quarters of people living with HIV also have TB,<sup>29</sup> and this is a leading cause of death among HIV-positive people.<sup>30</sup> It has been calculated that if co-infected people are treated and cured of TB, life can be extended by an average of three years.<sup>31</sup>



Increased treatment access is primarily dependent on the strengthening and expansion of health infrastructure and services to ensure that all those in need of drugs can access a long-term sustainable supply. Additionally, health infrastructure needs to be supported by an appropriate transport network to ensure a wide distribution and consistent supply chain.

Developing health *systems* to achieve scale up of HIV/AIDS prevention and treatment services moves the spotlight away from solely the issue of drugs on to how and by whom they will be delivered. Staff need training in the management and treatment of HIV/AIDS, including counselling and support. In many countries, ratios of healthcare personnel to patients are low. In Malawi, for example, there are just three doctors per 100,000 people (1 per cent of the proportion in the United States).<sup>32</sup> Poor pay, low morale and limited opportunities lead many qualified healthcare workers to leave the public health service and work abroad. This situation will continue to deteriorate as some health professionals, themselves with HIV, fall sick and cannot work. To maintain staff at the present level, training for doctors and nurses needs to be expanded by 25–40 per cent over the next ten years to account for the losses to AIDS.<sup>33</sup>

It is estimated that 90 per cent of HIV-positive people cannot access even basic healthcare facilities.<sup>34</sup> Healthcare coverage is mixed, with capitals and larger cities being served best, while some rural areas may lack even the most basic services.<sup>35</sup> Long distances, time and treatment costs restrict access to healthcare facilities, and expectations regarding the poor quality and breadth of care keep some from seeking care in the first place.<sup>36</sup>

There are significant limitations on current laboratory capacity in resource-limited countries. Increasing access to ART will require scaling up laboratory infrastructure and staff, introducing cost-effective methods and ensuring the supply and maintenance of equipment.<sup>37</sup> There is also insufficient infrastructure and expertise to adequately monitor viral load, immune status, and the side effects of the drugs for individuals requiring treatment.<sup>38</sup> This is a significant barrier to the long-term success of the treatment.

## **Beyond prevention of mother-to-child transmission**

Currently, less than 1 per cent of women in the most heavily affected countries (with the notable exception of Botswana) have access to prevention of mother-to-child transmission (PMTCT) services.<sup>39</sup> PMTCT services form an important element of a comprehensive care, support and treatment package as this provides a key opportunity for preventing the transmission of the virus from the mother to the child. Additionally, improving the quality and length of the lives of mothers living with HIV is paramount to protecting the welfare and development of their children.

It is beginning to be recognised internationally in HIV/AIDS policy that care for mothers needs to go beyond PMTCT. The UN Declaration of Commitment on HIV/AIDS (2001) recognises that care, support and treatment are integral to a holistic response. Article 54 demonstrates an expressed commitment to provide treatment for HIV-positive mothers.<sup>40</sup>

The PMTCT+ initiative was launched by the UN in December 2001 to expand the services for

HIV-positive women to include basic care and treatment of HIV/AIDS.<sup>41</sup> Family-centred models such as PMTCT+ offer families living with HIV/AIDS hope, not only in terms of accessing treatment, but also as a gateway towards meeting their other needs. PMTCT+ programming is a comprehensive, cross-sectoral model of care that includes facets such as clinical care and prevention, family planning and reproductive health services, nutritional support, counselling and supportive care, and prophylaxis and ART when appropriate. The objective of the PMTCT+ programme is to engage people 'in an HIV care programme at an early stage to maintain their health', rather than waiting for the advanced stages of illness. The nature of the PMTCT+ programme means that it is not only physicians who are concerned with providing care and treatment, but a wider team including nurses, counsellors, social workers, outreach workers and peer educators. HIV-positive women who are or have recently been pregnant are the entry-point to the PMTCT+ programme. The child from that pregnancy, other children in the family, and the partner (as identified by the woman), are enrolled in the programme. Thus, the family will be integrated into the longer-term model of lifelong care.

The PMTCT+ package encompasses more than just ART. Prophylaxis and treatment of opportunistic infections also play a vital role, in particular in the management of TB. Programmes are encouraged to maintain strong links with local TB control programmes and, in high prevalence TB areas, isoniazid is provided to people with TB or who have a positive tuberculin skin test. Treated bed-nets are also encouraged to prevent malaria, and routine childhood vaccinations and information about hygiene is also provided.

When ART is deemed necessary, the programme follows the WHO public health approach. Simple, low burden pill regimens are generally recommended with no refrigeration requirements. Generic drugs are also used where possible. Laboratory protocols that could be easily replicated without the need for sophisticated equipment were designed, and guidelines will be reviewed regularly.

PMTCT+ interventions ensure continued follow up with HIV-positive mothers after the birth of their child, providing a wide range of different types of support, including support for exclusive breastfeeding and rapid weaning to prevent transmission of HIV from mother to child. More importantly, in PMTCT+ interventions there is the recognition that a single prophylactic dose of ART may not be the best option for a mother, particularly if she is already medically eligible for other treatment. PMTCT+ interventions aim to integrate mothers and, over time, other members of their family, into a medical treatment programme that will enable them to have long-term, sustainable access to ART. To date, however, there are only a limited number of pilot PMTCT+ programmes and there are a number of challenges associated with the delivery of these services, not least the mobilising of resources available to ensure long-term follow-up and monitoring of mothers and their families.

In southern Africa, Save the Children is currently exploring the potential for providing PMTCT+ services and access to care, support and treatment. In particular, Save the Children is looking at: gaps in prompt diagnosis, treatment and follow up of sexually transmitted infections (STIs); provision of adolescent-friendly health services, linking maternity services with VCT; provision of antenatal, perinatal and postnatal support and



care; training of health staff; promoting support groups for people living with HIV/AIDS; supporting the livelihoods and economic interests of HIV-affected families; and supporting on-going research into the efficacy and long-term effects of ART for PMTCT. Save the Children is also increasing links with home-based care and support for AIDS-affected children in the region.

## Children living with HIV/AIDS

To date, more than 3 million children worldwide have died from an HIV-related illness.<sup>42</sup> It is estimated that 1,800 children are infected every day; the large majority of these infections are preventable. There is a growing recognition of the need to begin providing care and support to these HIV-positive children in addition to their parents. The vast majority of children with HIV acquired the infection from perinatal transmission. As children age, the early onset of sexual activity, the use of unsafe blood products, the increase in the use of drugs, and rape as a weapon in conflict situations increase the risk of acquiring HIV. Use of cutting tools and unsterile injection equipment continue to put children at risk. Ensuring that children are vaccinated using sterile, single-use injectables is essential.

Many children progress rapidly if they develop signs of HIV infection within the first year of life, while others have a better prognosis and can survive into young adulthood.<sup>43</sup> In a study of HIV-positive children in Kigali, Rwanda, death rates were 26 per cent at first birthday, 45 per cent at second and 62 per cent at five years.<sup>44</sup> Although cellular responses to the virus are similar, the course of infection in children differs significantly from that in adults. The disease progresses more rapidly with higher viral loads, resulting in more frequent recurrent bacterial

infections. Opportunistic infections often present as primary disease and are more aggressive because of the lack of prior immunity.<sup>45</sup>

Children with poor living conditions, lack of access to quality healthcare, higher exposure to infectious agents, lack of sufficient food, clean water and sanitation are at greater risk. Emerging connections between intestinal worm infection and viral load,<sup>46</sup> for example, indicate that improving access to clean water and sanitation, as well as mass de-worming programmes, are part of the HIV/AIDS prevention and treatment spectrum. HIV-positive children are rarely protected by early routine immunisations.<sup>47</sup> In sub-Saharan Africa less than half of all children are fully immunised by their first birthday. Quality primary healthcare and child survival interventions are essential components of HIV/AIDS prevention and care.

It is difficult to diagnose infants with HIV, as maternal antibodies persist in the infant's blood. Virological tests are the only way to make a definitive diagnosis of HIV in these children.<sup>48</sup> Such tests are expensive, and often not available where resources are limited. Furthermore, frequent, regular laboratory tests are essential for monitoring responses to and toxicities of ART, especially in children.

## Treatment and care

To date, children have not been prioritised as a key target group for accessing ART and there has been limited research into the impact of HIV/AIDS treatments on children. 'Child-appropriate' ART is available but costly, difficult to store and complicated to administer. ART for children consists of the same drugs as those used by adults, although frequently the medication is not approved for young children,

and dose recommendations are not always available.<sup>49</sup> Where it has been used, it would appear that treatment with ART has dramatically reduced mortality and morbidity in HIV-positive children, and its effectiveness is similar to that observed in adults, but further research is needed.

There are significant differences between adults and children in the way that drugs act within the body. Viral dynamics and the developing immature immune system of children complicate therapy and make diagnosis and monitoring

difficult. Many drugs do not have solid formulations in doses appropriate for paediatric use, and some solid formulations do not have drug components evenly distributed in the tablets.<sup>50</sup> Liquid formulations can be bitter tasting, and powders can be gritty and difficult to dissolve in food or milk. They often require refrigeration or clean water to mix, syringes for administration and have a short shelf life – making them impractical in many resource-limited settings.<sup>51</sup>

Parents or other caregivers are often the ones who have responsibility for treating children. It is

## Supporting families to care for HIV-positive children in their communities in Vietnam

In Ho Chi Min City, Vietnam, Save the Children is working with the Committee for Population, Families and Children to support families where the parent(s) are HIV-positive. In one family, just as the father was placed in a rehabilitation centre for drug users, his wife discovered that their third child was also HIV-positive. When she discovered her child's status, she was worried and confused and planned to abandon him. The child's paternal grandparents took care of him, but their own fears and stigma about his condition caused them to neglect him and fail to provide him with appropriate care.

Volunteers from the project approached the family and invited the mother to training

sessions where she was provided with information on how to care for her son and where to access the treatment he needed. In addition, she received counselling, a micro-credit loan so that she could strengthen her business to increase her income so she could care for her child, and a medical insurance card enabling her to access free healthcare for her child.

The support provided by the project enabled this mother to take care of her child and her family is supporting her.

Source: *Tuoi Tre* (youth) newspaper, 22 April 2004, page 9

especially difficult to adhere to a treatment regime if the family has health or economic problems. Absorption of some drugs can be affected by food and has to be timed around or with meals, which is especially difficult in young infants who require frequent feeding. If caregivers are reluctant to disclose the status of the child for fear of stigma and discrimination it may create further problems, especially the tendency to exclude midday doses while the caregiver is at work or the child is at school.<sup>52</sup> When the caregiver is a sick parent with HIV, or an elderly grandparent or an older sibling, there are more barriers to that child receiving their medication.<sup>53</sup> When resources are scarce, families will inevitably find it difficult to prioritise the treatment of a child over treatment of the income-earner.

Recent studies show that people living with HIV/AIDS have to adhere to treatment regimes by at least 95 per cent in order to manage HIV/AIDS.<sup>54</sup> Even brief episodes of missed doses can permanently undermine HIV treatment through resistance. Adherence problems occur frequently in children, and the few studies of adherence suggest that only 25–50 per cent of HIV-infected children being treated adhere completely.<sup>55</sup> The involvement of family or community members, family-based care when more than one family member is infected, the use of pillboxes or coblister packs, and direct observed therapy have all been shown to increase adherence.

Barriers to antiretroviral treatment in children are substantial. Clinical trials in children lag behind adult studies, but important paediatric protocols are being established. Further work is needed to define optimal drug dosing and regimens, as well as the role of resistance testing and therapeutic drug monitoring in children.<sup>56</sup> The WHO

strongly encourages the development of formulations more appropriate for paediatric use, and there is an urgent need to develop fixed dose combinations for use in children.<sup>57</sup>

## Supporting orphans and other children made vulnerable by HIV/AIDS

Keeping parents alive longer allows a pre-emptive approach to supporting children. In addition, expanding access to care and treatment allows for more vulnerable children to be identified. This will increase the *quality and coverage* of children's treatment and support.

Of immediate concern is paediatric healthcare in AIDS-affected families. Children under five are especially vulnerable when a parent falls ill or dies.<sup>58</sup> Research conducted in Blantyre, Malawi, demonstrated that young children who lost their mothers were 3.3 times more likely to die.<sup>59</sup> A study in Zimbabwe found that 65 per cent of households dissolved after the death of the adult female, putting the safety, health and development of their children at risk.<sup>60</sup> Being deprived of consistent, responsive care and interpersonal and environmental stimulation in early life leads to measurable increases in malnutrition, morbidity and mortality, and inhibits healthy psychosocial and cognitive development among AIDS-affected children.<sup>61</sup>

Adapting home care services to be able to support both the sick patient and children living with and affected by HIV/AIDS has been pioneered by Save the Children in Uganda. This resulted in the development of a practitioners' handbook to support the provision of home-based care and support to children affected by or living with

HIV/AIDS.<sup>62</sup> Efforts are currently being undertaken to adapt and scale up this process across the region.

Parents' sickness and death has huge repercussions for the mental health of children, and deprives many of proper care and nutrition within the home. Children under five are especially vulnerable, as it is at this age that they need most care.<sup>63</sup> Resources available in AIDS-affected households decrease dramatically when parents or other adults become chronically ill. More and more money has to be spent on medicines, and productive adults die. AIDS-affected households tend to be poorer and have smaller disposable incomes, so it is not surprising that the children are less well nourished and have a greater chance of being stunted or wasted.

In Asia, the Save the Children programme in Nepal has been providing basic care and support to families affected by HIV/AIDS for a number of years. This has mainly involved providing psychosocial support, reducing stigma and discrimination towards families affected by HIV/AIDS, and providing basic nutritional and material support where possible. There are plans to work in certain districts with the Government and other service providers to ensure the provision of good quality and accessible services, and to support and empower communities to access these services.

One of the best ways of ensuring that treatment and care programmes meet children's needs is to

consult children themselves. Also, involving children in programme design and implementation cultivates their abilities and increases their confidence. In Zimbabwe, Save the Children has established a child advisory board to improve the quality of programmes. This allows for continuous feedback throughout the programmes, allowing children to input into all aspects of programme development. The work takes time, but is worth the investment because the programme is more accepted, relevant and sustainable.

Keeping children within families is a priority. Increasingly, institutional care facilities are opening in areas of high HIV/AIDS prevalence, encouraged by the lack of an overarching policy framework, fuelled by external and often misguided financial assistance. Save the Children is calling for a significant global reduction in the use of institutional care as a solution for children who are in need of care and protection, together with the growth of durable and sustained forms of community care. One example of this might be fostering programmes developed with the active participation of both the affected children and community members.

Meeting these technical challenges requires a change in current thinking. To move beyond the provision of treatment to family-centred responses that are meaningful in the long term demands co-ordination and political will far beyond that seen so far. Section Three assesses global readiness to turn the pandemic around.

## Progressive care for HIV-positive children: St. Nicholas Hospice, Bloemfontein, South Africa

Manuel was only three months old when he arrived at the St Nicholas Children's Hospice in Bloemfontein. He had already lost both his parents, and he was HIV positive.

Manuel's elderly grandmother, left without support, couldn't cope with the needs of a sick baby. With care from hospice staff, Manuel gradually got better. Now, four years later, he is an active little boy who still lives with his grandmother but attends the hospice every day. *"I like the nice food here, and playing with my friends,"* he says. *"When I get sick Mama Matua gives me medicine to make me feel better."*

South Africa has the largest number of people with HIV/AIDS in Africa. Many children have seen their parents suffer and die from AIDS. By 2010, it is estimated that 20–25 per cent of all children will be orphans. In many cases elderly grandmothers or older siblings shoulder the care and responsibility for younger children.

Manuel is one of 700 children who come daily to the St Nicholas Hospice. The

children get two good meals a day, access to medical care and the chance to do things that healthy children enjoy – art, singing, horse-riding and listening to stories, and then most go home in the evening.

The hospice enables children with HIV/AIDS to lead as normal a home life as possible. "The idea is to support families so that children can remain in their communities," says Joan Marston from the Hospice Palliative Care Association. "Seventy per cent of the children we look after are orphans, so it's very important that grandmothers get a break, or older siblings get the chance to go to school."

As well as providing time off, hospice staff visit the children's homes to teach their carers about nutrition and how to care for children with HIV/AIDS, help them to apply for social grants and provide vital emotional support.

Source: *World's Children*, Save the Children UK, summer 2004

## 3: Shaping the future response

Connecting the drive for increased access to treatment with the care and support of orphans and other children made vulnerable by HIV/AIDS requires a practical as well as a conceptual shift. Recognising the interdependence of global initiatives is the first step towards recognising the treatment of adults as a first point of contact for supporting vulnerable children. The scale of the challenge begs serious questions about the nature of political and economic responses to date, and hence the prospects for the future. The current political climate is one characterised by targets, commitment and frameworks. Fulfilling these objectives requires careful and structured co-ordination and investments in basic programmes and services, as well as treatment for parents and children. On closer analysis, however, the responses that lie behind the proclamations indicate that children affected by HIV/AIDS are not being prioritised.

### The UN and government mandates

In addition to their obligations to fulfil the rights set out in the UN Convention on the Rights of the Child (UNCRC), governments across the world are also obliged to increase the accessibility of care, support and treatment through their agreement to the following targets laid down in the UN Declaration of Commitment on HIV/AIDS (2001).

- By 2003, ensure national strategies are developed to strengthen healthcare systems and address factors affecting the provision of HIV-related drugs.
- By 2003, ensure national strategies are developed to provide psychosocial care for individuals, families and communities affected by HIV/AIDS.
- By 2003, reduce the proportion of infants infected with HIV by 20 per cent (rising by 2005 to 50 per cent) by providing primary prevention and prevention of mother-to-child transmission (PMTCT) services for women.
- By 2005, develop and make significant progress in implementing comprehensive care strategies to strengthen family- and community-based care.

Most countries have signed up to the UN Declaration of Commitment, clearly stating national obligations around orphans and other children made vulnerable by HIV/AIDS. In spite of this, progress in planning and implementing such strategies has been painfully slow. Over 40 per cent of countries with generalised HIV epidemics do not yet have a national orphans and other vulnerable children (OVC) strategy. Countries need to be called upon to create and implement such plans and supported to ensure that they do so in a way that can be monitored over the long term.

In relation to child support, the inter-agency Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV/AIDS<sup>64</sup> sets out the key principles and strategies essential for a global response. Of the five strategies, the first explicitly links treatment with childcare:



“Strengthening the capacity of families to protect and care for orphans and vulnerable children by prolonging the lives of parents and providing economic, psychosocial and other support.”

This Framework – produced in consultation between UN, government, faith-based, civil society, private sector, academic and non-governmental organisations – acts as a guide to policy-makers and planners for the formulation of scaled-up, effective and resourced national responses to assist orphans and other children made vulnerable by HIV/AIDS. Priorities include ensuring that children orphaned or affected by HIV/AIDS have equal access to essential services, particularly healthcare and schooling, and that they live and grow up in protective environments. Endorsing and acting upon the Framework must be a priority for agencies responding to the AIDS crisis.

### **Raising the resources – the response of the donors**

There is a well-recognised need for a substantial increase in global resources to address the HIV/AIDS pandemic. UNAIDS estimates that by 2005 over \$10 billion annually will be needed to combat HIV/AIDS. In contrast, actual spending for HIV/AIDS in 2003 was just under half of that figure (\$4.7 billion).<sup>65</sup> In terms of costing the 3 by 5 initiative, the UN estimates an additional \$5.5 billion is needed over two years. This includes the costs of providing antiretroviral therapy (ART), and the costs of training 100,000 health personnel and upgrading 10,000 facilities. In March 2004, the World Health Organization (WHO) announced that \$2.3 billion had been secured, lowering hopes that funds on the scale required would be raised.

With regard to resources for orphans and other children made vulnerable by HIV/AIDS, the spending picture is even more difficult to ascertain. A spending review conducted by Save the Children in 2003 concluded that current allocations to AIDS-affected children are impossible to quantify with any degree of accuracy. Donors either do not disaggregate spending, or else ‘AIDS’ has been mainstreamed within and across programmes to the extent that identifying discrete allocations is an impossible exercise. For the purposes of transparency and accountability, it is imperative that donors agree on a classification system for expenditures. Holding donors accountable for follow-up on the rhetoric linked to global commitments will also help in avoiding false accusations of non-support when commensurate financial support is in place.<sup>66</sup>

The US Administration has set the pace on AIDS funding through the Presidential Emergency Fund for AIDS Relief (PEPFAR) with a \$15 billion commitment (2004–2008). Financial allocations from the UK Government’s Department for International Development (DFID) represent the second largest bilateral contribution (rising from £270m now to £320m by 2006). With this commitment comes responsibility to provide leadership on sufficient and appropriate pledges from other key actors.

### **The Global Fund for AIDS, TB and Malaria**

In addition to governments, multilateral funding mechanisms have a leading role to play. The intention of the Global Fund is to provide a substantial amount of money in a short period of time in support of aggressive interventions to combat HIV/AIDS, tuberculosis and malaria. It

seeks to achieve this by establishing a rapid, simplified and innovative grant-making process that operates transparently and with accountability. The Global Fund seeks to operate in a balanced manner in terms of regions, diseases and interventions, while pursuing an integrated approach to prevention and treatment across the diseases. To date, the majority of funding has gone to HIV/AIDS-related programmes.

In relation to access to care and treatment, half of the financial allocations are for drugs and commodities, with only 15 per cent reserved for infrastructure development. Health systems development should be part of all wide-scale antiretroviral therapy (ART) distribution programmes and unless this spending on infrastructure is increased in the future, the effective and safe delivery of drugs will not be sustainable.

Global financial mobilisation for AIDS-affected children has also been disappointing. In the first three rounds, only 21 per cent of proposals to the Fund mentioned orphans and vulnerable children as a target group.<sup>67</sup> One way to combat this omission is to involve children in the proposal process. By involving children and young people, as well as those representing their views, with the country co-ordination mechanisms (CCMs), children are much more likely to move to the top of the HIV/AIDS agenda. In April 2004, the Global Fund announced its intention to reach at least 1 million orphans with resources from funding rounds one, two and three. This welcome step must be taken forward at country level, where CCMs should view the Global Fund as one means of financing the implementation of the Framework, and contributing to the fulfilment of their commitments to orphans and vulnerable children.

## National governments

Governments burdened by debt and poverty have to make decisions about where they should spend the limited resources available. The ever-changing cost benefit analysis related to HIV/AIDS prevention and care should form a core part of the technical support that the UN and donors provide to host governments. With the cost of ART being relatively high, although dropping, tuberculosis care and prophylaxis for opportunistic infections are arguably more cost effective. However, concern has arisen that, with the drive to increase access to ART, exemplified by the 3 by 5 initiative and the resultant pressures upon governments, resources may be diverted away from prevention and care efforts towards ART for a few individuals. Often government subsidies of ART benefit the richest in society rather than extending the lives of the poorest. Additional sources of funding from international agencies, such as the Global Fund, are needed to provide ART *without* detracting resources from other important prevention and care initiatives. This needs careful monitoring.

Co-ordination among national governments, with both national and international organisations currently working with orphans and vulnerable children, is essential. The UN Declaration of Commitment on HIV/AIDS, along with the Framework, provides the overview but not the modalities for a co-ordinated response. The recent emergence of the 'three ones' framework – where all responses are linked together under one national HIV/AIDS strategy, co-ordinated by one national AIDS authority, utilising one monitoring and evaluation framework – shows an international political commitment to simplifying the way that international organisations support host governments. Its success will depend on early



buy-in from all actors, and a strengthened role for the UN in liaising with bilateral and private donors within a national response. Successful implementation of the 'three ones' must include real civil society engagement in all aspects of its design and delivery.

Strengthening government capacity to lead and own the national response is an overarching concern in heavily-affected countries. In many African countries, children's and social welfare ministries are under-funded and have a great lack of capacity. In Lesotho, for example, the children's sector is housed as a sub-section within the Ministry of Health. Consequently, although one in every eight people in Lesotho is an orphaned child under the age of fifteen, it has been hard to get children's issues on the agenda. Children's and social welfare ministries need greater support from within their governments, with a facilitated dialogue with the ministries of finance and planning. Some countries, such as Namibia, have made rapid and impressive strides towards child-focused budgets and policies. There needs to be more opportunity for such countries to exchange experiences, and more pressure from the international community to support a rapid

introduction of national strategic planning for orphans and other children made vulnerable by HIV/AIDS.

One priority is to ensure that where HIV/AIDS money is available, it is reaching affected communities, for example by strengthening welfare systems in rural areas. Save the Children's successful Child Social Care project in Rakai district, Uganda (see box) proved the effectiveness of district level, decentralised orphan-support structures, given the necessary political and financial commitment. Sustainability of such systems is dependent on ongoing commitment combined with a high degree of transparency and minimum standards of governance.<sup>68</sup>

The interconnections between the global, international and national are clear, but the means of implementation are not. The translation of the global frameworks for action in terms of HIV/AIDS care, treatment and childcare need to be synthesised. If the political will is there, the technical challenges described can be overcome. For the first time children affected by HIV/AIDS have a glimmer of hope. The opportunity must not be wasted.

## International NGOs and childcare model development in Uganda

The Child Social Care Project (CSCP) that Save the Children implemented in Rakai, Uganda between 1991 and 1996 was hailed as a success in creating more proactive government services. The project emphasised community participation and enabled communities to identify problems

facing children who had lost their parents or who were otherwise vulnerable to HIV/AIDS.

A recent review of the Project found that many of the CSCP activities had achieved a

*continued overleaf*

lasting impact – mostly, but not always, of a positive nature.

- Some community volunteers continued to be active, despite being unsupported, and there is evidence that they retain some confidence of the communities they live in.
- In former project areas, there was a greater confidence in the Probation and Social Welfare Officer. Continuity of staffing since the project ended was a contributory factor.
- The long-term impact of mediation in property dispute cases involving children and widows was generally positive, but ongoing poverty has eroded some of the benefits.

In general, this experience reflects the dangers of the NGO pilot project approach. It raises the dilemma of how long an NGO remains responsible for supporting communities, especially in sectors like this, which are not financially self-sustaining and where government has limited capacity.

- There has been considerable investment in Rakai by government and donors over the past decade. However, issues of capacity, good governance or poor co-ordination, and of lack of equal partnerships between different groups have been frequently cited as barriers to effectiveness and quality of support for vulnerable children and families.

- The distribution of resources within the district and between different departments has not favoured poor and marginalised families.
- Communities express a huge lack of confidence in the police, the courts and the local council system. Part of this can be attributed to lack of awareness, but much of it relates to alleged corruption.
- Sharing and learning across different organisations is weak as there are few effective co-ordination structures, resulting in much institutional knowledge being lost.
- Certain activities, such as information, education and communication, tend to get the lion's share of the resources within aid budgets. This may relate less to effectiveness of the intervention than to the rewards that it brings for local officers.

The model is sustainable, but only if all parties – government, donors, NGOs and communities – make a serious and long-term commitment. Such commitment must not be simply political and financial. It also requires improved governance, greater transparency and more effective sharing of experiences (both successes and failures).

Source: *Taking Better Care: Review of a decade of work with orphans and vulnerable children in Rakai, Uganda*, Save the Children UK, 2004

## 4: Recommendations

Expanding access to care and treatment, as promised in the '3 by 5' initiative, is a gateway into supporting orphans and other children made vulnerable by AIDS. The two parallel agendas, that of HIV/AIDS treatment and care, must be combined. Simultaneously, the care and treatment of children must be prioritised in international policy and practice.

**Women and children must be prioritised for treatment for HIV/AIDS.** Given pre-existing discrimination, it is likely that women and children, especially those in poorer households, will continue to be marginalised. Market forces will inevitably favour urban men. Governments, supported by the international community, must facilitate a distribution framework, both of the private and public sectors, where equity of access is assured and monitored, if necessary through positive discrimination policies.

**Appropriate treatment for children must be developed.** Increased investment in the pharmaceutical industry must reflect the urgent need to develop child-appropriate treatment regimes and administration procedures.

**Healthcare infrastructure must be developed as a matter of urgency.** The impact of HIV/AIDS on healthcare means that more resources are required to improve both infrastructure and health personnel. The Global Fund for AIDS, TB and Malaria must double its allocation to infrastructure development to 30 per cent of its total expenditures.

**Donors should assist governments in implementing the Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV.** So far, only 60 per cent of affected countries have developed a strategy for orphans and other children made vulnerable by HIV/AIDS.

**All user fees on healthcare must be removed.** The Framework already calls for the abolition of education user fees for orphans and vulnerable children. Although in principle the World Bank claims to have abolished user fees for health and education, in practice, in order for country programmes to receive funds from these institutions they have to show a mechanism of 'cost recovery'. This in reality means charging fees. As a result, education and healthcare are beyond the reach of many of the poorest children, including those affected by HIV/AIDS.

**All donors must specify their support for orphans and children made vulnerable by AIDS, in both financial and practical terms.** These financial contributions must be clearly disaggregated within development aid and be monitorable. At present the US administration is the only donor government to have done this.

**Multilateral funding mechanisms must allow for the specific and deliberate inclusion of children orphaned and made vulnerable by HIV/AIDS.** The methods of including support to these children in, for example, poverty reduction strategy processes are intended but

not defined. Bilateral donors and the UN must prioritise this discussion with host governments.

In order to reach and exceed the Global Fund for AIDS, TB and Malaria's target of supporting 1 million affected children, the **UK Government should take a lead role in assisting applications to the Global Fund**. DFID and other bilateral aid agencies can ensure that proposals include children affected by HIV/AIDS by encouraging children's participation at the country level within the Country Co-ordination Mechanism (CCM) and associated support structures.

**A global doubling of funding is the minimum required to respond to HIV/AIDS**. Global funding for HIV/AIDS interventions is still less than half that required. Targets and rhetoric are

meaningless without commensurate resource allocation.

**National governments must be supported in difficult decisions over resource allocation.**

Advocating to governments in sub-Saharan Africa to allocate resources to HIV/AIDS prevention, care and treatment is not in itself enough. Donors should seek to facilitate discussion within governments, especially between ministries of social welfare, finance and planning. Previous experience with mainstreaming processes has shown that dilution of responsibility can result when lines of accountability are not clearly marked and monitored. Resources for expanding access to care and treatment, along with supporting affected children must be **additional and not transferred**.

# Endnotes

- 1 UNAIDS (2003) AIDS Epidemic Report, December 2003, Geneva.
- 2 *Ibid.*
- 3 Saloojee H, Violari A, 'HIV infection in children', *British Medical Journal* 323: 670–4
- 4 USAID/UNICEF/UNAIDS, *Children on the Brink 2002*, July 2002.
- 5 See Palella F Jr, *et al* (1998) 'Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. HIV Outpatient Study Investigators', *NEJM* Mar 26;338(13):853–60. Detels, R, *et al* (1998) 'Effectiveness of Potent Antiretroviral Therapy on Time to AIDS and Death in Men With Known HIV Infection Duration', *JAMA* Nov 4:280, 1497–1503. Tassie, JM, *et al* (2002) 'Time to AIDS from 1992 to 1999 in HIV-1 infected subjects with known date of infection', *Journal of Acquired Immune Deficiency Syndromes* 30(1):81–87.
- 6 Farmer P, Leandre F, Mukherjee J, Sidonise Clude M, *et al* (2001) 'Community-based approaches to HIV treatment in resource-poor settings', *Lancet* 353:404–9.
- 7 UNAIDS (2001) Declaration of Commitment on HIV/AIDS. UNGASS on HIV/AIDS, [www.unaids.org](http://www.unaids.org)
- 8 Reported in *Mail and Guardian*, Johannesburg, 27 September 2002.
- 9 Cook, M (1998) *Starting from Strengths: Community care for orphaned children: Facilitator's guide*, University of Victoria, Unit for Research and Education on the Convention on the Rights of the Child, School of Child and Youth Care, Canada; and Chancellor College, Department of Psychology, Malawi.
- 10 WHO/UNAIDS (2003), *Treating 3 Million by 2005: Making it happen*.
- 11 *Access Alert* July/August 2003, Abuja, Nigeria.
- 12 WHO/UNAIDS (2003) *Op cit.*
- 13 Grow Up Free From Poverty Coalition (2003) *80 Million Lives: Meeting the Millennium Development Goals in child and maternal survival*, London.
- 14 Barnett T, Whiteside, A (2002) *AIDS in the 21st Century – disease and globalisation*, Palgrave Macmillan.
- 15 Seaman J, Petty C with Narangui H, *HIV/AIDS and Household Economy in a Highveld Swaziland Community*, Save the Children UK, forthcoming; Petty C, Sylvester K, Seaman J, *A Rural Trading Community in Manica Province, Mozambique: The impact of HIV/AIDS on Household Economy*, Save the Children UK, forthcoming.
- 16 Page L J ( 2000) *Longevity in HIV+ Mothers: The need to promote health, household food security and economic empowerment to ensure family survival in Southern Africa*. Paper prepared for the Expert Group Meeting on the HIV/AIDS Pandemic and its gender implications. November 2000, Windhoek, Namibia. [www.un.org/womanwatch/daw/csw/hiv aids/Page.htm](http://www.un.org/womanwatch/daw/csw/hiv aids/Page.htm)
- 17 WHO (2000) *Gender, Health and Poverty*, Fact sheet 251, WHO, Geneva.
- 18 UNFPA. *Gender and HIV/AIDS; Leadership roles in social mobilisation*, Report of the UNFPA African Development Forum. Addis Ababa, Ethiopia. [www.unfpa.org/africa/newdoc/](http://www.unfpa.org/africa/newdoc/)
- 19 Breslin L, D'Allesandro C (2003) *The Impacts of Chronic Disease on Families and Their Support Networks in Morrumbala Centre, Zambezia Province, Mozambique*, unpublished research.
- 20 WHO (2001) Palliative care. [www.who.int/hivtopics/PalliativeCare/en/print.html](http://www.who.int/hivtopics/PalliativeCare/en/print.html)
- 21 WHO (2001) *ibid.*
- 22 Gilks C, Floyd K, Haran D, Kemp J, Squire B, Wilkinson D (1998) Health and Population Occasional Paper, *Care and Support for People with HIV/AIDS in Resource Poor Settings*, DFID, London.
- 23 UNAIDS (2002) Report on the Global HIV/AIDS Epidemic 2002, Geneva.
- 24 Mukaso S, *et al* (2001) *Uganda: HIV and related AIDS discrimination, stigmatisation and denial*. UNAIDS Geneva.
- 25 WHO (2000a) Human Rights, Women and HIV/AIDS, Fact Sheet 247, [www.who.int/inf.fs/en/fact247.html](http://www.who.int/inf.fs/en/fact247.html)
- 26 Mukaso S, *et al* (2001) *op cit.*
- 27 Teixeira P, Vitória M, Barcarolo J (2003) 'The Brazilian Experience in Providing Universal Access to Antiretroviral Therapy', Chapter in *Economics of AIDS and Access to HIV/AIDS Care in Developing Countries, Issues and Challenges*, ANRS.
- 28 Holmes B, Losina E, Walensky R, Yazdanpanah Y, Freedberg K (2003) 'Review of Human Immunodeficiency Virus

- Type 1-Related Opportunistic Infections in sub-Saharan Africa', *Clinical Infectious Diseases* 36 652–662.
- 29 Harries A D, Hargreaves N J, Chimizi R, Salaniponi F M (2002) 'Highly active anti-retroviral therapy and tuberculosis controlled in Africa: Synergies and potential', *Bulletin of the World Health Organization* June 2002, Vol 80, No 6, p464–469.
- 30 De Cock K, Soro B, Coulibaly M, Lucas S, 'Tuberculosis and HIV infection in sub-Saharan Africa', *JAMA* 1992. 268 1581–87.
- 31 Creese A, Floyd K, Alban A, Guinness L (2002), 'Cost-effectiveness of HIV/AIDS interventions in Africa: a systematic review of the evidence', *Lancet* Volume 359 165–1642.
- 32 Haacker, M (2001a) *Providing Health Care to HIV Patients in Southern Africa*, IMF Policy Discussion Paper. Washington DC.
- 33 Haacker, M (2001b) *The Economic Consequences of HIV/AIDS in Southern Africa*, IMF working paper. Washington DC.
- 34 UNAIDS (2002) *op cit.*
- 35 Haacker, M (2001a) *op cit.*
- 36 Save the Children UK (2003) *Why the Poor do not Access Healthcare in Western Arua District, Uganda, Kampala*, www.savethechildren.org.uk
- 37 WHO/UNAIDS (2003) *op cit.*
- 38 Harries A D, Nyangulu D S, Hargreaves N J, Kaluwa O, Salaniponi F M (2001) 'Preventing anti-retroviral anarchy in sub-Saharan Africa'. *Lancet* Volume 358 410–414.
- 39 Press release on reports showing progress made in achieving the UN Declaration of Commitment Goals, September 2003.
- 40 UNAIDS (2001) *op cit.*
- 41 Global Health Council (2002) *MTCT Plus – Spearheading Prevention and Care for Mothers and Children*, Columbia University, New York.
- 42 Lwin R, Melvin D (2001) 'Pediatric HIV Infection', *Journal Child psychology and Psychiatry* 42:427–438.
- 43 Barnett T, Whiteside A (2002) *op cit.*
- 44 Haacker, M (2001a) *op cit.*
- 45 Saloojee H, Violari A (2001) *op cit.*
- 46 Infection with intestinal and urinary tract helminthic worms is associated with an increased HIV viral load, implying greater transmission probabilities in mother to child transmission and more rapid deterioration in the immune system. Wolday D *et al.*, 'Treatment of intestinal worms is associated with decreased HIV plasma viral load', *JAIDS* 31:58–62, 2002.
- 47 Taha T, Graham S, *et al* (2000) 'Morbidity among Human Immunodeficiency Virus-1 infected and non-infected African children', *Pediatrics* 106 (6)
- 48 WHO (2003) *Scaling up antiretroviral therapy in resource limited settings – treatment guidelines for a public health approach*, WHO, Geneva
- 49 Fraaij P, Rakhmanina N, Burger D, de Groot R (2004) 'Therapeutic Drug Monitoring in Children with HIV/AIDS', *Therapeutic Drug Monitor* 26: 122-26
- 50 WHO (2003) *op. cit.*
- 51 MSF (2003) *ARV Simplification for High Prevalence Countries*, available at [www.accessmed-msf.org/documents/nairobiworkshopreport.pdf](http://www.accessmed-msf.org/documents/nairobiworkshopreport.pdf)
- 52 Guidelines for the use of antiretroviral agents in paediatric HIV infection. <http://AIDSinfo.nih.gov/guidelines> accessed Jan 25 2004
- 53 Oleske (2003) 'Review of recent Guidelines for antiretroviral treatment of HIV-1 infected children', *Topics in HIV medicine* 11:180–84.
- 54 Paterson D, Swindels S, Mohr J, *et al.*, 'How much adherence is enough? A prospective study of adherence to protease inhibitor therapy using MEMSCaps', in: *Program and Abstracts of the Sixth Conference on Retroviruses and Opportunistic Infections; January 31–February 4, 1999; Chicago.*
- 55 Brackis-Cott E, Mellins C, Abrams E, Reval T, Dolezal C (2003) 'Pediatric medication adherence: the view from two primary care programs', *Journal of Pediatric Healthcare* 17:252–60
- 56 McKinney R, Cunningham C (2004) 'Newer treatments for HIV in children', *Current Opinion in Pediatrics* 16:76–79.
- 57 MSF (2003) *op cit.*
- 58 Save the Children UK (1996) *Starting Young: Principals and practice in early childhood development*. London.
- 59 Ainsworth M, Semali I (2000) *The Impact of Adult Deaths on Children's Health in Northwestern Tanzania*, Policy Research Working Paper No. 2266, World Bank, Development Research Group, Washington DC.
- 60 Mutangdura, G (2000) Paper presented at the AIDS and Economics symposium, IAEN, Durban 7–8 July.
- 61 The Consultation Group on Early Childhood Care and Development (2002) *HIV/AIDS and Early Childhood. Coordinators' Notebook*, An International Resource for Early Childhood Development No.26.
- 62 Save the Children UK, Uganda (2003) *Care for Children Infected and those Affected by HIV/AIDS: A handbook for Community Health Workers, Kampala.*

63 Wekesa, A (2000) 'The impact of HIV/AIDS on child survival and development in Kenya', *AIDS Analysis Africa* 10(4)

64 UNICEF (2004) thereafter referred to as 'the Framework'.

65 AIDS: The Need for an Exceptional Response to an Unprecedented Crisis, Peter Piot, A Presidential Fellows Lecture, 20 November 2003.

66 Sainz T, unpublished research, Save the Children UK, London.

67 *Meeting the Challenge? Unravelling the Global Fund: A comprehensive review of the first three funding rounds*, Save the Children UK, forthcoming.

68 Save the Children UK (2004) *op cit*.

