Aidspan

Independent observer of the Global Fund

Two Steps Forward, One Step Back

Five years ago, ordinary Kenyans who tested positive for HIV were doomed. They were no more likely to receive anti-retroviral drugs (ARVs) than they were to receive a liver transplant if their liver failed.

All this has changed now. Thanks primarily to the efforts of the Global Fund and of PEPFAR, ARVs are available for free in many Kenyan hospitals, as is HIV testing. The same is true in many other parts of the world.

But many Kenyans are unwilling to have themselves tested. They would rather not know their status than risk having it confirmed that they are indeed infected with the dreaded virus. And even among those who do know that they have AIDS, some are not willing to be seen queuing at the special units in hospitals where the free ARVs are to be obtained.

Furthermore, the biggest problem now faced by many poor HIV-positive Kenyans is not so much that of getting access to ARVs; it is that of getting enough of the right kind of food to meet the dietary requirements that go with such treatment.

As a result, many hospitals have had to budget not just for providing needy AIDS patients with ARVs, but also for providing them with free vitamin-rich, high-energy food supplements.

But these food-supplement programmes are not always available. So among slum dwellers who are HIV-positive, it occasionally happens that patients register at more than one centre for free ARVs; obtain a double – or even a triple – supply of the ARVs; and then sell their surplus to acquaintances who have AIDS but who are not willing to go out and get their own free supply because they do not want it to be known that they are infected. The money thus obtained is used to buy food.

This conversion of ARVs into a form of local currency in the slums would at first appear to be harmless enough, since the drugs are apparently ending up in the hands of those who need them.

But it is not that simple. For effective treatment, the patient's response to the drugs has to be monitored very carefully, and at times adjustments have to be made depending on this response.

As this anecdote illustrates, even the best thought-out plans regarding AIDS treatment may go awry, or require major modification, for reasons having to do with culture or local conditions.

This is particularly important to understand in the context of the looming deadline set by the world's leaders to achieve universal access to HIV treatment and prevention by 2010.

2010 is just round the corner. So it seems appropriate to ask: Is "universal access by 2010" still a realistic goal on which serious expectations may be pegged? Or is it already obvious that this is one more global target which will not be met within anything like the timescale laid down?

And a question of even greater significance is this: Is universal access to treatment and prevention really going to irreversibly lower the number of new HIV infections and of deaths attributable to AIDS?

For it is important to appreciate that there are actually two separate – albeit related – goals contained in that objective:

Treatment is intended to save lives, by providing ARVs to those who are already infected with HIV: this is primarily an issue of finance, logistics, planning and "capacity" in general.

Prevention is about stopping the spread of HIV and reducing the number of new infections: and that revolves around the far more complex issue of educating people as to the dangers of HIV infection – and by what means such infection can be avoided – and thus encouraging behavioural change at many levels.

Neither of these is an easy task in itself, and achieving both of them within the next two and a half years will be even more difficult.

The question regarding treatment has already been answered: According to a UN report released this month, seventy percent of the world's AIDS victims still have no access to ARVs, and – even more sobering – while one million people worldwide were started on ARVs in 2007, 2.5 million people were newly infected with HIV during that same year.

So it is fairly obvious that universal access to treatment is not going to be achieved by 2010 – nor by anytime soon after, for that matter.

Does this mean that setting the target was a naïve mistake? Or should we regard it as a noble goal to which we should all aspire, knowing that every step forward represents multiple lives saved, even if some steps end up being smaller than we had expected?

Here are a series of vignettes and anecdotes which illuminate the complexities and ambiguities of the situation:

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First, an extract from a series of emails from a friend of mine, a Kenyan doctor working in a developing country outside Africa:

"….Global voluntary HIV testing and free ARV treatment are not going to work in my view, because they

assume a sensible, altruistic perspective that is simply not common.

Access means far more than the availability of free or highly subsidized ARV drugs. In [the country where I'm working], where the rates of HIV are rising at horrendous rates, we have health institutions where people are dying of AIDS despite the fact that the drugs are there and are free.

So why are they dying? Because of the stipulation that the drugs may only be prescribed and supervised by doctors who have undergone training in prescribing ARV drugs and supervising patients on these drugs. Despite the fact that the average doctor is bright enough to learn how to treat AIDS patients from a booklet, doctors cannot simply refer to the relevant leaflets or ask a colleague what the correct dosages of drugs XYZ are. No, they have to attend a special course. That's the rule.

In many hospitals, especially where they are short-staffed, there may be no doctor who has been spared to go attend such a course, and yet the drugs have been delivered there, since the drug?distributing people and the trainers work independently of each other. And of course lower-cadre health workers at district hospitals and health centres are not even offered the opportunity to attend the course.

So we have stocks of ARV drugs expiring even as AIDS patients also expire.

Also, how can access be universal when it is distributed through health facilities? It should be obvious that health facilities are not universally accessible. The dream of Primary Health Care services being within a 5km distance of every home remains a dream.

The reason various chloroquine-based anti-malaria drugs were almost universally accessible (and also part of the reason for chloroquine resistance) was that they could be bought at every kiosk or bus stop. ARV drugs by their very nature can never be sold over the counter let alone on the streets. So, as long as health facilities remain inaccessible to some for whatever reason – distance, cost of transport (which may far exceed the cost of subsidized drugs), lack of passable roads – ARV drugs will remain inaccessible…"

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In late 2007, I travelled to one of the most remote and isolated parts of Kenya. My destination was a town called Wamba, in Samburu District.

Samburu is one of those areas of Kenya where you can still find local tribesmen living more or less as they lived before the advent of the British colonial government in the late 1800's. The local communities, the Samburu and the Rendille, are very much like their better known cousins, the Maasai of the lower Rift Valley.

They are pastoralists who move about with their large herds in search of water and pasture; judge their personal wealth in terms of how many cows they own; and have successfully resisted all attempts to get them to change their ways.

Wamba Hospital is famous in Kenya as an excellently equipped hospital "in the middle of nowhere".

And I was impressed to learn that this hospital also has an AIDS programme – similar to what is to be found in the major public and NGO-operated hospitals in the rest of the country – which provides for voluntary counselling and testing for HIV, and for the supply of free ARVs to those who are found to be HIV-positive.

I asked the clinician who was taking my group round the hospital, what sort of numbers they had forpeople on the free ARV programme, and if he could tell me what percentage of the local people were HIV-positive.

He shook his head sadly, did not give me any numbers, but only said, “Our people here do not like to be tested for HIV. It is considered a great shame to have AIDS. Even when you are treating someone for an injury, for example, and you can tell from various outward symptoms that they may be HIV-positive, and you ask them if you can do the test – they refuse.”

In the end what I gathered is that whereas I had been impressed at the long reach of the Kenya government’s AIDS programmes, and had marvelled that even in a place like Wamba, those afflicted by HIV could get free treatment, the reality was very different:

Just as generations of civil servants, NGO workers, Christian missionaries, and many others had completely failed to convince the Samburu tribesmen to give up their nomadic ways, so now had health workers failed to convince them that they should be tested for HIV.

And that was irony indeed: after all the effort made by so many people and so many organisations over the years to get rich countries to pay for free ARV programmes in Africa, here was a situation where the free ARVs were available, but there was virtually no demand for them from a community which almost certainly needed them.

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Professor Max Essex, head of the Harvard AIDS Institute, is famous for his pioneering work in formulating the GP-120 test, which remains the gold standard for all HIV testing and is the world’s most widely used HIV test.

Last year, he and I were discussing an article in which someone had put forward the idea that the cornerstone of AIDS policy in Africa should be compulsory HIV testing and notification. The writer’s assumption was that AIDS has spread very fast in Africa primarily because most Africans do not know their HIV status – and, by implication, that their behaviour would change if they did know their status.

Prof. Essex felt that the writer was misguided to place so much faith in compulsory testing. He then told me this story:

A few years ago, the Botswana/Harvard Partnership, which he chairs, conducted clinical trials in Botswana on various drugs used for blocking the transmission of HIV from mothers to their babies. Pregnant women who volunteered were tested for HIV, and if found to be infected, were informed of this and treated with a combination of these drugs.

As the project went on, the researchers were surprised to find that about ten percent of the volunteers who tested positive for HIV were already in their databank, from a different study three years earlier which had also involved testing volunteers for HIV and notifying them of their status.

What this revealed was that some of these women had in fact got pregnant while being very well aware that they were HIV-positive.

So even compulsory testing would not always prevent HIV-positive people from having unprotected sex.

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This takes me back to the emails from my doctor friend:

“…..About Voluntary Counselling and Testing (VCT), the one wrong assumption, in my view, is that knowing one is HIV positive will somehow make one less likely to spread it, i.e. that one will be noble and say, “Well, I am positive, but I will make it my life’s mission to ensure that this tragedy ends with me and I will spare any potential partners the risk of HIV.” Humans are more likely to reason, “Well, once I already have it, I can’t have it any more than I already have, can I? How can wearing a condom help me?”

Of course the reality is that even those who are HIV positive can dose themselves with more of the virus and go to an earlier grave if they continue their sexual ways, but most would not think of such fine-print specifics. Responsible future sexual activity would be for the sake of their partners, not for themselves, but unfortunately people who know they have a lethal condition are sometimes going to look out for themselves rather than look out for their sexual partners.

VCT itself is also problematic. The adverts here all seem to say things like, “I wanted to know my HIV status so I could be safe/responsible.” What they don’t say is what a man told me, who had brought his wife to hospital after she had been gang-raped: “I want to know her HIV status so that if she is positive I can send her away to her parents before she infects me or our children.”

Now, tell me, would a woman like that volunteer to be tested, knowing her husband and most of her acquaintances held such misinformed views? Not even if the VCT centre was next door to her own house. VCT would be a ticket not to safer sex but to instant divorce…..”

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It’s virtually impossible for anyone accustomed to middle-class comforts to foresee how poor people will assess any given situation. This is illustrated by the story I told of people with HIV queuing up for more than one batch of ARVs and then selling them to people who want to conceal their status.

And I have other examples which illustrate how psychological factors – and specifically what Balzac referred to as “the psychology of poverty” – can make a mockery of the best laid plans for effective medical interventions.

My first story is about a team of American doctors who set up camp near an isolated Kenyan village to conduct a medical study. They intended to go about this by taking blood samples from children, which would later be tested for various diseases. Each child was also to be given a complete medical check-up.

To encourage parents to bring their children to this camp, the doctors offered a gift of three dollars for each child registered with their study, and gave the parents a loaf of bread and a bottled drink for refreshment as they waited while their children were being examined.

It was only when the number of bottled drinks given out began to drastically exceed the number of children estimated to live in that village that the researchers realized that the parents had been bringing the same group of children to be examined over and over again.

Unknown to them, the incentives the doctors had given were strong enough to encourage behaviour that totally compromised the validity of their research. For these were Kenyans who lived on less than a dollar a day – and the three dollars on offer was guaranteed to appear to them as a major business opportunity.

It was later revealed that many villagers had actually stopped going to their farms altogether, and spent whole days discussing how best to get their children registered yet again under fictitious names, without the foreign doctors finding out what they were up to.

The medical team had to relocate to some other place, and start their study afresh.

But the consequences of this failure to understand how poor people will respond to what they perceive as commercial opportunity does not always have a funny ending:

In another case – also involving a medical NGO from outside the country – the incentive offered for Kenyan parents willing to bring their children for a vaccination campaign was an insecticide-treated mosquito net per child.

And because these nets are so highly valued in the homes of the poor, there were tragic consequences to this well-intentioned programme. Some parents somehow managed to deceive the program staff into vaccinating their children more than once, and collected three or four nets each. And in a few cases, the vaccination overdose killed them, according to newspaper reports at the time.

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About a year ago, Ugandan President Yoweri Museveni spoke out against the evolving consensus that male circumcision is an effective intervention against new HIV infections.

He complained bitterly about this new fixation on male circumcision and warned that if a message was sent out that male circumcision reduced the chances of HIV infection by as much as sixty percent, it would lead to a reversal of Uganda's gains in fighting AIDS.

I have heard President Museveni's assessment supported in private by AIDS researchers, who are in some cases employed in NGOs busy implementing this very policy of promoting male circumcision.

Where Museveni was merely quoted as saying that such a policy would "encourage recklessness among the youth," the researchers took it much further and argued that the reason why male circumcision is proving to be so popular among African tribes which did not practice it before is that the procedure is considered by many to eliminate the need to wear the condoms which they despise; and that it is precisely in anticipation of having unprotected sex that some of these volunteers are so keen to get circumcised.

As a result, offering male circumcision to those who don't traditionally use it could encourage a return to risky behaviour, thereby leading to more rather than fewer new HIV infections.

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And it is not only in Africa that the widespread availability of a means of preventing HIV infections or controlling its effects can lead to unexpected consequences:

In an article titled "AIDS is on the rise again" published last month in the Canadian newspaper The National Post, two researchers stated that "an unintended consequence of the development of life-saving ARVs may have been to convince thousands of members of vulnerable populations that an HIV infection status may not be harmful." As a result, they said, the easy availability in rich countries of life-saving ARVs "may be responsible for growing numbers of new HIV infections among gay men, intravenous drug users and disadvantaged individuals."

This, of course, is very much the same phenomenon as has been witnessed in Africa over male circumcision: once convinced – rightly or wrongly – that there is a readily available intervention that takes away the terror of HIV infection, people will often react to this by returning to behaviour that greatly increases the chances that they will end up being infected with HIV.

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Final email excerpts from my doctor friend:

"…It is clear that with more ARV treatment, there is an INCREASE in the number of people living with HIV.

If x numbers of people get HIV every year and a large percentage of them die of AIDS within say 5 years, then the total numbers of people living with HIV stay relatively low. If, on the other hand, ARVs are readily available and are used, then out of the x number of people getting the virus every year, only a small percentage are dead within 5 years and the majority are still not only alive but strong enough to get on with their lives – and also to pass on the virus.

It is short-sighted to predict the successful outcome of something that depends so heavily not on people's knowledge but on human nature itself – and assuming people will apply reasoned clinical logic to something as fundamental as personal sexual behaviour…"

The 19th century Russian novelist Fyodor Dostoevsky put all this rather more succinctly: "You cannot skip over human nature by logic".

In writing this, he was attempting to explain why so many of the elaborate schemes designed for the benefit of mankind – on the surface, theoretically sound, undoubtedly well-intentioned, and above all, apparently "scientific" – not only will often end up in failure, but also will frequently have unintended consequences which reverse the gains which have been made.

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This is what we must contend with in the fight against AIDS: we have to accept that effective AIDS interventions are not just about providing lifesaving drugs, or pushing people to learn their HIV status, or encouraging male circumcision. We have to go further, and determine what will persuade people to undertake profound and fundamental behavioural change – for in the end that is the only real defence against the spread of AIDS.

And the good news is that there have been cases in history in which entire communities within developing countries have gone through just such profound changes in their attitudes and values, on a matter they regarded as being of fundamental importance, and on which they had initially seemed to show the most resolute resistance to change. Let me tell you about just one.

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The economist Peter Bauer was one of the truly original thinkers of the 20th century. His work often ended up shattering the fashionable assumptions of his fellow economists.

Forty years ago, the populations of developing countries had started to increase rapidly. Leading scholars were haunted by the fear that this would lead to a "population explosion," eventually ending in wars over ever-diminishing resources.

A mass of "family planning" programmes in developing countries then followed, most of which were complete failures, at least in the short term goal of a prompt reduction of family size among the poor.

Prof Bauer saw it rather differently. He pointed out that most areas of Africa and Asia where this population explosion was considered likely had formerly been colonies of European countries. And colonial governments had generally ignored the urgent needs of the population, focusing instead on making such colonies commercially viable and self-sustaining. During that colonial era, parents chose to

have many children because they knew that a fair proportion would die in childhood, and that the only way of being secure in old age was still to have some surviving adult children at that time.

Once independence came, most post-colonial governments took their people's needs reasonably seriously, especially as concerns health and education. This led, in time, to the provision of improved educational and medical facilities, which in turn led to greater longevity, and in particular, to an abrupt drop in infant mortality rates.

But most communities in these countries were still very much attached to the idea that the more children one had the better.

Values which have been long ingrained in a community's psyche are not easily discarded, and will usually persist many years after they have ceased to have any economic advantage, or have even proved to be counter-productive.

In any case, as a result of this combination of circumstances, African and Asian families ended up being very large. Hence the great increase in the populations of these two continents.

Prof Bauer firmly believed that the anticipated "population explosion" was a myth, and that the increase in populations in the developing world merely reflected the success of the primary health programmes which many newly independent countries introduced. And he predicted that in time – and without any governmental coercion – smaller families would become the norm in these poor countries, just as they already were in the industrialized nations.

This, of course, has since been proved to be an accurate prediction, particularly in Asia. Starting first with the better off and better educated, and finally reaching down to the rest of the population, a trend toward smaller families has become established in many developing countries.

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So: The good news is twofold. First, there have been some "breakthrough developments" in the past decade (new financing sources, new drugs, new medical insights) without which the current situation would be unimaginably worse. And second, certain society-wide changes in attitude do indeed take place.

But the bad news is also twofold: First, these breakthrough developments all too often have unanticipated consequences or side-effects which reduce, or delay, their impact. And second, the required society-wide changes in attitude take a very long time, and require education, leadership-by-example, and a profound eventual acceptance by each person that the changes are in his or her interests.

It will be long past 2010 before there is universal access to prevention and treatment. And it will be much longer than that before enough people take full advantage of that access.

Where this leaves us is that while little or nothing that is being done to fight the AIDS pandemic is fundamentally "wrong", we have to accept that many people are more influenced by tradition, superstition, or short-term selfishness, than by logic. So they don't always behave in ways which could be rationally anticipated by those who plan these interventions.

Whatever new prevention and treatment technologies may come along, the HIV pandemic will still march remorselessly forward until there are some fundamental behavioural changes – ones which people truly want to do, rather than which they are simply persuaded to do.

Such changes may take a generation or more. But they'll come in the end.

[Note: This is the fourth of a number of GFO Commentaries by Wycliffe Muga (muga@aidspan.org). Wycliffe, a Kenyan journalist, is the BBC World Service's "Letter from Africa" correspondent, and last year served as the BBC's "Letter from the United States" correspondent during a fellowship at MIT. He

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