

## Health and human rights

### Health research and human rights in South Africa

The death of apartheid—symbolised by the multiracial elections in South Africa on April 27, 1994—was a defining moment of the 20th century. The tenth anniversary of this event is a time to consider how well the postapartheid government is fostering health and human rights through reforms in health research policy.

The realisation of health care depends, to an extent, on the formulation of a rational and responsive national research agenda; this has proven a challenge in post-apartheid South Africa.

Health research policy in predemocracy South Africa was motivated by racial considerations and mostly done on a wish to know rather than a need to know basis. It was—and still is—being managed and financed by a diverse number of organisations with little coordination, accountability, or analysis of the effect of research on the country's critical health needs. The government's 1997 White Paper on the Transformation of the Health System in South Africa (White Paper) was devised to address this predicament.<sup>1</sup> Of particular interest, from a human rights perspective, is its proposed Essential National Health Research (ENHR) approach.

ENHR is a health research philosophy that encompasses the goal of promoting development in a manner that achieves equity and social justice. The scheme has an inclusive ethos and advocates involvement of a range of research stakeholders—including community representatives, decision makers, and researchers—in setting national health research priorities. ENHR supports research to address health problems specific to South Africa, as well as global-health research to solve health issues of general importance.<sup>2</sup>

In 2001, the government outlined its Health Research Policy to remedy disparities identified in the White Paper.<sup>2</sup> The policy sets out the processes necessary for developing an equitable research agenda. It provides

guidance on priority setting, use of a range of methodologies for tackling health problems, and harmony between research and health needs. The goals and objectives provide an ethical framework under which research should be done and it could serve as a blueprint for other countries facing similar challenges.

South Africa's imminent National Health Act (NHA) is the enabling legislation for the above vision.<sup>3</sup> Once law, the NHA will provide for the establishment of the National Health Research Committee (NHRC). Its

Rights were not granted to include this image in electronic media. Please refer to the printed journal.

Freedom Day celebrations in South Africa

functions will include: determination of what research should be done; ensuring that research agendas and resources focus on priority health problems; development and advice for the Health Minister on the implementation of an integrated national strategy for research; and coordination of research activities of public-health authorities. However, the high degree of control that the National Health Act allows the Health Minister to exercise over the NHRC potentially threatens the realisation of the Health Research Policy.

The Act makes it possible for a Health Minister to pack the NHRC with members sympathetic to his or her own ideology and to strip from it dissenting voices. It does not provide explicit safeguards for those in the public sector who risk their careers by speaking against state policies. This danger is perhaps most relevant in AIDS research.

Health crises, like AIDS, ought to be met with inspired leadership and

the initiation of a responsive and conscientious national research agenda. Instead, the past 5 years have seen the government and others in South Africa openly question the link between HIV and AIDS; try to discredit activists who fought against government AIDS policies; prematurely endorse the anti-AIDS drug Virodene before its effectiveness could be assessed in clinical trials;<sup>4</sup> and openly undermine the South African Medical Research Council's findings on the country's AIDS-related death rate. Such poor research leadership frustrates the realisation of health access and underscores the possible danger that the national research agenda could be hijacked by misguided decision-makers who are driven by ideology rather than scientific evidence. Furthermore, there are obvious shortcomings of placing a national research regulatory body under such overbearing central control.

Notwithstanding its laudable attempts to redress the country's skewed national health research agenda, only when the South African government commits itself to transparent, competent research leadership free of ideological bias will the country truly graduate from erstwhile pariah nation to celebrated champion of health and human rights.

Jerome A Singh

Howard College School of Law, and Centre for the AIDS Programme of Research in South Africa (CAPRISA), University of KwaZulu-Natal, Durban 4041, South Africa (e-mail: singhj9@ukzn.ac.za)

- 1 Department of Health, South Africa. 1997. White Paper for the Transformation of the Health System in South Africa. <http://www.doh.gov.za/docs/policy-f.html> (accessed March 4, 2004).
- 2 Department of Health, South Africa. 2001. Health Research Policy in South Africa. <http://www.doh.gov.za/docs/policy-f.html> (accessed March 4, 2004).
- 3 National Health Bill (B32D - 2003). <http://www.polity.org.za/pdf/NationalHealthB32D.pdf> (accessed March 4, 2004).
- 4 Mbeki T. ANC has no financial stake in Virodene. <http://www.anc.org.za/ancdocs/history/mbeki/1998/virodene.html> (accessed March 25, 2004).