



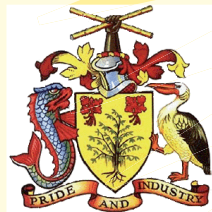
THE ECONOMICS OF DIGNITY

BRIEF FOR PARLIAMENTARIANS

ON UNPAID HIV CARE AND THE

PUBLIC DEBT CRISIS

June 2010



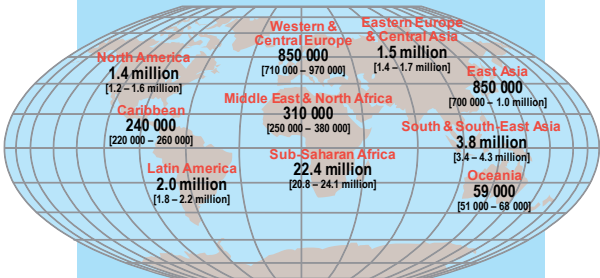
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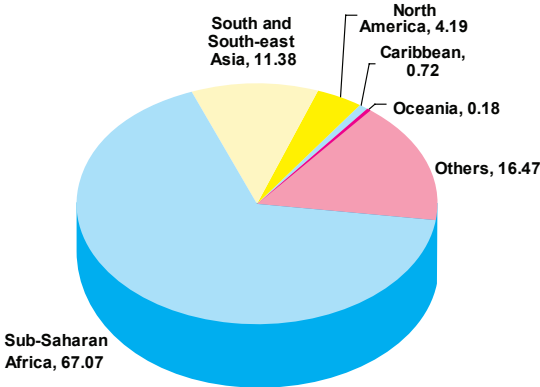
ON UNPAID HIV CARE AND THE PUBLIC DEBT CRISIS

Parliamentarians play a critical role in determining national budgets and priorities for health and social care expenditure. They are mandated to develop appropriate and gender-responsive policy measures that recognise the contribution of unpaid work in HIV care. As elected representatives, they oversee legislative processes and participate in governance. By holding governments accountable, and advocating for gender-responsive legislation in line with international human rights standards, they work to uphold and strengthen democratic principles.

ADULTS AND CHILDREN ESTIMATED TO BE LIVING WITH HIV, 2008



PERCENTAGE OF TOTAL WORLDWIDE HIV INFECTIONS



Data source: UNAIDS & WHO, 2009

WHO CARES?

At the end of 2008, 33.4 million people were living with HIV. Nearly two-thirds of them are Commonwealth citizens. 56 per cent are women.

The Commonwealth is home to all major epidemic profiles – ranging from the generalised epidemics of Sub-Saharan Africa, to epidemics in high risk groups such as sex workers in South and Southeast Asia and the drug-use and gay epidemics of Asia, North America and the Caribbean.

At the centre of the AIDS response are the estimated 12 million people who urgently require access to treatment, care and support. Of this 12 million, 8 million do not have access to treatment and will die of AIDS¹. The total resource envelope for HIV was nearly US\$13.7 billion in 2008, but estimates put the annual requirement to be nearly US\$25 billion in 2010.²

Access to treatment, care and support are the pillars of the global response to HIV and AIDS. Governments and the international community are focused on

1 UNAIDS 2008
2 UNAIDS Outlook 2010

preserving treatment enrolment targets and ensuring prevention dollars are invested according to epidemiological profiles.

The impact of the global public debt crisis on HIV programming has resulted in an increased focus on efficiency of resource use. Reaching or even maintaining treatment targets has therefore become a priority.

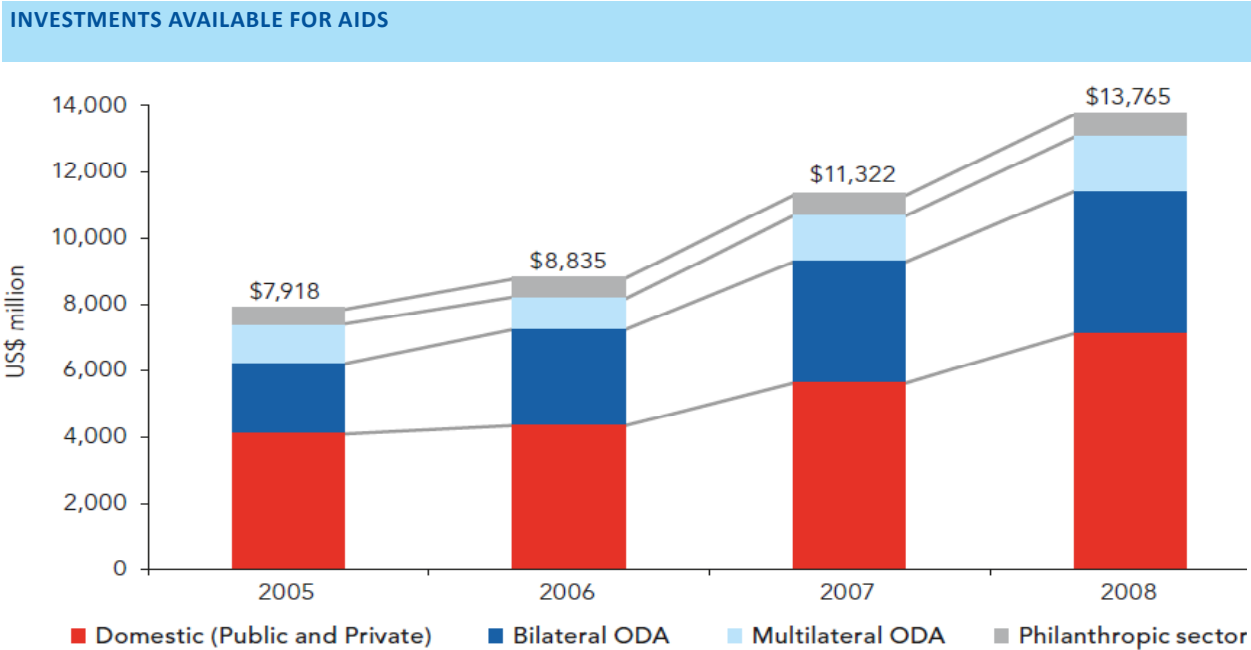
The missing factor in the treatment equation is those who care for the eight million requiring treatment and who cannot access it. Evaluation criteria to assess HIV programmes focus on reduction of the national burden of HIV and AIDS without acknowledging where that burden falls. AIDS is a crisis that hits hardest at the household level.

Measures which reduce the burden on the household receive the least financial and implementation support. But it is the household, and by and large, the women of the household, who subsidise HIV care. The role of the carer is not only limited to women – gay and transgender people also care for their partners, often under more difficult societal pressures and discrimination by the wider community.

The secondary impact on families is also rarely recognised, such as a lack of access to basic necessities due to stigma and discrimination. These and other direct and indirect effects cannot be easily measured in monetary terms.

WHO PAYS?

In terms of resource allocation, UNAIDS estimated that in 2008 nearly US\$ 13.7 billion was mobilised for combating HIV worldwide. The recent trend has seen an increase in domestic and bilateral donor financing of country programmes.



Source: *What countries need: Investments needed for 2010 targets*. UNAIDS, 2009.

However, the resource requirement estimated by UNAIDS in its 2010 report is just above US\$25 billion, nearly double the amount mobilised in 2008, and nearly a quarter more than the estimates for 2009. The resource needs for sustaining HIV programmes are increasing rapidly, mainly due to the success of many countries in expanding their prevention and treatment programmes.

In light of the current public debt crisis, the HIV national funding targets are clearly unsustainable.

| INVESTMENTS NEEDED FOR HIV SERVICES IN 132 LOW – AND MIDDLE-INCOME COUNTRIES (US\$ BILLION) | | |
|--|-------------|-------------|
| Country-defined targets | 2009 | 2010 |
| Prevention | 9.0 | 11.6 |
| Treatment and care (including palliative care) | 5.5 | 7.0 |
| Orphans and vulnerable children | 1.7 | 2.5 |
| Programme support costs | 3.4 | 3.7 |
| Prevention of violence against women | 0.2 | 0.3 |
| Total | 19.8 | 25.1 |

Source: *What countries need: Investments needed for 2010 targets. UNAIDS, 2009.*

| INVESTMENTS NEEDED – CATEGORISED BY ACTIVITY AREA (US\$ BILLION) | | |
|---|-------------|-------------|
| Country-defined targets | 2009 | 2010 |
| HIV-specific health services | 7.6 | 9.4 |
| Health system strengthening and cross-cutting activities ^a | 7.5 | 9.2 |
| Multisectoral services | 4.7 | 6.5 |
| Total | 19.8 | 25.1 |

^a cross-cutting activities include: programme costs, strengthening of civil society, global advocacy and coordination, policy, human rights and tackling stigma

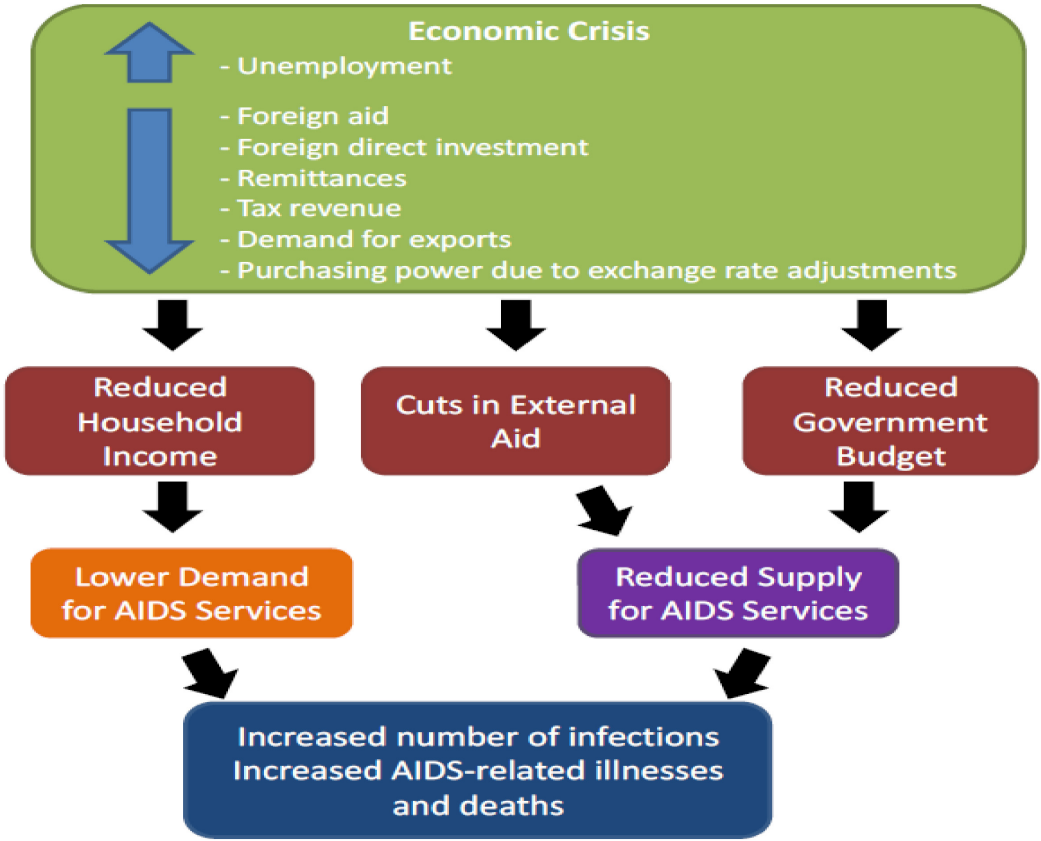
Source: *What countries need: Investments needed for 2010 targets. UNAIDS, 2009.*

To date, the main focus of AIDS care has been on treatment, yet this focus fails to acknowledge the vital contribution made by unpaid carers in the household. Undoubtedly, cutbacks will impact severely on institutional and cross-sectoral aspects of health care. As a result, HIV-related advocacy, human rights protection, and civil society activism towards achievement of gender equality and empowerment of women and men will be disadvantaged, under-resourced and compromised.

The current public debt crisis that developed countries are facing will have serious consequences for funding global HIV programmes. The impact of the economic downturn on national budgets

and the resultant reduction in public spending will lower household capacity to access HIV and AIDS related services that are already under severe pressure due to cuts in external aid. Consequently, unpaid carers in the household will be required to shoulder even more burden as they effectively subsidise public health provision. The illustration shows the routes by which the economic crisis is contributing to increased infections, illnesses and deaths.

THE ECONOMIC CRISIS AND HIV PROGRAMMES



Source: Impact of the global financial and economic crisis on the AIDS response. UNAIDS, 2009

DUTY OF CARE

Being part of the international community and its commitments towards the Millennium Development Goals (MDGs), Commonwealth governments are working towards the achievement of the MDG targets. Protecting the rights of unpaid carers in the household is not only part of their commitment to international human rights standards but also crucial to their commitment towards the achievement of the MDGs.

Research on unpaid HIV care in the household commissioned by the Commonwealth Secretariat demonstrates that upholding the human rights of unpaid household carers in accordance with international human rights standards is key to protecting the dignity of all people living with HIV/AIDS.

The right to dignity is inalienable and enshrined in all human rights conventions. As duty-bearers, governments have a duty to protect the human rights of their citizens and protect their dignity. Most Commonwealth governments have ratified key international human rights conventions particularly the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on Elimination of All forms of Discrimination Against Women (CEDAW) and the Convention on the Rights of the Child (CRC). They are also part of the Universal Periodic Review³ process. Reports to treaty bodies place a moral responsibility on governments to uphold the human rights of their citizens. CEDAW and CRC, in particular, outline the commitment of governments and the international community to the rights of women and children, who are most likely to bear the brunt of unpaid care as households are hit hard by HIV/AIDS and the recent developments in relation to funding.

Giving voice to unpaid carers provides the foundation for national treatment and care strategies to combat HIV/AIDS in a resource-reduced context. Amplifying those voices serves to bring home the duty of care.

SAYS WHO?

‘He was in the same clothes in a corner bed [of the hospital], no sheets nothing. The food that they had taken for him was lying there. He was blind, crippled, and not talking’

UNPAID CARER, JAMAICA

‘When we started getting the basket people use to laugh at us saying we are eating AIDS food...’

UNPAID CARER, BOTSWANA

‘Right before she was brought to the hospital she was found lying in her own vomit with rotting food in her cell, cigarette butts everywhere and fruit flies all over’

UNPAID CARER, CANADA

‘There is nobody on earth who can really stand beside me. Today I cannot do any work properly due to my HIV infection because people rebuke me or neglect me’

UNPAID CARER, BANGLADESH

³ The Universal Periodic Review (UPR) is a unique process which involves a review of the human rights records of all 192 UN Member States once every four years. The UPR is a State-driven process, under the auspices of the Human Rights Council, which provides the opportunity for each State to declare what actions they have taken to improve the human rights situations in their countries and to fulfil their human rights obligations. As one of the main features of the Council, the UPR is designed to ensure equal treatment for every country when their human rights situations are assessed.

'The most difficult is that you have to stay indoors, you don't go out. Since she don't walk you have to stay indoors. She needs drinking water, she wants to go to the toilet, you have to carry her'

UNPAID CARER, NIGERIA

'My anger was with my own family because they would not come and visit us or bring food for her like what is normally done when someone is sick. It was like I had no family'

UNPAID CARER, PAPUA NEW GUINEA

The carers interviewed across the Commonwealth all speak about living without human rights, living without dignity, living without protection, living without freedom and equality. Living with fear, living with want. Living in servitude.

It is imperative, therefore, that the voices of unpaid carers are recognised when formulating national and international HIV policies. Greater involvement of people living with HIV is now an accepted part of policy formulation, but the dignity, needs and rights of unpaid household carers must also be recognised.

As we develop policy and programming to address the needs of those struggling with AIDS-related illnesses, we need to move to – greater involvement of people living with HIV/AIDS and their carers.

'The only way in which we will deal effectively with the problem of the rapid spread of the epidemic is by respecting and protecting the human rights of those already exposed to the virus and those most at risk'.

HON. MICHAEL KIRBY, FORMER HIGH COURT JUDGE, AUSTRALIA, 1996-2009; EXPERT, UN GLOBAL COMMISSION ON HIV AND THE LAW, 2010.

Justice Kirby's four key components for an effective response to the HIV/AIDS epidemic:

- * Base strategies, interventions, laws and policies on good science (HIL-highly ineffective laws and policies based on myth, fear and prejudice must be avoided)
- * Shared sense of urgency
- * Decisive and pro-active political will to mobilize efforts to combat the HIV/AIDS epidemic
- * Promote and protect the rights of those who are infected and those most at risk

