

South Africa has progressive legislation regarding disability rights and we are unusual in our region in making provision for disability grants. The rights of disabled people are constitutionally enshrined and disability is a recognised category within employment equity legislation.

In the past things were different. Disability was seen as a medical issue. It was assumed that the degree of bodily impairment determined how disabled a person was, and that the core of disability research was to cure or alleviate bodily impairments. Care for disabled people was narrowly defined as nursing or medical care and was linked, by extension, to religious care. Working with the disabled was



# NOT WITHOUT US

By Leslie Swartz

## the challenges in researching disability

charitable, undertaken by people who through their convictions or their professional training, were merciful enough to work with the "afflicted".

Though much good has been done through the interest of medicine and religion, there has been a dramatic world-wide change in perspective. Disability work is now seen, fundamentally, as addressing issues of social exclusion, and promoting access for all citizens to full participation in society – including work, recreation, creative pursuits, and the health and justice systems.

A key slogan of the disability movement internationally is "Nothing about us without us" – a slogan which has been taken up by Disabled People South Africa. This slogan, in keeping with the doctrine of self-representation for disabled people, is an important counter-balance to earlier paternalistic beliefs that "experts" knew what was good for disabled people.

This approach links clearly to issues in feminist, black and gay studies, all of which emphasise self-representation by women, black and gay people respectively, in their own research agendas. There are, however, divergent interpretations of what "Nothing about us without us" implies for disability research in practice.

At one end of the spectrum, there are those who say that the only legitimate disability research is that in which disabled people themselves ask the questions, conceptualise

and conduct the research, and interpret and disseminate the results. At the other, more cynical end, some feel that a token nod to disabled peoples' views at some point in the research process is sufficient.

Navigating the complexities of producing disability research that is both credible and policy-relevant is not easy. But it is also very exciting. Some key principles are helpful here:

► **Consultation.** Even when disabled people themselves do not primarily define a research issue, it is important to have a credible consultation process with representatives from the disabled community. The disability sector in South Africa is well organised and experienced at providing constructive and invaluable feedback.

► **Participation and leadership.** Wherever possible, disabled people should have meaningful roles in research concerning disability. Research leadership by disabled people should be a goal.

► **Capacity-building and workforce diversity.** We face major challenges in the developing cadres of disabled researchers, of whom there is a shortage. This relates partly to "downstream issues". Many competent disabled people in South Africa have been denied access to adequate education, even at school. A good example is that of a colleague who had a keen interest in electronics, but was advised at school that, since he was blind, he could not study mathematics. This colleague has now excelled in an area of the humanities, but

South Africa has lost the potential contribution to the "hard" sciences of a person who had both the interest and aptitude to study further in this area. There are many people of talent who have been denied any hope of tertiary education, let alone specialist research careers. Stereotypes still abound, such as the idea that blind people should become telephonists, wheelchair users should become call-centre operators, and that deaf people should become stock controllers. We have a long way to go before it is universally accepted that it is not the disability which should determine a person's career path, but the person's talents and abilities.

An interesting feature of disability research is that it can combine fascinating technical questions (such as the design of computer software to increase disabled people's access to print and other media) with questions about how to change social attitudes (such as how to assist companies and departments to develop an integrated, skills-based workforce).

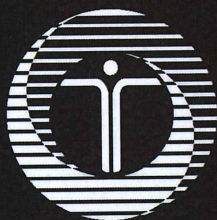
It is important for researchers, and for all concerned with building a cohesive society, to realise that research which brings us closer to the goal of what is called, a "barrier-free society" in disability literature, is not only necessary for our social role, but is also very intellectually stimulating. •

*Professor Leslie Swartz is a Research Director at the Child, Youth, and Family Development Research Programme, which has as one of its foci the area of Disability Studies.*



# HSRC review

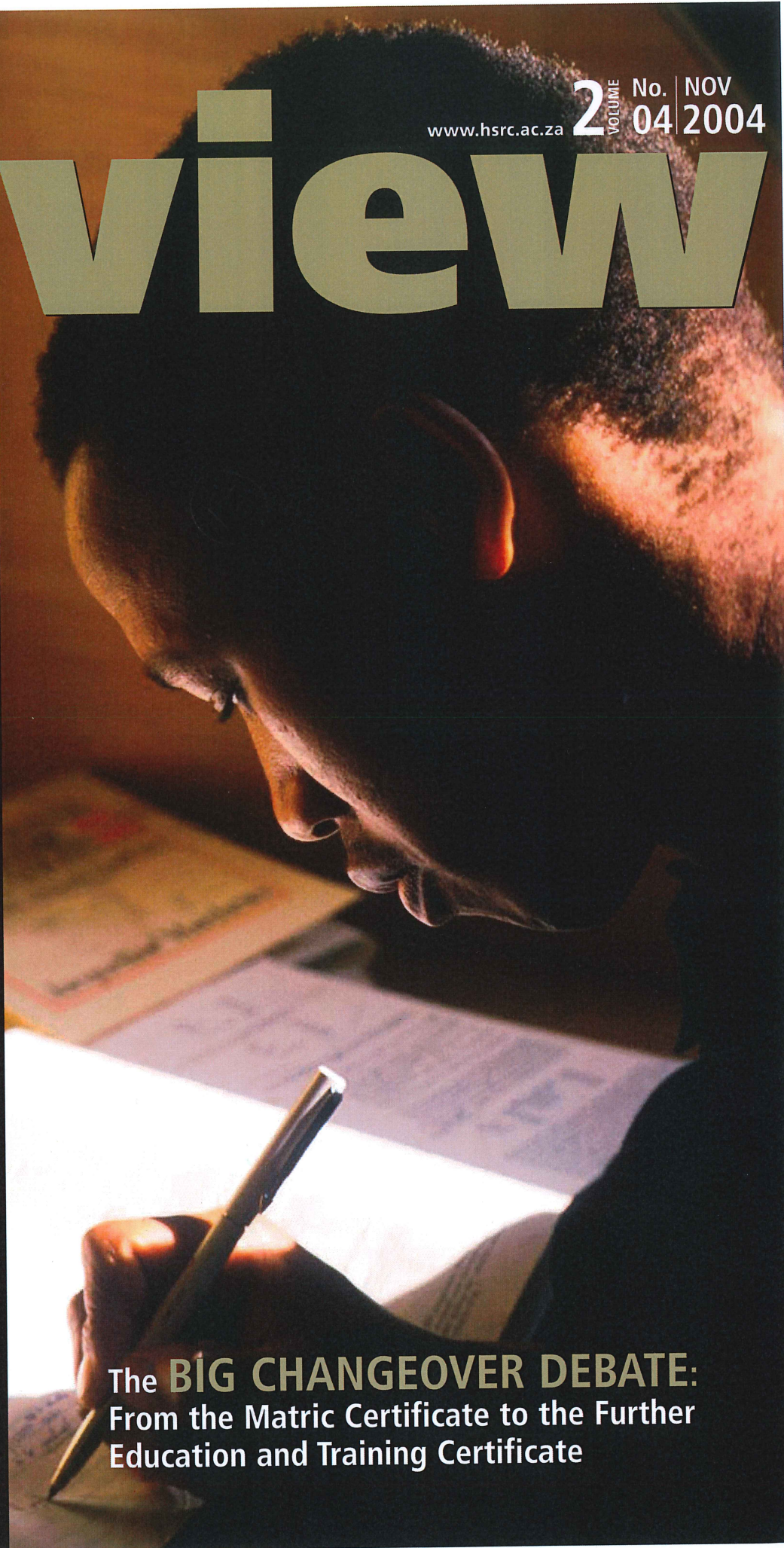
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The **BIG CHANGEOVER DEBATE:**  
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