

3<sup>rd</sup> March 2005

# Out of Reach

Why money for HIV&AIDS  
related care is still not reaching  
those who need it most

*"We fought very hard for the money, and will continue to fight for more, but now let's fight equally hard for making the money work for people."*

Peter Piot, UNAIDS Executive Director

Closing address to the XV International AIDS Conference Bangkok, 16 July 2004

*"The Global Fund money has been approved in our name, and for us positives to prolong our lives. The money should not be floating around, while we are dying!"*

HIV activist, member of Navakiran Plus, Nepal

### **About ActionAid International**

We are an international development agency whose aim is to fight poverty worldwide.

Formed in 1972, for over 30 years we have been growing and expanding to where we are today – reaching over 13 million of the world's poorest and most disadvantaged people in 42 countries worldwide, helping them fight for and gain their rights to food, shelter, work, education, healthcare and a voice in the decisions that affect their lives.

In December 2003 we began the process of making all our country programmes equal partners with an equal say on how we operate, and in April 2004 we established a new head office in Johannesburg, South Africa. In all of our country programmes we work with local partners to make the most of their knowledge and experience. Our partners range from small community support groups to national alliances and international networks seeking education for all, trade justice and action against HIV&AIDS. Our work with these national and international campaign networks highlights the issues that affect poor people and influences the way governments and international institutions think.

We have a unique vision and direction. We do not impose solutions, but work with communities over many years to strengthen their own efforts to throw off poverty. We constantly seek new solutions and ask ourselves how we can make the greatest impact with our resources. We make the most of our skills and abilities by working at many levels - local, national, regional and international.

### **Acronyms**

AAI – ActionAid International

AIDS – acquired immune deficiency syndrome

ART – antiretroviral therapy

ARV – antiretroviral

DAC – Development Assistance Committee

HIV – human immunodeficiency virus

MSM – men who have sex with men

PEPFAR – President Bush's Emergency Plan for AIDS Relief

UNAIDS – United Nations Joint Programme on HIV&AIDS

UNICEF - United Nations Children's Fund

WHO – World Health Organisation

### **Acknowledgements**

Written by Linnea Renton, with thanks to the ActionAid International HIV&AIDS Campaign Team, and particularly to staff and partners in India, Italy, Kenya, Malawi, Mozambique, Nepal, Nigeria, Pakistan, South Africa, Spain, UK, Vietnam and Zimbabwe for their contributions and support.

Thanks most of all to the HIV-positive women and men and other community members who shared their time, their stories and their views with us.

## Executive Summary

ActionAid International is campaigning for the right and access to HIV&AIDS related care for poor and excluded people, especially women and children. An essential part of this is **making the money work**: ensuring that the increasing global resources for HIV&AIDS actually result in tangible benefits for those in whose name the money is raised.

In this paper we highlight the voices of those at the centre of the struggle, and examine the major blocks standing in their way. All of the case studies presented are rooted in ActionAid International's everyday experience, working with communities and partners worldwide. We focus on seven major barriers to HIV&AIDS related care:

1. Resources are not reaching the poorest.
2. Women, who bear the heaviest burden in caring for others, are often last in line to receive care themselves.
3. Children's needs are being ignored.
4. Those already excluded by society face additional barriers.
5. Stigma and ignorance among health care staff remain widespread.
6. Governments and international donors are not earmarking or tracking resources for women, children and excluded groups.
7. There is a lack of civil society participation, in particular by HIV-positive people, in decision-making about care and treatment.

**In order to make the HIV&AIDS money work, ActionAid International has the following recommendations. Governments and international donor institutions must:**

- Make specific efforts to target the poorest members of the population, not only for HIV&AIDS care but also to tackle poverty and food insecurity. Without attention to livelihoods, any care and treatment programme will be undermined.
- Address the particular care and treatment needs of women and children – including their need and right not to bear the full burden of care for others.
- Actively fight discrimination against stigmatised and excluded groups. Those already pushed to the margins of society should not become further disadvantaged as a result of their HIV status.
- Provide adequate training for health care providers, relating to attitudes as well as skills. Good practice can never be built from ignorance and fear.
- Earmark resources separately for target groups and monitor on the basis of clearly disaggregated data. Only with careful monitoring can the real impact of care and treatment initiatives be measured.
- Ensure active and meaningful participation by positive people in planning, implementing and monitoring care and treatment interventions. The principle of "Nothing about us without us!" must be respected in order to deliver relevant and high quality HIV&AIDS care to all who need it.

Please note that this report is also available in full on [www.actionaid.org](http://www.actionaid.org).

## Introduction

ActionAid International is campaigning for the right and access to HIV&AIDS related care for poor and excluded people, especially women and children. An essential part of this is **making the money work**: ensuring that the increasing global resources for HIV&AIDS actually result in tangible benefits for those in whose name the money is raised.

Throughout 2005 and 2006 – with the help of the communities and partner organisations with whom we work – we are tracking HIV&AIDS resource flows from international donors and national budgets down to community level, to identify the biggest blocks and barriers to care and to fight for the rights of those left out.

Despite the focus on antiretroviral drugs (ARVs) of current initiatives such as ‘3 by 5’<sup>1</sup>, care in relation to HIV&AIDS goes far beyond drug treatment. Alongside ARVs and the provision of medicines to deal with opportunistic infections, care also includes aspects of prevention; voluntary counselling and testing; nutrition; palliative care; and support to families and the wider community, including psycho-social support and building self-esteem.

To be truly accessible, HIV&AIDS care must be:

- free or affordable to all, including the poorest

---

<sup>1</sup> ‘3 by 5’ is the global initiative by the World Health Organisation (WHO) and UNAIDS to put 3 million people living with HIV&AIDS in developing and middle-income countries on antiretroviral therapy (ART) by the end of 2005.

- non-discriminatory, accountable and transparent
- gender-equitable, with a focus on the needs and rights of women and children
- delivered close to the users, and available throughout all geographical areas within a country
- the legal right of all those infected and affected.

In this paper we highlight the voices of those at the centre of the struggle, and examine the major blocks standing in the way of poor and marginalised people, especially women and children, achieving their right to HIV&AIDS related care.

All of the case studies presented are rooted in ActionAid International’s everyday experience, working with communities and partners worldwide.

## Why the money isn’t working

### 1. Resources are not reaching the poorest

*“The Global Fund money has been approved in our name, and for us positives to prolong our lives. The money should not be floating around, while we are dying!”* – HIV activist, member of Navakiran Plus, Nepal.

Despite increased international resource flows through mechanisms such as the Global Fund, HIV&AIDS related care is still not accessible to vast numbers of those who urgently need it.

The World Health Organisation reported on 26 January 2005 that 41 per cent of those who need but are not receiving ARV treatment live in just three countries – South Africa, India and

Nigeria. According to WHO's Director of HIV&AIDS Dr Jim Kim, "Those three countries have to get moving, and they have to get moving now."<sup>2</sup>

*"The challenge is that these people have come out to join us with the hope they can receive help for treatment and economic support but there is no help, and because of that, they are withdrawing. To me really it is very painful that with this area being the 3rd highest prevalence rate in the country, there is no access to ARV in the area. Many of our people are dying because they don't have access to drugs."* – Mercy, 28-year-old accountant and member of Hope Restorers, a support group of positive people in Zango Kataf Local Government Area, Nigeria.

There are several key reasons why resources for HIV&AIDS related care are not getting through to the poorest segments of society. Part of the problem lies in **lack of political will and government commitment**. For example, the South African government failed over many years to take urgent action while the numbers of its HIV-positive citizens continued to climb. In November 2003, the Cabinet approved the Operational Plan for Comprehensive HIV&AIDS Care, Management and Treatment for South Africa, which provides for ARV medicines to be made available at public health facilities for the treatment of poor people who cannot afford ARV medicines already available in the private health sector. However, even now, the government has not matched its public pronouncements with an equally urgent plan of training and human resource development for ARV roll-out.

<sup>2</sup> *Global Fund Observer*, Issue 39, 1 February 2005.

**Denial** continues to play a major role in many countries. In Pakistan, for example, successive governments have insisted that HIV&AIDS is associated with "moral turpitude" and there is no major threat to the country.

*"There was no support to the patients from the government in 1995 when I was tested HIV-positive, and even today they practically do nothing for us. I still am working on my own resources and doing what the government departments should have been doing."* – Shukria Gull, 35-year-old positive widow and mother of two, Lahore, Pakistan.



However, even where political will and commitment are present, formidable obstacles remain. **Bureaucratic blockages** in both national and multilateral institutions are hindering access, especially by poor people.

*In Argentina, even though the law guarantees the cost-free provision of treatment and medication for people living with HIV&AIDS who do not have resources, this access encounters various obstacles in practice, resulting in interruptions and, in some cases, the abandonment of treatment.*

- *Delays in purchasing processes and failure to spend the budget have resulted in the unavailability of medicine, interruptions in treatment or incomplete deliveries of medicines. This situation forces affected people to travel repeatedly to health facilities in different areas.*
- *In many cases, the treatment centres are found in major urban areas, and a “travel voucher”, that would allow lower-income people to access them easily, does not exist.<sup>3</sup>*

In such circumstances, the dangers of the development of drug resistance are high. In El Salvador, Otoniel Ramírez (diagnosed four years ago) recently found that one of the medicines he takes, Efiravenz, was not being supplied and he was asked to come back one week later to find whether it was back in stock. He even tried to exchange medicines with other patients who might have spare pills. The stock-out lasted for a whole month, during which many positive people had to take their pills only every other day. Salvadorean physician Dr. Panameño confirms that *“it is neither correct nor advisable to take the medicines in an irregular manner, as they could create resistance even in such short periods of time”*.<sup>4</sup> Thus not only access to care and treatment, but also their consistency and effectiveness, can be compromised.

<sup>3</sup> Teresa Guthrie and Alison Hickey, eds., *Funding the Fight: Budgeting for HIV/AIDS in developing countries*, AIDS Budget Unit, Idasa, Cape Town, October 2004, p. 274.

<sup>4</sup> *El Diario de Hoy*, San Salvador, 28 August 2004.



For the poorest people in the poorest countries, the situation is much worse. In Kenya, for example, HIV&AIDS is now the biggest health challenge. The National HIV prevalence was estimated at 7.1% in 2003 after a population-based survey (the Kenya Demographic Health Survey conducted by the Central Bureau of Statistics). There are 1.25 million Kenyans estimated to be HIV-positive, and about 200,000 currently need ART.

In a bid to provide treatment for its population, the Kenyan government received funds from the Global Fund and initiated the ART program. Further through the 3 by 5 initiative, Kenya was to put about 144,000 people on treatment by 2005. Kenya also received PEPFAR funds to support scaling up. The overall goal of the government's program is to expand ART to public health facilities including 8 provincial hospitals and 30 “high-burdened” districts by the end of 2004, and to 70 districts by the end of 2005.

Despite all these major initiatives, it is now evident that Kenya's poor and excluded, especially women and children, still lack access not only to ARV treatment but also to the general care that is needed for people living with HIV&AIDS.

Charity Mbula, for example, a 33-year-old positive single parent who lives in Kiandutu slum area in Thika town on the outskirts of Nairobi, has been ailing for the last two years. She shares a 10 by 10 foot mud-walled room with her ageing mother and her four children. She indicates her walking stick and says, *"This illness has reduced me to this. The furthest I can walk with this stick is outside the house."*

In what seems to be constant pain, Charity continues, *"There are these drugs that are sold at the district hospital at KShs 500 [US\$6.54] per month. I was in the same hospital ward with another lady, her family raised money to buy her the drugs. Within months, she had regained strength and was up and about her business. I wish I could get those drugs but I cannot afford them, leave alone buying our food in this house. Look at him [she points at her 7-year-old son Mutuku]. He is always sick. He is just like me. Both of us are supposed to go for medical review but I do not have money. Only TB drugs are available for free. Now I need to collect TB drugs from the hospital but I have no bus fare. At the same time I am too weak to walk to the nearest district hospital [10 kilometres away]."*



Charity Mbula, Kenya

**Charges for care and treatment** (even when the costs are minimal) and **limited geographical spread of health facilities** disproportionately affect those who are poor. Poverty is costing many HIV-positive Kenyans – and others worldwide – their lives.

**2. Women, who bear the heaviest burden in caring for others, are often last in line to receive care themselves**

*"My biggest want now is to access HIV&AIDS treatment so I could care for my son longer. I want to get ARV to keep my life longer, so I can earn more money for my family. A pill costs me 2 dollars: that is extremely horrible for me."* – Nguyen Thi Kieu, 19-year-old positive woman, Ho Chi Minh City, Vietnam, also caring for her grandmother, her mother, her husband and their 3-month-old baby.

Steven Lewis, the United Nations Secretary General's Special Envoy on HIV&AIDS, has described home-based care as "conscripted labour". The vast majority of this labour is carried out by girls and women, even if they are ill themselves. For example, in Malawi, it is common that men who are infected are nursed

by their wives during illness, while a sick woman is nursed by a female relative, neighbour or friend who has other responsibilities of her own at home.

Magdalena Sosten is a 35-year-old positive woman in Mponela, Malawi with four children aged fifteen, thirteen, eight and one. Her eldest daughter nurses her when she is ill. Magdalena does piece work, which mainly consists of collecting water from a bore-hole for restaurants at the trading centre. She is given 10 kwacha (US\$0.09) per pail. On a good day she makes 50 kwacha (US\$0.45). When she gets paid she buys some food for herself and her children. On days when she gets no work, she just explains to her children that there is no food to eat.

In Zimbabwe, with 70% of hospital beds being taken up by patients with HIV&AIDS related illnesses, the demand on health delivery services has been immense. Here as well, women and girls bear the brunt at home. The family of 47-year-old Zimbabwean Catherine is a case in point. She is a divorced mother of three, diagnosed HIV-positive following the death of her twins, one at 8 months and the other at 11 months, in 1999. Catherine has no access to medication, including basic painkillers. As a result she is enduring considerable pain. The local clinic has no medication for her condition. As she puts it, *"There is no incentive for me to visit the clinic because I get no assistance."* She feels there is no need for her to waste the meagre energy that she has going to the clinic, just to come back empty-handed.

To compound her problems, Catherine's daughter Fadzai ran away in December 2004. When the police found her, she told them she was tired of looking after her HIV-positive mother who *"was not getting better."* Fadzai was – at the age of 16 – the family's breadwinner, looking after her mother and two sisters from money made working at a flea market. As with Magdalena's daughter above, Fadzai's case illustrates all too clearly that girls are bearing a huge and unfair burden of care.

Limited access by girls and women to information (both within the household and in the public sphere) compounds their difficulties. For many women, the entry point for information and services on issues related to HIV & AIDS is during visits to antenatal clinics – obviously after they have already had unprotected sex. In Nigeria, women attending antenatal clinics in government hospitals undergo mandatory HIV screening as part of the routine test. In most cases, the HIV test is done without any form of counselling. The case of 33-year-old Esther James is no different, as she recounts: *"When I was 3 months pregnant, my husband and I were required for blood screening and he said we were not going to do it. We went to different government hospitals and the requirement was the same but my husband warned me not to carry out the test and I did not understand the purpose of the test. I got to know my status when I was 8 months pregnant and visited my parents in Abuja. My father took me to the state clinic where the test was conducted. I could not share this information with my husband for fear that he would abandon me with my parents. I*

*refused to go back to the government hospital and had to deliver my baby at a private clinic”.*



Esther later lost her child, something she believes need not have happened if she had had appropriate information and advice. *“Access to treatment is very important but it is not the answer, we need to challenge the stigma around HIV&AIDS. We must empower women to access their rights to health related care and services.”*

Many other women come to know their status only after the death of their husbands. Often, despite other members of the family knowing what is wrong, wives are not told the real cause of sickness till the death and burial ceremonies have been completed. Mary Tanko, a Nigerian widow with two children, reports, *“I was with my husband and started seeing changes in his body. I encouraged him to go for HIV test which he did, but he did not tell me the result”.*

34-year-old Anna Ngoepe, of Mamelodi Township, South Africa, has three children, two of whom are HIV-positive. Her husband never disclosed his HIV status but she discovered that he was secretly taking medication. When she

asked him about this, he told her that it was for treating *amadlozi* (a Zulu word for ancestrally-induced illness). She however took her husband’s medication to a doctor to ask what it was for. The doctor told her that the tablets were for treating HIV.

Anna herself, diagnosed HIV-positive in December 1992, suffers from a multitude of health problems such as asthma, epilepsy, arthritis and high blood pressure. She feels tired all the time and spends most of her time sleeping. She reports that her children’s health is also getting worse. Anna wants to stop the stigmatisation of her children at school and gets very angry with the teacher who tells her son to stay at home *“because he coughs like a grandfather.”*



The caring burden on women’s shoulders lasts right into old age. 64-year-old grandmother Molina Namabaca lives in Calanga, Manhiça district, Mozambique. When her young grandchild João was taken into hospital, she stayed with him there for two weeks. Although João had not yet recovered fully, Molina told the doctor: *“I left behind my husband and three*

*other grandchildren [14, 10 and 7 years old whose parents died of AIDS and no one knows their HIV status] who need me. They all go to school and if I am not there I suffer in double by knowing what they are going through. Let me go home so that I can take care not only of this baby but of four more people. My husband is weak, he can no longer do the farming which is our only means of subsistence, and my three grandsons and daughter are all in school. I need to go to the farm everyday, because if I don't then there is nothing to eat. But because of this sick baby, every time I go one of the others cannot go to school but has to stay with the little one."*



When presented with the possibility that perhaps an institution would be able to take care of João, Molina's response was: *"I do understand you and now you have to understand me ... this baby has my blood in his veins. I am an old woman with strong beliefs and I would never forgive myself if I give the baby to a person or institution who has no blood links with the baby. Can you tell me how I am supposed to live with that guilt on my shoulders?"*

### 3. Children's needs are being ignored<sup>5</sup>

*"I hope that like me, she can also get ARV treatment when she needs it. I pray that the paediatric formulations are made available which will be easy to administer to my child,"* Anuradha, positive widow and peer counsellor in Bangalore, India, talking about her positive daughter Bhavya.

According to UNICEF, just under half a million children died of AIDS in 2003. The vast majority of these were in sub-Saharan Africa, where the disease has become one of the leading causes of mortality in children under the age of five. ART, however, is not reaching children in resource-limited settings. Paediatric HIV&AIDS has not received high priority in most settings, and many national treatment programmes have omitted children from their plans altogether. There are few skilled health personnel with expertise in treating children with HIV. But it is estimated that at least 15% of the global need for treatment is in children and that 500,000 children are in immediate need of ART. There are a number of reasons for this treatment gap in children.

#### **\*Obstacles to HIV testing and diagnosis in children**

Antibody tests are unreliable in infants born to HIV positive mothers, as the children may have maternal antibodies present in their blood up to the age of 18 months. However, waiting for

<sup>5</sup> This section draws heavily on material compiled by Theo Smart, *HIV&AIDS Treatment in Practice #40*, January 28, 2005, "Children with HIV are being left behind in the rollout of antiretroviral therapy".

these antibodies to clear is not an option in most infected infants, the majority of whom are likely to show signs of AIDS-related illness within their first year. If left untreated, half of them will die by the end of their second year.

**\*Lack of suitable and affordable child-friendly antiretroviral medicines**

The form, volume and flavour of a medicine influence whether it is acceptable to a child - and whether he or she will be adherent to treatment. For young children, pleasant-tasting, low-volume liquid formulations are the easiest to administer (though taste varies from culture to culture). Older children often prefer simply swallowing solid formulations. However, many antiretroviral drugs are only available as adult-dosed pills. The costs for all paediatric formulations are currently well above the reduced prices achieved for adults.

**\*Confusion regarding dosage adjustments for weight and age**

Because of difficulty in accessing paediatric ART formulations and the difference in cost, many caregivers are simply crushing up adult formulations and giving them to children. According to WHO's Dr Charlie Gilks, "Of the few children who have access to treatment, almost all rely on adult capsules or tablets broken or mixed by parents or caretakers."

However there is a significant danger of over- or under-dosing with this practice. While children are smaller than adults and naturally need smaller volumes of drug, one cannot simply calculate the child's dose based on the adult dose/weight ratio. Drugs are processed differently in an infant's body. Also, there are no

published data on the bioavailability or stability of opened capsules or crushed tablets of the adult formulations – particularly when dissolved in water, juice or mixed into food. The adult formulations were not designed with that use in mind.

**\*Little advocacy on behalf of children with HIV**

Treatment advocacy is desperately needed to push for the inclusion of children in national treatment programmes, demand reductions in the cost of paediatric formulations and reduce unnecessary regulatory hurdles that are delaying the production and marketing of ART for children.

**\*Lack of specific attention to the needs and rights of girls**

Many studies have shown that household expenditure (on food and education, for example) in poor families routinely favours fathers and sons over mothers and daughters. As with data on care and treatment of adults, it is very difficult to obtain specific figures about children by gender. However, given the different societal and cultural expectations of the roles of girls and boys, aggregated statistics are likely to be disguising significant inequalities in their respective access to care and treatment.

**4. Those already excluded by society face additional barriers**

*"In Pokhara, there is an increasing number of people living with HIV, as well as injecting drug users. Yet we have not been on government's priority to receive ART. Why this exclusion?" –*

An ex-drug user from Community Support Group, Pokhara, western Nepal.

Individuals and groups who already experience stigma and discrimination within society – such as injecting drug users, men who have sex with men, sex workers and street children – are also more likely to face difficulties in obtaining their rights to the full range of HIV&AIDS related care.

This has been the case in a number of Latin American countries, such as Chile, Ecuador and Nicaragua, where there have been no consistent campaigns in which the use of condoms has played a central role.

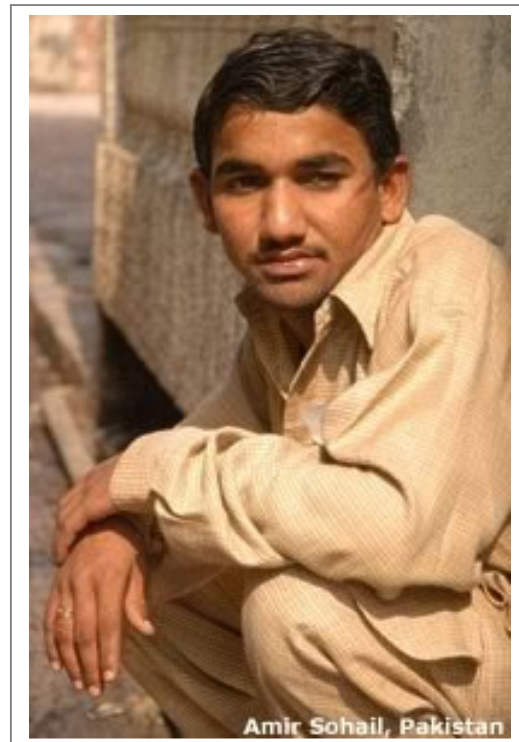
*“Unfortunately stigma and traditional religious teachings have played a role in hindering prevention activities, since the epidemic is still concentrated among men who have sex with men (MSM). Governments have thus ignored, to different degrees, the need to address prevention efforts for MSM.... It should be clear that whatever the amount of money invested in treating the disease, it will never be enough if prevention is not strengthened.”<sup>6</sup>*

Women forced into sex work are among the most excluded and stigmatised groups in India, and also more vulnerable to HIV&AIDS. In the annual sentinel surveillance carried out by the Karnataka State AIDS Prevention Society in 2004, for example, HIV prevalence was 21.6% among female sex workers. ActionAid India is working with over one thousand sex workers in the Karnataka districts of Davangere and Shimoga through a project called ‘Abhaya,’ meaning ‘without fear’. Abhaya works to create

<sup>6</sup> Guthrie and Hickey, op. cit., p. 336.

awareness on safer sex options, provide STI treatment to reduce the risk of HIV infection and strengthen the community to fight violence, stigma and discrimination and access their rights.

Street children are also extremely vulnerable to infection, with little or no access to care and treatment.



Amir Sohail, living on the streets for over a decade in Lahore, Pakistan, describes the fight for survival that he and other children and young people like him face every day. *“They have sex with anybody and it does not matter how many people they have to deal with in a*

day. The only important thing is the amount of money. Nobody uses condoms and there is not question of using them while having sex with a boy or a girl. The people from the refuge centres often detain children for sending them back home. But they have never detained me or those who live with me. They simply hate us.”

#### **5. Stigma and ignorance among health care staff remain widespread**

“They simply handed me the results saying that my husband was going to die soon and I was also infected. They had no idea about counselling the family and gave us no information whatsoever as to how to deal with the situation. The hospital staff spent no time in shifting my husband to the worst room available, stopping all treatment and waiting for him to die. Even the senior-most doctors at the hospital would examine him while standing several feet away behind the partly open door.”  
– Shukria Gull, 35-year-old positive widow and mother of two, Lahore, Pakistan.

The negative attitudes of health care providers can be major blocks to proper care and treatment. Unfortunately such views amongst those who “should know better” both reflect and reinforce the fears and prejudices of wider society.

“The doctors called the entire family to the hospital and told them I was HIV-positive. I did not know what that meant but faced humiliation when everyone fought and nobody wanted to have anything to do with us. All they had to say

was we would soon die for our sins.” – Jasmin, 25-year-old woman, Bangalore, India.



#### **6. Governments and international donors are not earmarking or tracking resources for women, children and excluded groups**

“Government allocations for, and actual spending on, HIV/AIDS activities require far greater accountability and disaggregation, in terms of programme prioritisation, regional distribution and beneficiary type.”<sup>7</sup>

In most government budgets, there is no disaggregation of data based on gender, age or socioeconomic status. This makes it extremely difficult to tell where spending is going and who is benefiting – or not benefiting – from it. Lack of transparency and accessibility of information are major stumbling blocks.

Many international donors, including the Global Fund, also do not disaggregate their disbursements by gender. Within the Development Assistance Committee (DAC) of the Organisation for Economic Co-operation

<sup>7</sup> Guthrie and Hickey, op. cit., p. 345.

and Development, despite directives on gender reporting, a number of member countries – including France, Ireland, Luxemburg, Netherlands, UK and USA – do not comply.<sup>8</sup>

**7. There is a lack of civil society participation, in particular by HIV-positive people, in decision-making about care and treatment**

*“In this fight every single voice matters. If an uneducated, positive woman with two positive children can bring herself to the front line, all others can. Therefore, let us speak up and strengthen our solidarity in the fight against HIV.”* – Preeti Subba, 29-year-old positive mother of two, Taplejung, far eastern Nepal.

*“The state is obliged to adopt and apply, on the basis of epidemiological information, a national public health strategy and action plan, in order to confront the health issues of the population; the strategy and the action plan are to be devised and periodically revised through a transparent and participative process; the strategy and the plan must provide methods, such as ... indicators and health reference bases, that allow the close monitoring of realised progress; the process for conceiving the plan and the strategy, as well as their content, has to consider vulnerable groups and marginalised populations.”* – UN Committee on Economic, Social and Cultural Rights<sup>9</sup>

---

<sup>8</sup> Based on the DAC on-line special database on HIV&AIDS donors' bilateral allocations <http://stats.oecd.org/ODB/DisplayOWC.aspx?DataSetCode=CRS%20HIVAIDS>

<sup>9</sup> General Comment No 12, para 43f, quoted in Guthrie and Hickey, op. cit., p. 346.

Despite the calls from the grassroots all the way up to the UN, active and meaningful participation by positive people continues to be more a myth than a reality. There is no doubt that this is sometimes the result of deliberate exclusion of positive people's organisations (and indeed of wider civil society) from decision-making processes. Tokenistic consultation is also all too common. However, even when there is genuine receptiveness and good will by statutory agencies and other authorities, positive people's groups may lack the capacity – the skills, confidence, time and resources – necessary to put their views forward in a coherent and effective way. Whatever the cause, without such participation, decisions will not reflect the true impact of the epidemic and will go on failing to meet the real needs of those infected and affected.

## Recommendations

### Making the money work

*"We fought very hard for the money, and will continue to fight for more, but now let's fight equally hard for making the money work for people."* - Peter Piot, UNAIDS Executive Director, closing address to the XV International AIDS Conference, Bangkok, 16 July 2004.

*"The Commission on Human Rights [c]alls upon States to pursue policies... which would promote: (2b) The accessibility to all without discrimination, including the most vulnerable sectors of the population, of such pharmaceuticals or medical technologies and their affordability for all, including socially disadvantaged groups."* – United Nations Commission on Human Rights resolution 2001/33, Access to medication in the context of pandemics such as HIV/AIDS, 23 April 2001.

**In order to make the HIV&AIDS money work, ActionAid International has the following recommendations. Governments and international donor institutions must:**

- Actively fight discrimination against stigmatised and excluded groups. Those already pushed to the margins of society should not become further disadvantaged as a result of their HIV status.
  - Provide adequate training for health care providers, relating to attitudes as well as skills. Good practice can never be built from ignorance and fear.
  - Earmark resources separately for target groups and monitor on the basis of clearly disaggregated data. Only with careful monitoring can the real impact of care and treatment initiatives be measured.
  - Ensure active and meaningful participation by positive people in planning, implementing and monitoring care and treatment interventions. The principle of "Nothing about us without us!" must be respected in order to deliver relevant and high quality HIV&AIDS care to all who need it.
- 
- Make specific efforts to target the poorest members of the population, not only for HIV&AIDS care but also to tackle poverty and food insecurity. Without attention to livelihoods, any care and treatment programme will be undermined.
  - Address the particular care and treatment needs of women and children – including their need and right not to bear the full burden of care for others.