

SA says no to aid cuts

Amid the havoc wreaked in South Africa's health sector by Donald Trump's guillotining of the United States' international aid programme, Zackie Achmat reminds us that the earliest action against the HIV and AIDS epidemic started as an international grassroots movement that mobilised support from the wealthiest countries. He spoke to **MOIRA LEVY** about the lessons learned from active citizen engagement in decision-making, especially in the context of the current emergency.



Introduction

ackie Achmat, prominent human rights and AIDS and HIV treatment activist since the 1980s, has kept a low profile in the past few months. That is until he reemerged in May in a fairly dramatic disruption of a Health Portfolio Committee meeting at Parliament. Ignoring the chair's repeated instruction to take his seat, he called on Committee members to put pressure on the government to address the terrifying consequences of the abrupt withdrawal of the US President's Emergency Plan for AIDS Relief (PEPFAR) funding from the health sector in South Africa and across the developing world.

We hadn't heard from Achmat for more than a year since the run up to the 2024 national and provincial elections when he campaigned for a seat in Parliament as an Independent. He didn't win, but that clearly hasn't stopped him.

Now he stands at the forefront of an international call for government action as part of a delegation from the Global HIV Treatment Coalition. The matter on the agenda for that Portfolio Committee meeting was a briefing from the National Economic Development and Labour Council (NEDLAC) on its inputs on the Tobacco Products and Electronic Delivery Systems Control Bill. But before any of that could get underway Achmat rose to his feet. He made it clear that he had no wish to disrupt the Committee proceedings, only his organisation had still not received a response to a letter they sent a month before requesting the parliamentary committee to respond to the impact of US funding cuts on HIV treatment programmes. Meanwhile, patients were suffering and dying, he said.

Chairperson Sibongiseni Dhlomo confirmed that the Committee had received the letter, and was awaiting further information and guidance from the Department of Health before convening a meeting on the matter. And he called on the Department to issue a statement. Achmat attempted to speak three more times until, amid grumblings from Committee members who demanded a halt to the disruption, he and his delegation were unceremoniously sent packing.

Achmat's performance was reminiscent of his earlier activist days after he launched the Treatment Action Campaign (TAC), which was part of a world-wide wellspring of grassroots political advocacy that ultimately, directly and indirectly, resulted in the formation of the Global Fund to Fight AIDS, TB and Malaria and the saving of billions of lives.

Two days later, the Health Portfolio Committee met with the Minister of Health, Dr Aaron Motsoaledi, who delivered a presentation on "The status of the HIV/AIDS and TB Campaign in South Africa: The aftermath of PEPFAR withdrawal". And just a week after that the Committee had a follow-up online meeting with Achmat and his colleagues in which the chairperson thanked him for his contribution.



I asked him how it felt to be back in the game, suggesting that perhaps the seat in Parliament where he would feel most comfortable was in the public gallery as an activist. I had a sense he may agree with me, but he reminded me of the reasons he had stood for Parliament, among them the hope that he could play a useful role as an independent voice in Parliament's National Assembly and its committee system.

Failure of global representative democracy

In our interview, Achmat reflected on the importance of Parliament including genuine public voices. "This has become all the more important given the current depth of global dissatisfaction with representative democracy -- and not simply dissatisfaction, but total despair and anger. All of us must reclaim our public institutions, particularly our legislators -- Parliament, Congress, the Knesset, and so. They are not the only instruments of democracy, but they are fundamentally necessary, democracy cannot exist without them.

"Similarly we have to create a democratic process in global institutions," he said. Referring to the Pan-African Parliament, which is located in Johannesburg, he bemoaned civil society's failure to engage with that institution, "which is sad because it should be central to dealing with questions of the global political economy, of unequal exchange and unequal trade. It should be central in dealing with the Trump emergency.

"Yet the Pan-African Parliament is doing nothing on those questions and broader civil society is absent from that field, leaving it occupied by the powerful, the corporations, the imperialist countries. By us leaving the field empty, we are leaving their hands untied. We're not regulating their participation through a pan-African representative institution."

Declaring his support for South Africa's Government of National Unity (GNU), he said the decline in ANC support in the May 2024 election was welcome because it created the opportunity for "greater intervention" in parliamentary processes.

"Not that we have made any use of it," he noted. "The duty of the Left in dealing with the Government of National Unity is to put the pressure on it for social democratic reforms. As the Left we have failed to put pressure on political parties, we have failed to address the constituents of those parties."

Role of Parliament

Achmat suggested what may be necessary, "from a radical social democratic perspective," is the creation of a political "front" comprising independents and the small political parties "and anyone else who wishes to join" to put pressure on the other councillors to work with radical social democrats. Critical for its success would be "serious support from outside," namely the research and other skills and capacities found in civil society.

He emphasised that such political interventions would need to be made at all levels of government -- "there has to be a continuum from local [to] provincial and



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national" – and believes it is crucial to put pressure on Parliament, he said – "because ultimately it has power over the Executive, and not simply the Executive, but over all private power in the country. Parliament could call in the Chamber of Mines, it could call in the private health sector and say 'what's your contribution?".

He quotes Lenin who argued in *Left-Wing Communism: An Infantile Disorder* that it is essential for any movement of the Left to have at least one representative in Parliament, to push a radical socialist agenda and keep the powerful on their toes.

"It is necessary to put forward a programme to expose those who cannot deliver or those who are willing to oppress and repress and extract surplus from working-class people."

Achmat believes there are individuals in the House and Committee meetings who are willing "to do, as MPs, what I did, though maybe without the screaming … who will stand up in the committee and say 'we are not paying attention to this'.

"We need to find one or two MPs who are willing to stick their necks out because they believe that there needs to be budgetary reform, or that global social public goods need to be addressed, that the debt crisis locally, on the continent and globally need to be tackled.

"We have so many tools at our disposal to engage the public."

Achmat referred to the importance of constituency offices in parliamentary and municipal work. He expressed some reservations about just how many functioning constituency offices there are and how many MPs actually do constituency work, but nevertheless argued, "it is the constituents who should put their demands to the MPs. We shouldn't wait for the MPs to engage the constituency. It is the people who have to demand 'where are our MPs? Why aren't you holding townhall meetings?'"

Role of civil society

He makes the point that it is up to citizens to keep a watching brief on councillors, and that must continue throughout their terms of office. We should not be turning to the courts for help when our representatives fail to deliver, or revert to what Achmat calls "radical abstentionism".



He believes civil society movements "in an urgent manner" need to identify five or six communities in each province to address the question of municipal power. They must ensure that municipal councillors escalate citizens' demands to provincial legislators and that pressure is consequently exerted on national MPs to raise the communities' issues in Parliament.

"There's no way that we can fix Parliament, or the country, without addressing Parliament from below. It's about being accountable and making the Constitution and Parliament the tools of the people to better their lives."

Achmat talked at some length about the different forms citizen participation in legislative decision-making could take, all the time emphasising the importance of what he called the communities' "knowledge base", which is drawn from their lived day-today experience. Those on the ground are best qualified to direct their representatives when it comes to the provision of social services to effectively meet basic needs.

The community knows where a pedestrian crossing should be placed, for example. "Not where the Council or the councillor or the head of the traffic department say we need it. After consulting a community, councillors would know how to deal with traffic and how to protect pedestrians and how to make a township or a CBD pedestrian-friendly and people-friendly. The knowledge base that the community has must be stronger than the knowledge base of the councillor, must supplement that of the councillor and the community must help the councillor."

He reminds us that public representatives "are not the implementers. The bureaucracy is, and in order to deal with the bureaucracy, we need to use the multiple tools [we have] in the sense of approaching MPs, approaching MPLs (Members of Provincial Legislature), approaching councillors."



The point he is making is that our elected leadership can only meet its mandate to be accountable, address communities' needs and meet citizens' demands if we engage actively and effectively with them.

Withdrawal of US aid

Achmat founded the Treatment Action Campaign (TAC), which became part of a world-wide wellspring of grassroots political advocacy that resulted in the Global Fund to Fight AIDS, TB and Malaria and the saving of billions of lives. He reminds us that the earliest efforts to access HIV treatment and halt the AIDS epidemic started as an international grassroots movement of citizens from different parts of the globe that forced the richest countries to make medicines for these devastating but treatable conditions more affordable and accessible, especially in countries that desperately needed them.

It pushed the US into a position where former president Bill Clinton had declared HIV and AIDS a national security emergency and then-president George W. Bush in 2003 launched the US President's Emergency Plan for AIDS Relief (PEPFAR)

"All that was what the movement did. It has been the most successful sustained programme of keeping people alive, while building health care systems throughout our continent and beyond," including Vietnam, Laos, in India and Nepal, Central America, the Dominican Republic, Chile, Malaysia. "It created a truly global set of institutions that came out of global, democratic, public pressure. That movement ensured that HIV prevention and treatment became a global social and public good. These programmes came from people's power."

The World Health Organization (WHO) was the first to declare that essential life-saving medicine was something that countries should be able to afford. To make this enforceable TAC and others launched a campaign to pressure the world body to include all life-saving drugs in its Essential Medicines List (EML), demanding that the prices of these medications be reduced so that all countries could access them.

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They consulted the whole gamut of civil society from the International Confederation of Free Trade Unions (ICFTU) to the World Council of Churches, as well as international and local business organisations (one of the first HIV programmes in South Africa was set up by Anglo-American to provide antiretrovirals to miners).

Today there is now a real possibility of ending the epidemic for good, at least in some parts of the world. In South Africa the rate of infection has come down significantly because this country has five and a half million people on treatment. The advent of pre-exposure prophylaxis (PrEP) is now available in the form of a twice-ayear injection.

"The tools are there to end the epidemic," say Achmat, but he cautions we are not there yet. What is urgently needed right now are mass information and sign-on campaigns targeting the numbers of vulnerable people who do not yet have access to the PrEP treatment. While the pool of infection has shrunk significantly, 50,000 people a year still die of AIDS-related illnesses.

In addition, people like Achmat himself who are on long-term antiretroviral treatment, whose viral loads have been much reduced or are even undetectable, are at increased risk for serious co-morbidities resulting directly from HIV itself or as side effects of certain antiretroviral drugs. These can include cardiovascular, renal, liver and bone diseases, certain cancers, metabolic and neurological conditions and mental disorders. Due to their higher risk of comorbidities, individuals on antiretrovirals need regular health screenings and appropriate management and treatment for any developing conditions.

This means that disrupting HIV treatment at this time threatens to upend all that has been achieved.

Achmat was blunt about the consequences of America's abrupt and catastrophic withdrawal of crucial aid. He warned that the majority of the people whose access to antiretrovirals has been disrupted will, in all likelihood, be dead by the end of Trump's five-year term in office.

It is not only the hundreds who will die that he is concerned about. There are many thousands more living in the impacted communities who will bear the



consequences. Unlike Covid, for example, which kills 1% of those infected, AIDS has a 99% mortality rate when people are denied treatment.

As he points out, AIDS patients take time to die. "Within six months of coming off your medicines you start getting ill. Within a year you become desperately ill." During that process there are interminable admissions to hospitals, "or you get sent home to die," said Zackie. The massive burden on hospitals and local health services, already weakened by persistent inequities in the health services, has been intensified by the closures of health clinics, retrenchments of health workers and closing down of HIV treatment programmes.

"The impact on households, on families, who suddenly have to take care of children because their mom doesn't recognise them because of AIDS dementia is huge. These pose very real questions which parliamentarians and governments are not engaging with.

"An HIV movement needs to be created that deals with all those questions. [It would] not be starting from the beginning because we have a powerful platform from what we have already achieved, but [we have] to go forward. Now we sit with a situation where literally 20 million people have been placed on death row by Donald Trump.

"Therefore global funds are essential," said Achmat. Moreover, in the face of growing catastrophic emergencies, such as climate change-created disasters for example, even wealthy countries will require emergency funding transfers.

In short, he argues, the international architecture of grants and funding will need to be thoroughly restructured so that global public goods can be redistributed to where ever they are needed, "and rather than aid, we will have international solidarity and public goods will be shared by all of us."

BIOGRAPHY

Former journalist, long-standing media manager in the NGO sector and for a time Content & Information Manager in Parliament's Communications Department, Moira Levy is Production Manager at IFAA, responsible for New Agenda: South African Journal of Social and Economic Policy.