TAC Comments on Anthony Butler Article in Business Day

By *moderator*
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Anthony Butler wrote the article below in Business Day on 27 February 2006. It raised some interesting points. In particular, TAC is also concerned about a lull in the media on HIV in recent months.

However Butler makes a few points which need to be corrected and some which require further comment:

Butler states: "This approach has been facilitated by the Treatment Action Campaign?s protracted and selfdefeating refusal to register the substantial element of good sense in the health minister?s claims about poverty, the potential side-effects of AZT, and the importance of healthy living."

TAC comments: It is difficult to enumerate the numerous occasions on which TAC has emphasised the role of poverty, talked in detail about the side-effects of ARVs and written about healthy living. It would be difficult however to find one, just one, scientifically accurate statement by the Minister of Health related to any of these. Despite the Minister's rhetoric (almost entirely inaccurate) about nutrition and AIDS, the government has not brought out a single fact sheet for lay people on nutrition and HIV. A few references to TAC should show that Butler's criticism is unfair:

Side-effects of ARVs

- *Talk About ARVs* is perhaps our most widely distributed pamphlet. It lists in detail the side-effects of ARVs.
- *ARVs in our lives* is a TAC booklet on ARVs and discusses side-effects in details
- We have published many articles over the years which talk about ARV side-effects. Click here for an example from Business Day.
- Another example: See our founding affidavit in the current case against Matthias Rath, the Minister etc.

There's much, much more.

Poverty
TAC's entire discourse has been routed in the role of poverty in exacerbating the spread of HIV, the more difficult problems that poor people with HIV encounter etc. Butler's assertion is simply wrong, as shown by the following:

- TAC actually organised, paid for and led the first large march (of about 3000 people) for a Basic Income Grant. This took place in 2002.
- Most of our work takes place in poor communities. Our members have been extensively educated on social grants.
- Do a search on "poverty HIV" under the search toolbar on our website (www.tac.org.za) to see the numerous occasions on which we have talked about the role of poverty, frankly far more systematically and scientifically than anyone in government. Here are links to a few of the 155 documents returned by google on our website:
    - http://www.tac.org.za/newsletter/2002/ns22_02_2002.txt
    - http://www.tac.org.za/Documents/TreatmentPlan/CongressReportVersionTabledAtNedlac.doc
    - http://www.tac.org.za/newsletter/2001/ns010612.txt
    - http://www.tac.org.za/Documents/Pamphlets/health_local_gov_manifesto.pdf

    - http://www.tac.org.za/newsletter/2003/ns04_02_2003.html
    - http://www.tac.org.za/newsletter/2004/ns24_06_2004.htm
    - http://www.tac.org.za/newsletter/2001/ns16_07_2001.txt
- All see Mark Heywood's Price of Denial.

Again, there's much, much more.

Nutrition

- *Talk About Nutrition* is TAC's widely distributed nutrition pamphlet, which has been published as an advertisement in many newspapers including the M&G, Daily Sun, various community newspapers, Independent Newspapers etc.
- *HIV in our lives* is our booklet on living with HIV, which talks extensively about nutrition and healthy living.
- The Business Day piece referenced above deals with nutrition.
- Zackie Achmat, Mark Heywood, Sipho Mthathi, Nathan Geffen and many other TAC spokespeople have talked about nutrition in radio interviews on numerous occasions. Admittedly there have been times where we have reacted defensively, angrily and counter-productively to the Minister's pseudo-scientific comments, but these have been the exception.

Again, there's more.

Healthy/Positive Living

- HIV in our lives - noted above.
- See the latest issue of our magazine Equal Treatment: http://www.tac.org.za/Documents/EqualTreatment/ET19.pdf

Again, there's more.

Butler states: "Presumably government?s approach is intended to accelerate the public opinion cycle to the ?post-problem? stage, while providing political cover for the systematic development of the health systems and infrastructure for a wider drug roll-out."

TAC responds: This is unsupported by evidence. There is overwhelming evidence that government's poor response stems from President Mbeki and Minister Tshabalala-Msimang's pseudo-scientific beliefs. Postulating convoluted reasons is counter-productive; Occam's razor applies - Mbeki and Tshabalala-Msimang are AIDS denialists hence the public information campaign is a disaster.

There is very little systematic development of the health system going on. The system is actually degrading. Public health experts are furious at government's lack of vision. There is no proper human resources plan, just a draft framework with empty rhetoric. Although Treasury is pumping more money into health-care, there's no systematic planning to ensure the money is spent properly, a problem that lies squarely with the Minister of Health.

Butler states: "Government?s public message must negotiate the reality of limited provision and the de-facto rationing of treatments. In such circumstances, any public information campaign would overload existing urban ARV sites and generate an unprecedented wave of community protest."

TAC responds: This is a highly speculative point that Butler provides without evidence. We don't suggest that rolling out ARVs is easy but in communities where it has happened and where this has been coupled with community mobilisation and public information campaigns, there have been tremendous successes, e.g. Khayelitsha and Lusikisiki (admittedly there have been protests too, but these have been peaceful and organised in contrast to the riots over service delivery elsewhere). Also, the burden on ARV sites was preceded by a very fast growing burden on the public health

system because of the huge increase in opportunistic infections. Various statistics show this. If government had to encourage people to get tested and to go onto treatment long before their CD4 counts dropped below 200 they would substantially slow the increasing burden of opportunistic infections. The average CD4 count in the public sector according to statistics from the NHLS is about 100, indicating that mostly people who are really ill are accessing ARVs. This is a direct consequence of not having a proper public information campaign.

Butler states: "The denigration of ?western medicine? eases the immediate burden on clinics, but encourages scarce professionals to leave the public sector and undermines public awareness campaigns."

TAC responds: We agree. It also causes death by people not seeking appropriate help. But take a look at queues outside public health clinics across the country at 6am in the morning: there is no easing of burden.

It should be noted though that the recently released HSRC household survey on HIV indicates that less than 1% of the population see traditional healers as their usual source of health-care. Most see the public health system playing this role. It's possible the HSRC question might not be obtaining the real picture, but it does indicate that the role of traditional healers in SA has been overstated.

Butler states: "Government efforts to contain business panic about AIDS create complacency around workplace prevention and treatment. In all these ways, short-term public quiescence is purchased at the cost of deepening and prolonging the epidemic itself. "

TAC responds: We agree.

Butler states: "Animosity towards AIDS sufferers may yet transform into sympathy and political protest once antiretrovirals prove that the virus is no mark of death."

TAC responds: It's worth noting that in areas where treatment is widely available, (e.g. Khayelitsha, Lusikisiki) stigma/animosity is already much reduced.

Butler states: "Today?s calm about antiretrovirals may represent not the twilight stage of the treatment issue but rather the lull before a political storm."

TAC responds: Butler may be right here, but despite all the anti-ARV rhetoric, the numbers on treatment are picking up.

Finally, if the media is indeed tired of HIV, it's primarily a reflection of the fact that poor people affected by HIV and without ARVs (urban and rural) do not have much say in what goes into the mainstream media. Butler is right in implying that middle-class HIV+ people can easily access treatment and as such HIV becomes less of an issue for them. Surely it is the duty of responsible editors to realise this and continue highlighting the dismal situation for poor people with HIV.

Butler's article in Business Day, 27 February 2006

The road from outrage to apathy
Anthony Butler
E-Mail article Print-Friendly

MORE than 500000 South Africans who need antiretroviral (ARV) drugs are not receiving them. What then can explain the eerie quiet that has

settled over the battlefield of HIV/AIDS treatment?

In a landmark article ? Up and down with ecology, published more than 30 years ago ? American policy analyst Anthony Downs argued that even the most important problems cannot sustain public attention for long. In fact, he predicted, almost any social issue would pass through the same five stages, in which outrage ultimately turned to apathy.

At first, an issue interests only experts and bureaucrats working in the field. Then, after some triggering event, the public makes an ?alarmed discovery? that a problem exists. Newspapers and the airwaves are suddenly dominated by popular discussion of it. Citizens experience ?euphoric enthusiasm? about the capacity of their society to solve the problem, and demand action from their political leaders. This is stage two.

The third stage, however, brings a gradual realisation that there is no ?magic bullet?. Recognition of the costs of action steadily grows. Powerful beneficiaries of the status quo mobilise to oppose change, and government stalls to avoid budgetary commitments.

Downs?s fourth stage sees public interest slipping away. Citizens cannot sustain concern about a problem that causes them no personal suffering. They become discouraged by the complexity and expense of implementation, and allow the issue to be displaced by another pressing social concern or by some ?good news? story. The cycle culminates in a fifth ?post-problem? stage, a ?prolonged limbo? in which there will be only spasmodic recurrence of interest.

Downs?s analysis helps to illuminate the first stages of the AIDS treatment controversy. HIV/AIDS did move from expert preoccupation, through alarmed discovery, to euphoric enthusiasm for antiretrovirals. Are we moving inevitably towards a ?post-problem stage??

For politicians and bureaucrats, citizens? cycles of alarm, euphoria, and disaffection present a major challenge. In a democracy, leaders are supposed to respond to the voice of the people. According to Downs, however, it is important to distinguish what government does from how it portrays its actions. Politicians can usually ignore the peoples? demands for action, safe in the knowledge that public attention will drift away. If necessary, a commission of enquiry, empty promises of action, or a campaign of public disinformation will tide things over until the excitement dies down. Meanwhile officialdom can continue quietly to address the ?real problem? in its own way.

In the case of HIV/AIDS treatment, the real problem is unusually intractable. Directing financial resources into a treatment programme can rapidly bring drugs, equipment and new buildings. But the lesson of recent international antiretroviral initiatives is that rapidly growing financial resources can create bottlenecks, drain other clinical services of personnel, and generate costly new processes and bureaucracies.

The obstacles to sustainable and universal ARV provision in SA are

entrenched and systemic. The number, skills levels, and placement of health professionals are drastically inadequate to the demands of such a programme. Counselling and testing capacity still needs to be developed. Monitoring systems require radical strengthening, supply-chain management must be revolutionised, and essential education, water, and power infrastructures still have to be created. The imperative to act is obvious.

The political communications challenge, however, is different. Government knows only a fraction of HIV-positive South Africans requiring antiretrovirals will receive them. Most of these citizens will probably die without receiving treatment. However successful the drug roll-out may be, this politically dangerous gap between need and provision will remain.

These risks are heightened by government?s tacit rationing policy. SA?s public-sector employees and skilled private-sector workers increasingly benefit from medical aid scheme ARVs. Urban citizens are closer to effective ARV public treatment sites, and educated ones are better able to secure admission to programmes.

Government?s public message must negotiate the reality of limited provision and the de-facto rationing of treatments. In such circumstances, any public information campaign would overload existing urban ARV sites and generate an unprecedented wave of community protest.

Perhaps it is for this reason that government communications strategy seems to be to permit ? or even to encourage ? confusion among the most vulnerable sections of society around HIV/AIDS science, antiretroviral toxicity, nutrition, and traditional medicine. This approach has been facilitated by the Treatment Action Campaign?s protracted and selfdefeating refusal to register the substantial element of good sense in the health minister?s claims about poverty, the potential side-effects of AZT, and the importance of healthy living.

Presumably government?s approach is intended to accelerate the public opinion cycle to the ?post-problem? stage, while providing political cover for the systematic development of the health systems and infrastructure for a wider drug roll-out.

It remains unlikely, however, that HIV/AIDS treatment will work its way through a conventional issue-attention cycle. First, a paradox underlies government?s efforts to dissociate the ?real? problem of HIV/AIDS from citizens? perceptions of it. With AIDS, the reality of the problem is decisively influenced by the public?s beliefs about it. When government confuses citizens about HIV/AIDS causation, it suppresses demands for antiretrovirals but at the same time undermines safe-sex messages. The denigration of ?western medicine? eases the immediate burden on clinics, but encourages scarce professionals to leave the public sector and undermines public awareness campaigns. Health administrators told that antiretroviral programmes are nothing special will deny them the resources they need to succeed. Government efforts to contain business

panic about AIDS create complacency around workplace prevention and treatment. In all these ways, short-term public quiescence is purchased at the cost of deepening and prolonging the epidemic itself.

Second, Downs?s analysis is based on his view that human beings cannot focus for long on the suffering of others. After a burst of alarm and euphoria, he believes, the privileged and the lucky find the problems of others a bore. They may even cruelly blame the victims themselves or point the finger at government.

The political blame game, at least, cannot go on forever. In three years? time we may lose both our president and our health minister. When the systemic obstacles to a universal antiretroviral programme do not depart with them, who will the armchair critics blame then? Also, wider public responses to AIDS suffering have been marked by anger and stigmatisation rather than by the disengagement Downs would predict. Animosity towards AIDS sufferers may yet transform into sympathy and political protest once antiretrovirals prove that the virus is no mark of death.

Finally, issue-attention cycles normally unfold where only a relatively small minority is disadvantaged. The AIDS crisis is still a very long way from its worst, and the number of citizens needing medication is going to grow dramatically by 2009. Our ability to deny our obligations to others is unlikely to survive an epidemic that will touch almost every family in the society. Today?s calm about antiretrovirals may represent not the twilight stage of the treatment issue but rather the lull before a political storm.

?Butler teaches public policy at UCT.

- AIDS Denialism

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