

# Foreword

At the launch of the book *Nobody ever said AIDS*<sup>1</sup> Eddie Maluleke recited her poem from which the title of the book came. The final verse reads:

... We all died  
Coughed and died  
We died of TB  
That was us  
Whispering it at funerals  
Because nobody ever said AIDS

The vibrancy of her performance lay in sharp contrast to the muted response to the HIV and AIDS epidemic by the state – muted in all aspects except for denial, prevarications, neglect, stigma and discrimination. It was also in contrast to the muted response from industry, civil society, the medical profession and most citizens. It was a performance that showed how a state and the society should be responding to the epidemic and was a performance of passion, commitment and energy that shamed all but a few people.

This epidemic calls for a robust and vibrant response. It calls for commitment, energy and passion. Over the past five years, the Centre for the Study of AIDS, based at the University of Pretoria has published an annual *AIDS Review*. Each of these

*Reviews* has taken a seemingly intractable issue and tried to develop a critical and robust engagement with it and give a critique of the issue and its ramifications. Starting in 2000, with *To the edge* which asked how it was possible that with the vibrant and committed NGO sector, the energy of the NACOSA process, the flawed but the starting point of the ATICs and media campaigns prior to 1994 and the development of the National AIDS Plan in 1994, South Africa by 2000 appeared to have got it so wrong in terms of the AIDS response. This was followed in 2001 with the analysis *Who cares?* – asking who really cares about the African epidemic, who will care for the people who are living with HIV and AIDS, who cares about how the state responds and in the end, who cares about how a society will be affected by this lack of compassion, humanity and urgency.

In 1844 Hegel compellingly wrote:

when one individual inflicts bodily injury upon another, such injury that death results we call the deed manslaughter; when the assailant knew in advance that the injury would be fatal, we call his deed murder. But when society places hundreds of proletarians in such a position that they inevitably too meet a too early and an unnatural death, one which is quite as much a death by

violence as that of the sword or bullet; when it deprives thousands of the necessities of life, places them under conditions in which they cannot live ... knows that these thousands ... must perish, and yet permits these conditions to remain, its deed is murder just as surely as the deed of the single individual ... we read these things every day in the newspapers and take no further trouble in the matter. But society cannot complain if after the official and non-official testimony here cited must be known to it – the offence may be more one of omission than of commission. But murder it remains.<sup>2</sup>

A commentary, as fitting in 2001, about the failure to care about the AIDS epidemic as the failure to care about health and livelihoods in 1844.

The 2002 *Review* followed on this lack of caring by examining the relationship between AIDS and human rights – *Whose right?* – does the lack of understanding of this epidemic and its wide ramifications lead to a lack of understanding about how this failure to care allows for a failure to protect and ensure human rights? How do we measure the theory against the reality? Good legislation and good policies exist in most of the countries reviewed, but this does not translate into programmes that allow people with HIV and AIDS and their families and

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1 Rasabotsa N, Samuelson M & Thomas K (2004). *Nobody ever said AIDS*. Kwela Books. Cape Town. (p 20).

2 Black N et al. (1989). *Health and disease. A reader*. Open University Press. Philidelphia. (p 61).

communities to access their rights. In 2003 the examination moved to the level of the family – *Over extended* – asking how families, the bedrock of society, cope with such an epidemic and the demands it makes on individuals, their families and that communities in which they are located. Far from finding the we have families and communities that generate safety, compassion and comfort we observe that families are over-extended, unable to cope, and struggling to come to terms with the reality of stigma and discrimination and with the demands of care for people with HIV and AIDS, orphans and other affected family members. There were stories of families and communities that did cope. They were in a twilight world and living precariously on the edge.

In 2004 the lens shifted to the individual and in *(Un)real* we challenged the stereotypes that have developed around men in the epidemic. We challenged the notion of men as isolated and uncaring and looked at how they have been positioned by the discourse of the epidemic. The *Review* considered the social construction of masculinity and sexuality and how men's role in society has been and will be fundamentally challenged by HIV and AIDS.

***Buckling*** starts to pull all these themes together and takes a critical look at how we should be **measuring the impact of HIV and AIDS on South Africa**. What have we learned from our past, from the ways in which we have described and understood the epidemic and from the ways in which we have chosen to analyze and interpret its impact? Can a society such as South

Africa come to terms with the impact of AIDS and generate a brave, vibrant and robust response? Can we understand the lessons of the past and create a future that protects and supports us all as we negotiate our way through this most fascinating of all epidemics and the many social, political, economic and personal ramifications it will produce? For in the end

This disease not seldom attacks the rich, but it thrives among the poor. But by reason of our common humanity we are all, whether rich or poor, more nearly related here than we are apt to think. The members of the great human family are, in fact, bound by a thousand secret ties, of whose existence the world in general little dreams. And he that was never yet connected with his poorer neighbour, by deeds of charity or love, may one day find, when it is too late, that he is connected with him by a bond which may bring them both, at once to a common grave.<sup>3</sup>

These are the words of William Budd writing about typhoid fever in 1874, and as with Hegel, providing as perceptive a social commentary for AIDS in 2005.

*Buckling* tells us how and why *Nobody ever said AIDS* and why it is imperative that we do.

The University of Pretoria is committed to a comprehensive HIV and AIDS programme and institutional response that includes all aspects of the University – the Rector, Vice Rectors, Deans, staff, students, community and government. The Centre for the Study of AIDS has international collaboration with key HIV and AIDS research units, and with UN agencies, and is working with regional and national tertiary institutions to increase our knowledge and develop effective responses.

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The views expressed in this *Review* are solely those of the author and the Centre for the Study of AIDS.

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3 Drexler M (2002). *Secret agents*. Joseph Henry Press. Washington, DC. (p 275).

