

SPEAKING TRUTH TO POWER:

THE ERA OF HIV DISSIDENTS



Dr Olive Shisana during an interview at the HSRC

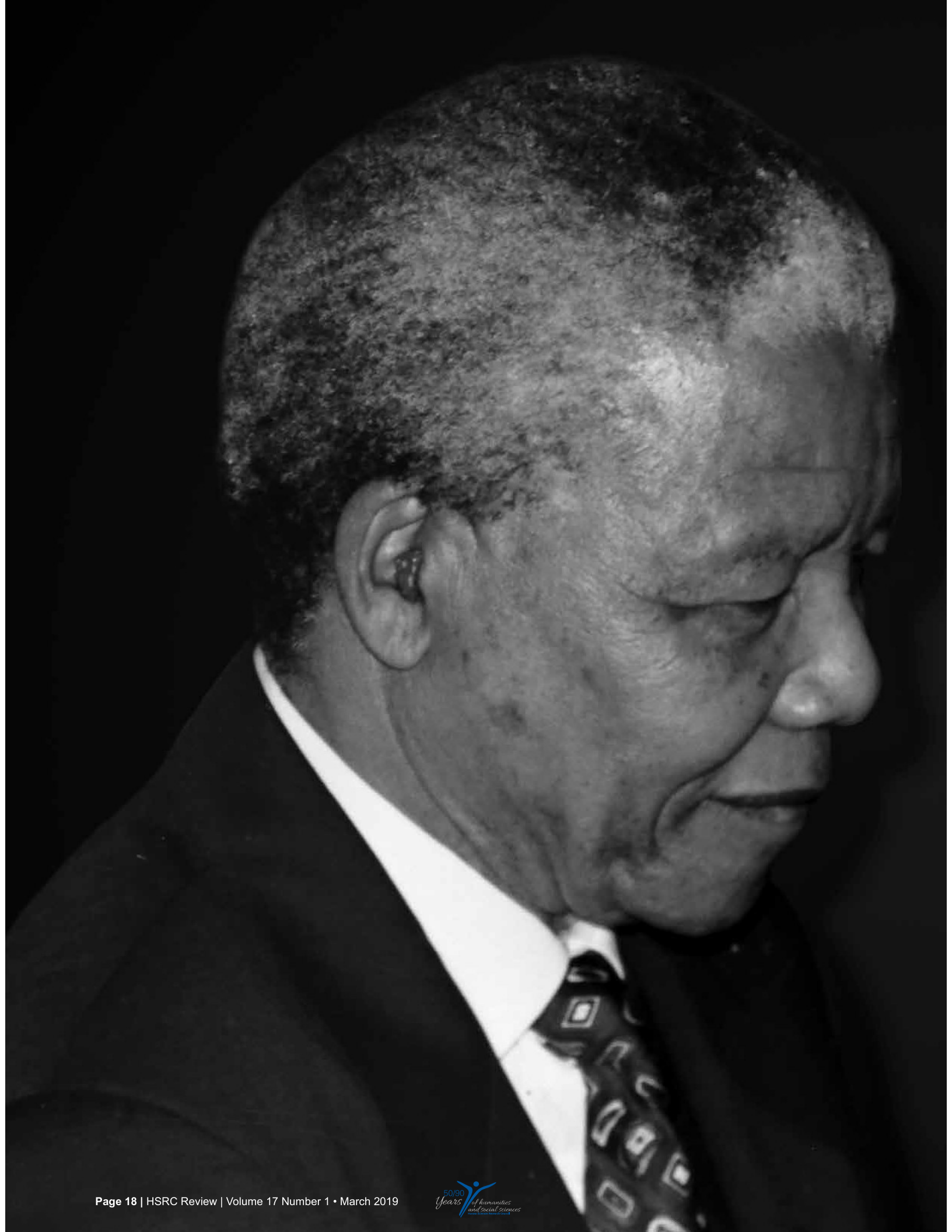
Photo: Antonio Erasmus

In 2002, at the height of HIV and Aids denialism in South Africa, Dr Olive Shisana led a seminal HSRC study on HIV prevalence that showed an infection rate of 11.4%. She later became the CEO of the organisation from 2005 to 2015. In an interview with the *HSRC Review*, Shisana emphasised the need for researchers to speak the truth to those in power and for leaders to trust scientific evidence when they make policy.

Dr Olive Shisana became interested in the field of HIV and Aids during her time in exile in the 1980s while she worked on her Doctor of Science degree at the Johns Hopkins University in Baltimore in the USA. She later worked as a senior health statistician at the City of Washington where she helped to collate death-record data in an effort to understand HIV-related causes of mortality.

Shisana realised that HIV, which initially seemed to affect only men who had sex with men, had the potential to spread to the general population. After her return to South Africa in 1991, while working at the Medical Research Council, she was one of the first experts to warn the government of the devastation that the virus could cause.

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A team from the Social Aspects of HIV/Aids and Health research programme analysing results from the 2002 Nelson Mandela/HSRC Study of HIV/Aids. From left: Geraldine Dyson, Prof. Leickness Simbayi, Prudence Ditlopo and Sean Jooste.

A potential wildfire

“I knew that ours was a virgin population – from a public health perspective – and that an epidemic could spread from just a few people.” Only about 1% of the population had been infected at the time, but Shisana realised that people’s reluctance to protect themselves against sexually-transmitted infections, along with other effects of the societal changes during South Africa’s period of transition, could fuel the spread.

“I said, if it spread, it would spread like wildfire. It was going to change the demographics of the country. And people said, ‘No, you can’t be serious’.”

But she was supported by Dr Nkosazana Dlamini-Zuma, who had returned from exile with similar concerns. Shisana was appointed as the first director-general of health in the late President Nelson Mandela’s administration and they set up several HIV programmes in the country. According to Shisana, former President Thabo Mbeki, who was the deputy-president at the time, was very supportive of HIV-awareness initiatives.

HIV denial

Years later, while working at the World Health Organization, Shisana realised that Mbeki, and the late Dr Manto Tshabalala-Msimang who had become health minister in 1999, were “taking a different turn” and saying that HIV was not causing Aids. It shocked her that politicians were debating the causes of Aids in parliament instead of relying on the scientific evidence.

She raised her concerns with Tshabalala-Msimang, who she knew had also cared about HIV in the past, but the minister referred her to books written by HIV dissidents and repeated her doubts about whether HIV caused Aids. “I said, come on, you should know better, but she did not want to listen. She became angry.”

The first evidence

In 2001, Shisana was appointed the executive director of the Social Aspects of HIV/Aids and Health (SAHA) research programme at the HSRC. The HSRC approached the Nelson Mandela Foundation for funding to conduct a study to estimate the HIV prevalence in South Africa. Mandela recognised the importance of the study and was prepared to launch the results with the HSRC.

The Nelson Mandela/HSRC Study of HIV/Aids found that 11,4% of the participants were HIV positive. In addition, among those who did not believe that HIV caused Aids, the prevalence was higher than among those who believed it, indicating the danger of HIV denialism among leaders. Many participants did not believe that the government was committed to addressing HIV and Aids. The HSRC scientists urged the government to take action.

“We warned that HIV/Aids was going to devastate the country, and it did because the bulk of the budget for health is now going to HIV. We now have big problems with cancer and other non-communicable diseases, but we never took care of them, because we had to focus on taking care of people living with HIV so that they don’t die. The death rate is just unacceptable. People spent weekends at funerals,” says Shisana.

Attacked by dissidents

After the release of the report, the HIV dissidents attacked Shisana relentlessly. “They called me a daughter of the soil. They wrote a letter that went to every cabinet member of the Mbeki administration. It said that I was influenced by white

people, that I was on the wrong course when I said that HIV was high among black people, which it was.”

A cabinet minister phoned Shisana asking her to apologise. She stood her ground and insisted on her right to conduct scientific research and to share the evidence. Shisana was willing to argue with other scientists but refused to answer to dissidents.

She later addressed the dissidents issue with Mbeki. The HSRC had done a study on HIV among educators, which found that the epidemic was ravaging the education system, having killed thousands of teachers. Mbeki had contradicted her and she then received a call from IRIN News, a publication focusing on humanitarian issues, based in Switzerland.

She responded that, as a scientist, she knew that HIV caused Aids and that she knew from the data that some 4000 teachers had died. “I could not sit there and say I was not going to address the issue because a politician was telling me that HIV didn’t cause Aids.”

Mbeki then asked the HSRC to prepare a paper to explain its position. So, it duly prepared a paper on the impact of HIV on society and delivered it to his office. “We said we were not backing down. HIV caused Aids and was devastating our society and we provided the evidence. And he backed off.”

Working with the government

After the release of the Nelson Mandela/HSRC Study of HIV/Aids, the HSRC’s work in the field attracted national and international attention. As a result, the organisation received significant funding for research, which had a positive impact on its financial health.

Shisana was appointed as the first female CEO of the HSRC in 2005. The government continued to consult her, despite their earlier disagreements. After Mbeki’s resignation, Jacob Zuma became president in 2009.

The government then immediately started using science to address HIV. “The focus on HIV actually helped to reduce maternal mortality, to extend the lives of people and to reduce the number of orphans,” says Shisana.

She saw the HSRC as an institution that should speak the truth to those in power, on the basis of evidence. “We pushed the concept of evidence-based policy. Scientific evidence needs to back what you want to spend money on. We don’t have money in the country to waste.”

During her time as CEO, the HSRC’s relationship with the government became very positive. “They looked to the HSRC for solutions. We worked hand in glove, but not in a way that we were tendering to the government’s wishes.”

If it needed solutions, the HSRC helped by providing scientific information.

Speaking the truth

“We got a lot of contracts from the government. They saw us as a really important instrument for generating knowledge and evidence that could actually be used to improve the quality of life of South Africans,” says Shisana. But she stresses that the HSRC continued to speak the truth to those in power.

“But we did it in a way that was not insulting to the government. The idea was not to insult but to deal with issues, to play the ball, not the man.

“They understood our role. We had managed to position the HSRC as a strategic partner with the government, but coming in from the science side, telling the truth based on science, and the government needed that information.

“We would be called by the appropriations committee in parliament and be asked to talk about the programmes, to say which programmes they should be funding, and which ones not. We went there

and we were able to respond without jeopardising our chances of actually getting funding from those very people in parliament.

“We were aligned to the governing party. They didn’t see us as an enemy. They always said that they learned a lot when we were there because we used the power of knowledge to help to advance the agenda for our country.”

Going forward

There is still a crisis, because, with close to 8 million people living with HIV, it is probable that the disease will continue to be a burden. “We need to close the tap so that we don’t go beyond 9 million people,” says Shisana.

She believes the behavioural and structural factors that fuel the HIV epidemic are still not adequately researched, in particular, the role of gender-based violence. The education system has also been devastated, just like the health system and the economy. “HIV has done untold damage to this country, mainly because those who were in power at the time decided to go against science.”

Shisana is currently a special adviser to President Cyril Ramaphosa on social policy, which includes the government’s planned National Health Insurance (NHI) system. This work needs partners like the HSRC, for example, through population-based surveys to gauge the nation’s thoughts on the NHI, and those of health economists who can look at the financing aspect, she says.

“My message to scientists is to never be intimidated by politicians about science. Do what you know is correct. You will survive. Even after I took on the politicians, they still respected me.”

Author: Antoinette Oosthuizen, HSRC science writer

aoosthuizen@hsrc.ac.za