Heloise Emdon Acting Manager (T4D Africa, IDRC, South Africa Chris Seebregts Division Manager, Biomedical Informatics, Medical Research, Council

The Dutch have an idiom for speaking directly and unashamedly, they call it "speaking from the back of your tongue". Stephen Lewis, in his 2005 Massey Lectures, although rhetorical, discloses deep personal perceptions of the workings of the UN and other multilateral systems and candidly attacks national leaders. Via his disclosures, Lewis breaks with formal diplomacy.

At the time of writing, Lewis was the UN Secretary-General's special envoy for HIV/Aids in Africa, and this is a book of his five-part lecture series broadcast by the Canadian Broadcasting Corporation (CBC) radio during October 2005. No one is spared from his punishing criticism: not the United Nations (UN) diplomats; the World Bank and International Monetary Fund (IMF) policies and statements; its high ranking officials' behaviour; the United States – and the President's Emergency Plan for Aids Relief (PEPFAR); Tony Blair; Bob Geldof; the Swazi King, nor South Africa's President or Minister of Health. Lewis also discloses his own failure to speak out at times. In *Race Against Time*, he provides an unprecedented level of disclosure.

Lewis likens the growing number of orphans from Aids who face near certain death by their teenage years to the holocaust, which claimed two generations. He exclaims that it is "morally reprehensible to embrace silence when there is so much at stake!" He embraces the 'right to protect' as the international right to intervene in situations where nation states neglect their responsibilities, or where their priorities are skewed against the challenges of the Aids pandemic in Africa. Though the Aids pandemic is not equal to genocide, he does believe there is a growing impatience with the behaviour of some nation states. This is Lewis' call for a more forthright approach to them.

1 "Het achterste van je tong laten zien".

By way of example, having privately castigated the King of Swaziland, in whose country 42% of mothers in antenatal clinics are infected, the highest rate in the world, he laments not doing so publicly when the two later met with the media.

"Look at what our silence hides: Polygamy, which denigrates women and spreads the virus; early marriage, which directly violates UN conventions (ratified by Swaziland!); monumental extravagance in the face of pernicious illness and misery. It's alright to speak out about Darfur, about the Congo, about northern Uganda, but not about Swaziland? Conflict is indictable, but wanton death from disease is acceptable?" (p.185).

He identifies South Africa "as the toughest of all" his missions. South Africa's own figures show that there are well over six million people infected by HIV/Aids – the highest absolute number in the world. However, the slow roll-out of antiretroviral therapy (ART) – despite budgetary allocation, prevention and care being addressed – means the country is lagging behind and too many people are dying.

"Every senior UN official, engaged directly or indirectly in the struggle against Aids to whom I have spoken about South Africa, is completely bewildered by the policies of President Mbeki...what is true, I believe, of all of us, is a tremendous commitment to South Africa – a confidence that South Africa is the centerpiece of the continent, and that we would do anything and everything in our power to support its growth and development. Many of us were in some way involved in the international battle against apartheid ..." (p.185).

Lewis finds the utterances of the South African Minister of Health "unfathomable" because of the perpetual and public advocacy of nutritional remedies "as though they are equal or transcend antiretroviral treatment" and the "public confusion she generates through rumours" of the drugs' side effects, not least of which result in non-compliance with the lifelong drugs and could lead to multi-drug resistance. "If my colleagues and friends are confused by the position of the president, they are incredulous at the words and actions of the Minister of Health."

Africa is losing the war against HIV/Aids. Lewis says this is the case because neither Africa nor the international community have prioritised UN Millennium Development Goals (MDGs)<sup>2</sup> commitments, and will not achieve them by 2015. This is the theme of the book. It is presented as deep disclosure from within the UN and frank details of interactions with other international agencies, and

For a full description of the eight Millennium Development Goals set for achievement by 2015, go to: http://www.undp.org/mdg/

several anecdotes of experience in Africa amongst the sufferers of Aids and the vulnerable women and children and orphans for whom he puts up such a valiant fight. Lewis' overriding concern becomes the empowerment of women and universal access to education, as well as the need to manage antiretroviral therapies nationally and to continue to support innovation in technologies to find solutions against the deadly virus.

Lewis observes that the MDGs are all inextricably linked to fighting the HIV/Aids pandemic. However, he does not believe that by 2015 the goals will be met to eradicate extreme hunger; achieve universal primary education; promote gender equality and empower women; reduce child mortality; improve maternal health; combat HIV/Aids, malaria and other diseases; and develop a global partnership for development. He does not address the environmental sustainability goal.

On several occasions Lewis describes how the UN is often divided against itself, and how the World Bank is pitted against the UN. Starting from the UN special assembly on Africa 1986, which he chairs, he describes how, despite the squabbling over wording, agreement is reached over Africa's plight and future policy directions. The unintended effects on Africa came from the upshot of the UN's Africa focus. Premised on this UN declaration on Africa the World Bank and IMF followed with policies on structural adjustment plans (SAPs), which treated the African economies as if they were mature and able to respond to Western economic protocols. In their place came conditionalities on African governments imposed through World Bank loan agreements.

"I have come to the conclusion, as I travel, that the IMF simply doesn't understand the combined ravages of HIV/Aids and poverty; simply fails to understand that you can't deny the hiring of health professionals, in the face of an apocalypse, just because you adhere religiously to some rabid economic dialectic which says that no matter how grievous the circumstance, you can't breach the macro-economic environment. I saw it in Zambia and I saw it in Malawi, and in each case the governments were frantic, but the IMF wouldn't budge" (p. 166).

Later in the book Lewis describes how during a visit to Rwanda the World Bank representative asks him to persuade the Bank headquarter to allow a small percentage of money to go towards treatment for HIV/Aids. Lewis describes a phone call he makes to an official whom he had admired in a former position. Lewis laid out the request and the response he got was: "You see, Stephen, it's difficult. Let's face the painful truth: the people with Aids are going to die. The money would probably be better used for prevention. It's all a matter of trade-offs."

He calls it "this pernicious frame of mind ruled the dialectical roost. Somehow the people living with Aids were expendable, in vast numbers, while people in power persuaded themselves that it was better to practice prevention." Maintaining this level of disclosure as indictment against the international community, Lewis does not give up on hammering home what kind of commitment would be required to support what he calls the "courageous" Global Fund to Fight Aids, tuberculosis and malaria established by the UN. The outcome of the G8 summit in Gleneagles, during which the Commission for Africa called for a "fully funded" Global Fund focused public attention almost exclusively on Africa. He says the Live 8 concert was a brilliant co-option and effective muzzling of the NGO community by Blair.

Within two months of the G8 Summit the "inviolable pattern of betrayal of Africa" emerged. The US refused to support funding in 2006, offering between US\$400 and US\$600 million when it should have committed double that to ensure the fund would meet its US\$2.9 billion target. The G8 commitments to increase their aid to Africa to US\$50 billion a year pales in insignificance against the 20:1 ratio of global spending on military expenditure – which passes the trillion dollar mark. A committed democratic socialist, he is forced to conclude that governments are unreliable and that the private sector has started to play a role ranging from the Gates Foundation to the Global Business Coalition on HIV/Aids, and from companies in Angola to Anglo-American, demonstrating their commitment to fight the epidemic.

Advancing a 10-point proposal to be applied to Africa to give it a better chance for survival Lewis puts emphasis on improved trade with Africa and the need to do away with agricultural subsidies in the north; the rights of the child especially to "universal access" to free primary education; and the rights of women – and campaigns for a full UN agency for women. These are good agenda setting points, but in the reviewers' opinion they remain very much at a high-level policy realm.

While Lewis' optimism is necessary to balance his candour, it is naïve for an outsider to assume that his cutting remarks will not be met by a closing of the ranks. He has not exactly set the UN up for an easy policy job. Having put the cat amongst the pigeons, UN officials working in close proximity with African governments would have to either thank him for his firebrand politics if it opens doors, or dismiss him if they need to pry open others. Lewis might have won some friends, but he certainly will have lost several key role players. Since publishing this book and the public criticism of the SA government at the HIV/Aids global conference in Toronto 2006, Lewis has praised the new direction ushered in by the Deputy President of South Africa.

Although the Massey lectures presented in this compilation deal with issues other than disease, the HIV epidemic is a theme underlying much of what Lewis writes, along with the Millennium Development Goals, which he strongly supports. His critiques of the worldwide response to other MDG issues, such as poverty, hunger and women's rights, are written in the context of the overriding impact of the HIV epidemic and the devastating effect it is having on attempts to achieve all other goals, reversing the gains of previous years and profoundly changing the destiny of Africa.

While recognising the importance of HIV prevention programmes and the potential of microbicide and vaccine development programmes, antiretroviral treatment receives special attention in the Lewis lectures. ART is possibly the most controversial intervention against HIV and Aids and Lewis presents insightful and probing reviews of issues such as international drug patents, donor interests and country-level responses. Developing countries afflicted worst by the epidemic are not spared from his scathing criticism and special mention is reserved for Government policy, particularly Lesotho, and the Ministry of Health in South Africa, the country with the greatest number of infected people in the world.

Perhaps ART receives special mention because Lewis, the great champion of human rights, particularly in Africa, recognises the injustice of disregarding those who appear to be doomed as a result of HIV infection. One of his strongest statements in the book is reserved for the otherwise respected colleague, mentioned above, who makes the mistake of proposing that limited resources should rather be spent on trying to prevent infection rather than treating infected patients who "will die anyway". All lives are valuable and there are frighteningly devastating effects of limiting access to treatment on prevention itself and other Aids-related issues, not least of which is the issue of Aids orphans and child-headed households.

ART is also central to effective prevention programmes by reducing the level of virus in patients and thus reducing the likelihood of transmission. Sexual stereotypes and entrenched behavioural practices are difficult to change and the development of effective vaccines and microbicides, as yet, has proven elusive. However, antiretroviral treatment is effective and accessible in most, if not all, situations. Logistical and health systems issues are potentially solvable and Lewis finds it intolerable that more is not being done to improve access to this proven and effective intervention.

In support of treatment programmes, Lewis praises the World Health Organisation's "three-by-five" initiative (3 000 patients on ART by 2005), brainchild

of the late Director General, Dr Lee Jong-Wook. According to Lewis, it is not of primary importance that the aims are unachievable, but rather that the initiative has rallied support for treatment programmes and given birth to the concept of universal access to ART for all by 2010. Importantly, the "three-by-five" initiative has given the world measurable goals to assess progress in addressing the Aids epidemic.

In addressing the Millennium Villages Projects (MVP), initiated by celebrated economist and special envoy on the MDGs, Jeffrey Sachs, Lewis, while admitting they are in different ideological camps, focuses on the importance of information and praises the MVP policy of spending at least as much on evaluation as on the intervention itself. Although this is probably restricted to experimental sites, it underlines the importance of information in addressing any epidemic, particularly that the size of the Aids epidemic. It is essential that we instil a culture of learning in what is done so that we don't repeat the mistakes of the past and learn what works and what doesn't.

Although information technology (IT) is not the subject of the book, IT is essential to efficiently monitor and evaluate interventions against Aids and is a huge challenge in Africa. Without efficient monitoring and evaluation (M&E) systems it is unlikely that programmes will be durable enough to be scaled and sustainable to meet the numbers of patients who will likely require treatment. It is critically important to reduce drug resistance, maintain first-line drug regimens and develop data policies and systems that provide clinicians, facility managers and public health policymakers with just enough critical information to understand regional programmes without overburdening already overworked clinicians with irrelevant detail and lack of access to information. Information is also a critical requirement for an effective health policy and the setting of political agendas.

It is unfortunate that Lewis did not see the Academic Model for the Prevention and Treatment of HIV/Aids (AMPATH) programme, a joint initiative of the Moi University Treatment and Referral Hospital and Indiana University in Eldoret, Rift Valley province in Kenya. Apparently Lewis was heading there when he needed to return back home.

This programme epitomises treatment and care of HIV/Aids patients that goes way beyond providing drugs. It also addresses a bunch of Millennium Development Goals. When ART is prescribed patients also receive a nutritional prescription which enables them to receive fresh locally grown food. If needed, vulnerable patients, especially pregnant mothers can qualify for World Food Programme parcels. The programme has several other developmental approaches such as an innovative

approach to the prevention of mother-to-child transmission involving fathers; microcredit and entrepreneurial opportunities for patients living on treatment, care for orphans and vulnerable youth; psycho-social support and bereavement counselling; as well as large-scale food production and the training of HIV-positive people in farming methods on micro-plots.

AMPATH is currently treating 50 000 patients and would never have been able to scale up to this level without the development of its own electronic medical records system. It is this system that is now a collaborative open-source system that the Canadian International Development Research Centre (IDRC), through its Acacia and Connectivity Africa programmes has funded in support of an African network of users and developers. Open Medical Record System (OpenMRS) continues to grow and was recently accepted as one of 131 mentoring organisations worldwide for the prestigious and competitive Google Summer of Code for 2007, a programme in which Google pays student programmers from around the world to work on quality open-source projects over the summer.<sup>3</sup>

In South Africa, IDRC has been working in the field of ICTs and HIV/Aids with the development and implementation of M&E systems using both personal computers and handheld computers (PDAs) to overcome the challenges of connectivity in rural areas; and a central data warehouse to compile aggregate data by the Free State provincial Department of Health, the South African Medical Research Council and the universities of Cape Town, Free State and Toronto. Data is captured on paper by clinicians (the preferred means of data capture) and then entered into a dedicated hospital information management system by dedicated data capturers and compiled into management reports using a data warehouse. The system provides vitally important data on indicators of programme performance to guide government policymakers.

Since implementation in May 2004 the data collected and analysed indicates that of those patients that started the treatment, 75% are alive and remain in the clinical care system. This gives testimony to the Lazarus effect of these drugs, literally raising people from their deathbeds. Integral to this approach is the use of ICTs for decision support. Results show that ART is extremely effective – as effective as in any developed country where they were first produced and used. However, the negative side of the data and evaluation is harder to deal with politically. It shows that many patients are dying while waiting for treatment. In the Free State, of the 26 000 patients registered on this system, only 5 500 are being treated! This

<sup>3</sup> See: http://code.google.com/soc/

province has the second highest infected population in South Africa, second only to KwaZulu-Natal (and therefore in the world, although India is quickly catching up). The Free State has a population of three million people, and an estimated 382 000 people are infected with HIV/Aids. The picture is probably similar in other provinces but the lack of reliable data makes it difficult to know with any degree of certainty. Amongst the many constraints to achieving more equitable access to antiretroviral treatment is the shortage of doctors. The Free State province is not taking this lying down and the outcome of this monitoring and evaluation process has led to the Free State continuing to work on solutions, amongst which will be to allow nurses to prescribe the treatment in uncomplicated cases and not have to wait for doctors to prescribe. Augmenting earlier work to provide nurses in-service training, the University of Cape Town (UCT) Lung Institute is developing a new programme to provide training and support of nurses called Streamlining Tasks and Roles to Expand Treatment and Care for HIV (Stretch). What is known from the monitoring and evaluation data is that the Free State has a durable programme that will scale well and these additional interventions will build on this base to provide a scaleable system with high numbers on treatment.

Given that South Africa has moved on since Lewis wrote the lectures in this book, it is incumbent on him to acknowledge these successes. He could also broaden the scope of the evident short-term successes by becoming a clear advocate for primarily creating access to ART. He could support efforts attendant to develop the health management systems, the human capacity and the ICTs that are required to address this epidemic. As a change strategy our evidence suggests that every effort should be thrown into ensuring that infected people get access to the treatment. People who get treatment get up and leave hospices. Palliative care demands can be diminished. Behaviour change is the most difficult to address, and working on the political, cultural and sexual environment must continue, but immediate effects are being achieved with treatment. This is where Lewis should put his efforts!

In a further IDRC-funded project, a South African Medical Research Council team has partnered with other African developers and programme managers to provide open-source and low-cost software systems for patient monitoring. In resource-constrained settings, where the vast majority of resources are rightly being spent on improving access to treatment, these systems will contribute to creating robust, durable systems and will save money for drugs.

