

Law and politics: History, politics and context of HIV/AIDS in South Africa

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Structure

- What causes an epidemic?
- Civil society driven responses
- South Africa's AIDS epidemic
- The Civil Society Response in South Africa
- Drawing conclusions



PART I

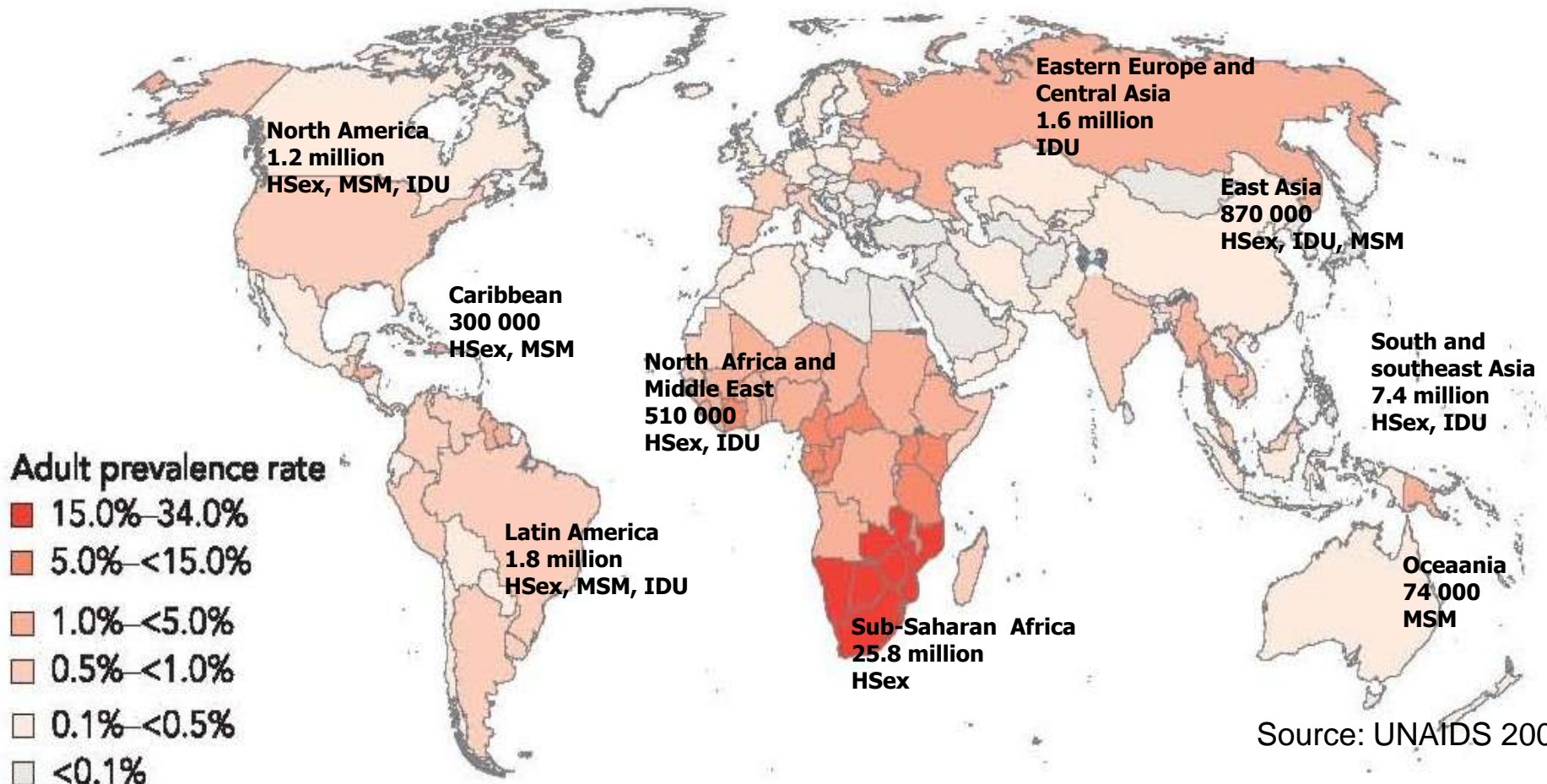
WHAT CAUSES AN EPIDEMIC?

State of the global HIV epidemic - 2005

38.6m living with HIV, 4.1m new infections, 2.8m deaths

A global view of HIV infection

38.6 million people [33.4–46.0 million] living with HIV, 2005



Source: UNAIDS 2006

History of disease

- HIV/AIDS not the first global epidemic
 - Black death
 - Bubonic plague
 - Typhoid
 - Cholera
 - Flu
- Politics and law always associated with *transmission* or *containment* of disease

The HIV epidemic – like state of health – is socially determined

- “Public health is purchasable .. A community can determine its own death rate .. No duty of society is paramount to this obligation to attack the removable cause of disease.”
 - *H. Biggs, New York State Commissioner of Health, 1913*
- “The risk of acquiring HIV does not depend on knowledge of how the virus is transmitted, but rather on the freedom to make decisions. Poverty is the great limiting factor on freedom.”
 - *Paul Farmer, Infections and Inequalities*

Political determinants of the AIDS epidemic

- *“There is nothing in this whole bloody AIDS mess that is not political”*
 - *Larry Kramer, 1987*
- *“The HIV/AIDS epidemic is being managed, not solved. For HIV/AIDS to be rolled back, the right political incentives for HIV prevention need to be in place.”*
 - *Alex De Waal, AIDS and Power, 2006*

North and South: Contrasting epidemics

SUB-SAHARAN AFRICA

Number of people living with HIV

- 2008: 22.4 million
- 2001: 19.7 million

Number of new HIV infections

- 2008: 1.9 million
- 2001: 2.3 million

Number of children newly infected

- 2008: 390 000
- 2001: 460 000

Number of AIDS-related deaths

- 2008: 1.4 million
- 2001: 1.4 million

7/28/2010

N AMERICA AND WEST AND CENTRAL EUROPE

Number of people living with HIV

- 2008: 2.3 million
- 2001: 1.9 million

Number of new HIV infections

- 2008: 75 000
- 2001: 93 000

Number of children newly infected

- 2008: <500
- 2001: <500

Number of AIDS-related deaths

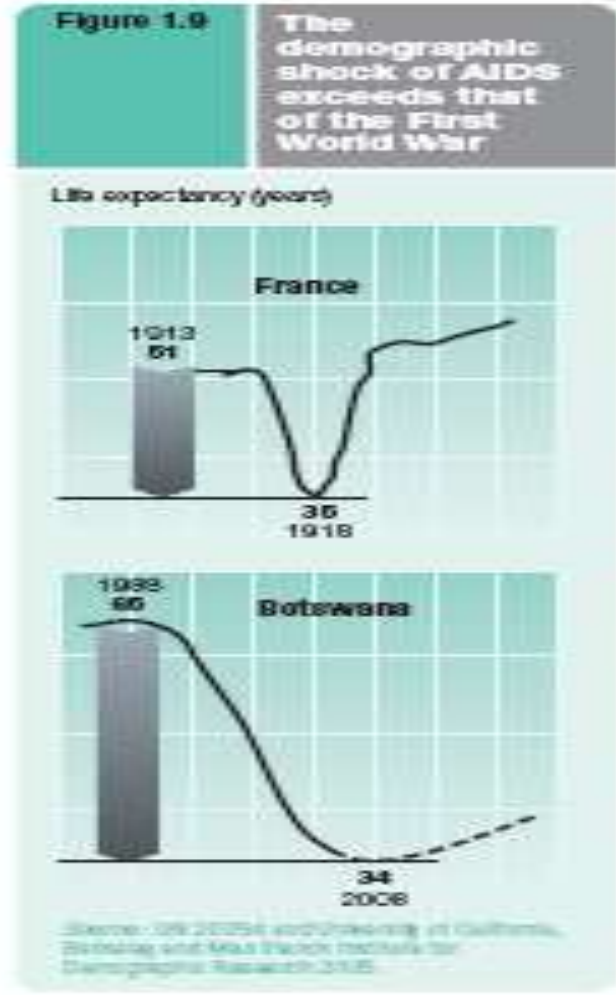
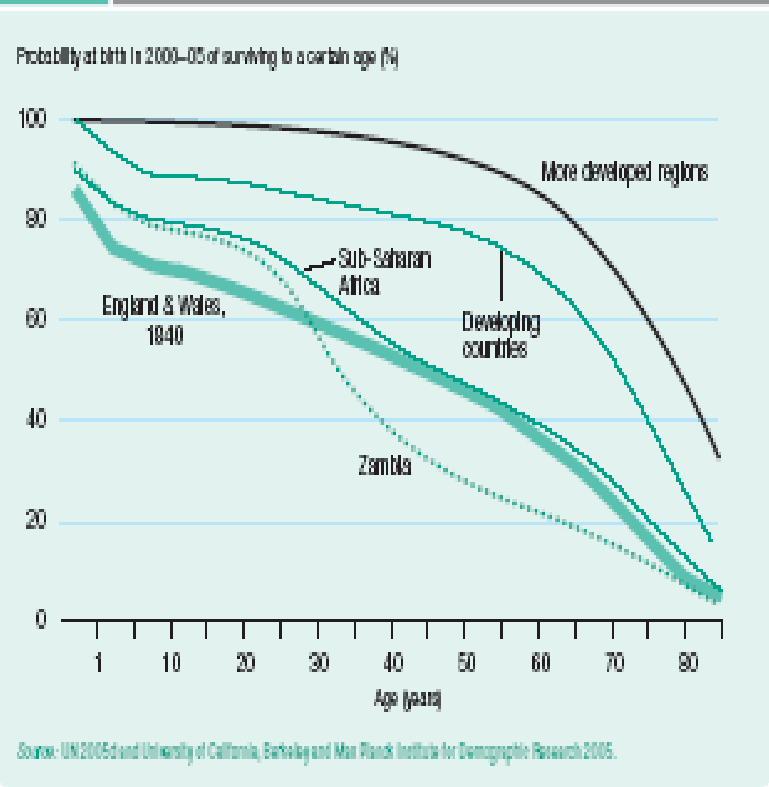
- 2008: 38 000
- 2001: 27 000

Africa's third crisis of development: Running to stand still

- AIDS and the elimination of social capital:
 - “In Sub-Saharan Africa the lethal interaction of economic stagnation, slow progress in education and the spread of HIV/AIDS has produced a free fall in HDI ranking. Southern Africa accounts for some of the steepest declines—a fall of 35 places for South Africa, 23 places for Zimbabwe and 21 places for Botswana.”
 - UNDP Human Development report, 2006

The impact of increased mortality among adults (UNDP, 2006)

Figure 1.8 Chances of survival in Sub-Saharan Africa are not much better than in 1840s England



Questions ..

- Why did HIV assume pandemic proportions in Africa, but was (largely) contained in most communities in Northern America and Europe?
- Why is AIDS tolerated... but Bird Flu (H5N1) feared?
- Where are the new AIDS epidemics?



PART II

CIVIL SOCIETY DRIVEN RESPONSES

The role of Civil Society: lessons from the First (World) AIDS epidemic

- First cases 1981
- First meeting of People with AIDS 1983
- Formation of organisations to respond: Gay Men's Health Crisis, ACT-UP
- Successful forcing in from the margins:
 - Kramer: "What are you doing to save my fucking life?"

Successful civil society responses:

- Respond to the threat **internally**
 - Behavior change
 - Information and service provision
 - Education and tooling-up
- Respond to the threat **externally**
 - Human rights Protest
 - De-marginalisation of the group
 - Influencing the political agenda

Outcome of developed country civil society responses

- Epidemic (largely) contained by community action
- Public awareness of threat achieved (among vulnerable groups)
- Research agenda influenced:
 - New drugs – AZT, ARVs
- Resources made available

Early African responses:

- “Despite courageous work on the part of many activists in Africa, there is little “aroused public interest”; indeed, debate often seems more vocal and intense outside the continent”
 - De Cock et al, Lancet 2002
- ***Why the paralysis?***
 - Fragmentation of civil society
 - Weakness of civil society vs government
 - Disease fatalism: malaria, cholera, TB, ... HIV/AIDS
 - Impact of globalisation -- reducing the power of nation states?

Later African responses: forcing democracy

- The AIDS Support Organisation, TASO (Uganda)



- The AIDS Law Project, 1993 – 2010



- The Treatment Action Campaign, TAC (South Africa), 1998 –



- AIDS and Rights Alliance of Southern Africa (ARASA), 2001 -

Globalising a human rights based AIDS response:

■ Achievements of civil society:

- Rapid advances in medicine & scientific understanding of HIV
- Pressure on medicine prices and international IP law

Dramatic increases in funding

- Attracting massive new investment for AIDS & health
 - Annual international funding for AIDS has risen more than ten-fold over the past decade, to \$13.7 billion in 2009.
 - Donations to global health have quadrupled over the past two decades—from \$5.6 billion in 1990 to \$21.8 billion in 2007.
- Forming new institutions:
 - The Global Fund on AIDS, TB and Malaria (GFATM)
 - PEPFAR

Reaching the limits?

- The political backlash:
 - Running out of money or running out of commitment?
 - Setting an unfortunate precedent for global health – accountability, civil society involvement
 - Exposing developing country neglect of health



PART III

SOUTH AFRICA'S AIDS EPIDEMIC

What the researchers said in 1991

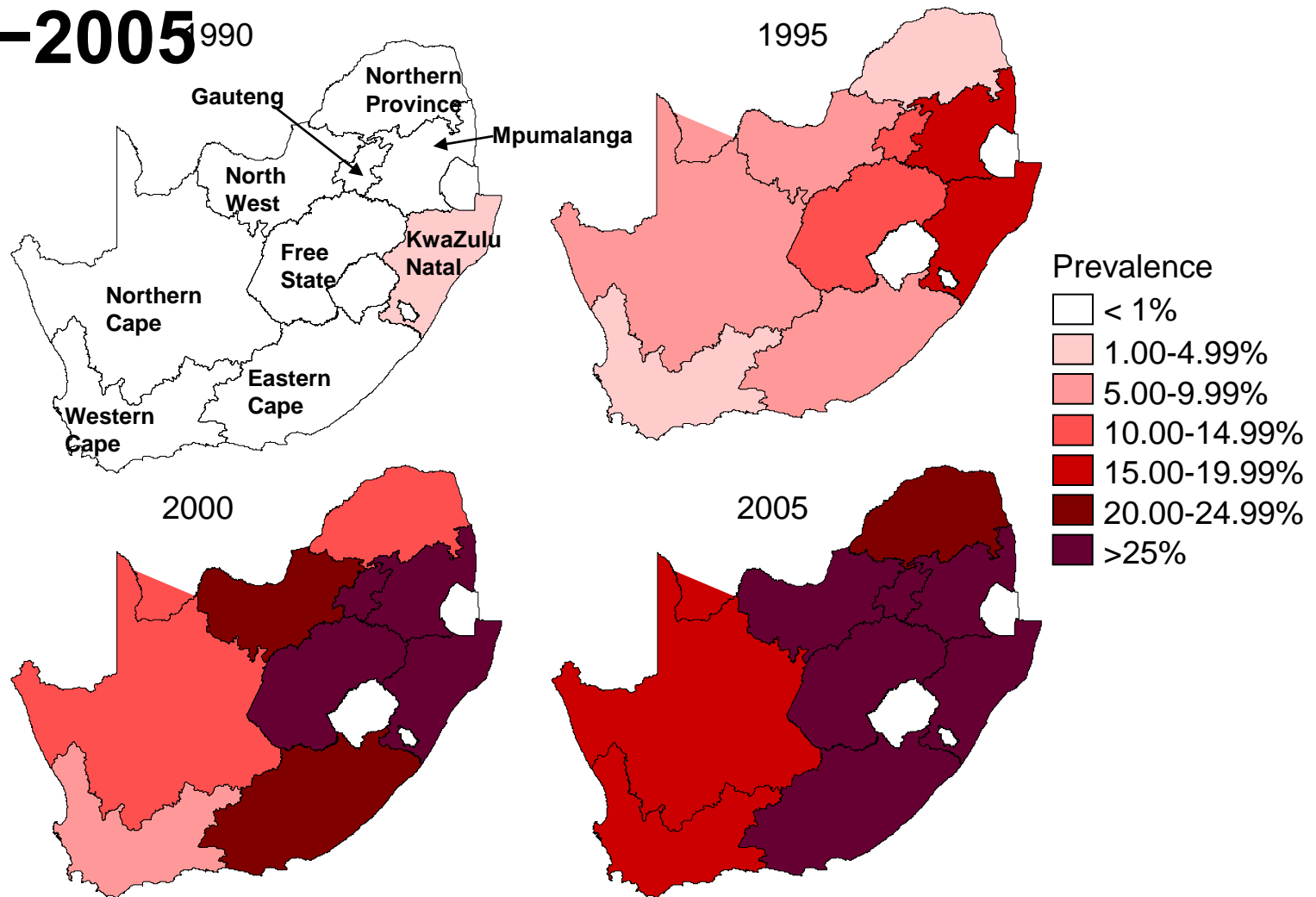
- “it appears that the migrant labour system has institutionalised a geographic network of relationships for spreading STDs. This network suggests that once HIV enters the heterosexual mining community it will spread into the immediate urban area, to surrounding urban areas, within rural areas, and across national boundaries.”

Jochelson K, Mothibeli M, Leger J-P ‘Human Immuno Deficiency Virus and Migrant Labour in South Africa’
International Journal of Health Sciences. 1991: 21 157-173

From Africa to South Africa

Epidemiological history- South Africa

1990-2005



Political History of AIDS in SA

The Four Phases of AIDS Denial:

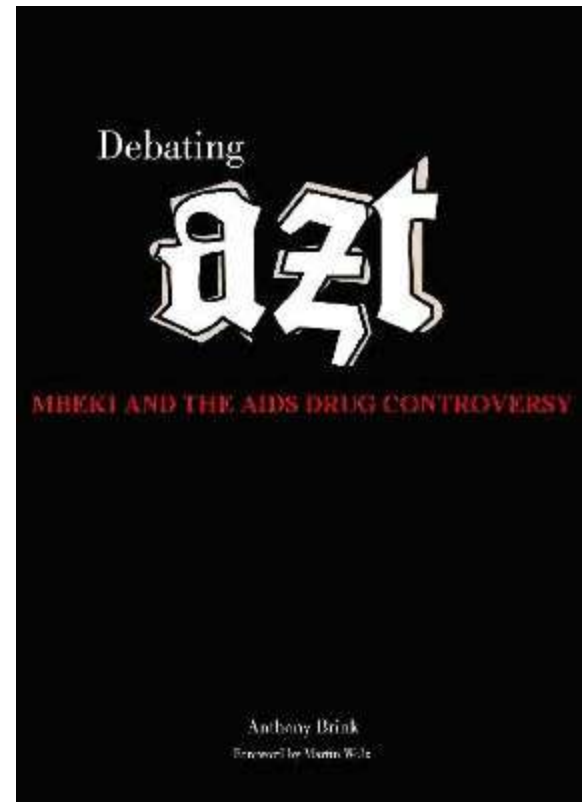
- 1983 – 1994: National Party:
 - Racially based responses

- 1990 – 1999: 1st ANC-led Government of National Unity – Mandela:
 - Benign denial & neglect
 - NACOSA plan with little implementation



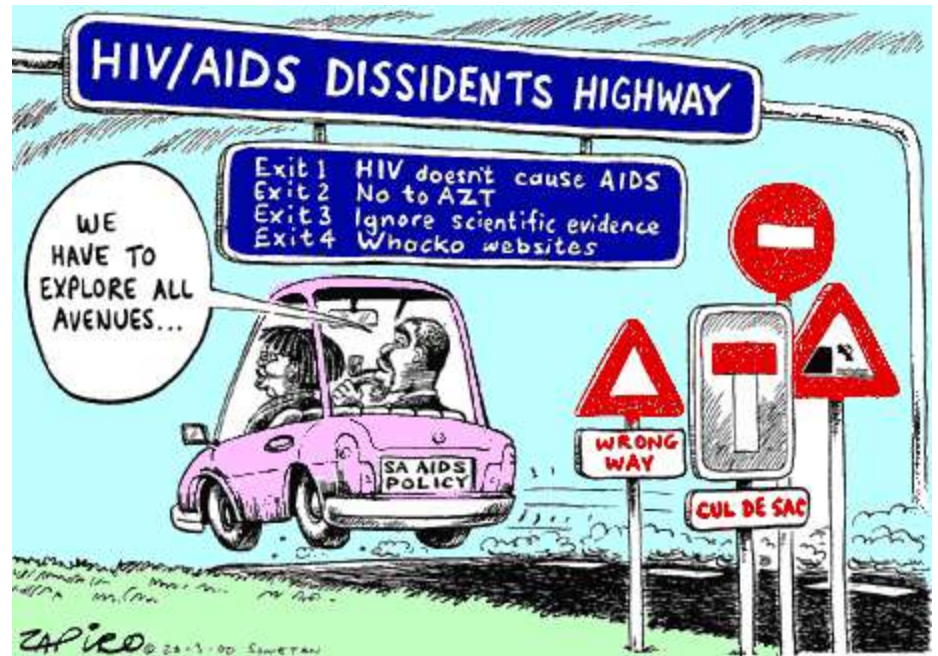
- 2nd ANC Government -- Mbeki (1999-2004):
 - Malign denial

- Mbeki govt 2 (2004 – 2007):
 - Phase 1: The reinvention of AIDS denialism – Dr Rath
 - Phase 2: The ‘normalisation’ of AIDS



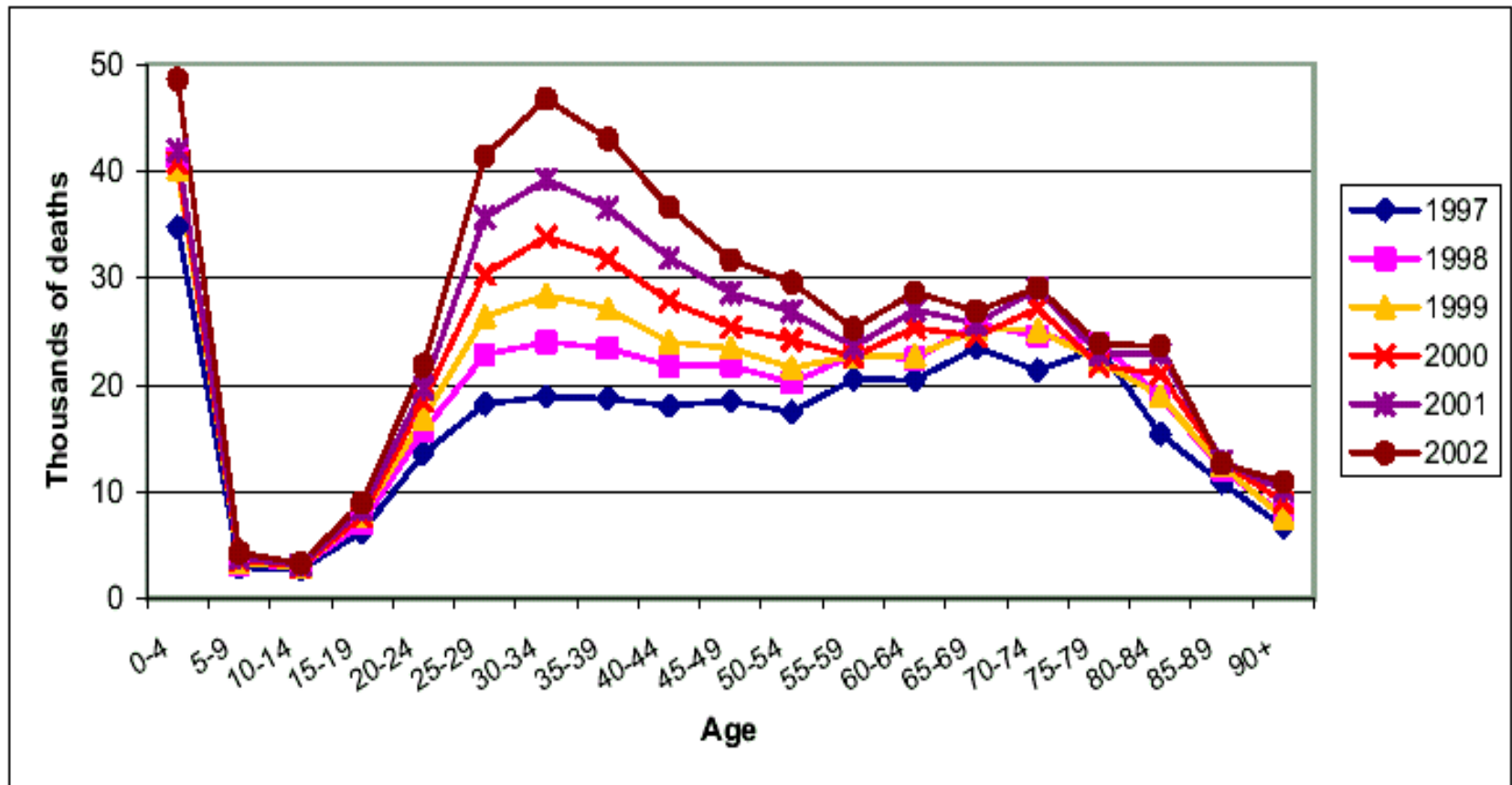
The poverty of AIDS denialism

- HIV doesn't cause AIDS
- Virus never isolated
- ARV's don't cause AIDS
- AIDS is a disease of poverty



The price of denial?

Figure 3.3: Distribution of deaths by age and year of death, 1997-2002 (thousands)



Note: The completeness of the death register has increased by year so that 2002 is more complete than 1997. Numbers for 2003 are excluded, as Stats SA has not yet received all the death notification forms for 2003 from the Department of Home Affairs.

Mbeki Aids policy 'led to 330,000 deaths'

- [Sarah Boseley](#), health editor
- [The Guardian](#), Thursday 27 November 2008
- The Aids policies of former president Thabo Mbeki's government were directly responsible for the avoidable deaths of a third of a million people in South Africa, according to research from Harvard University.

The end of denial (2007- 2010):


- Post-Polokwane (ANC Congress):
 - September 2008: Recall of Mbeki
 - Appointment of Barbara Hogan as Minister of Health (2008-2009)
 - May 2009: Appointment of Aaron Motsoaledi as Minister of Health
 - October 2009: Address of Jacob Zuma to National Council of Provinces on HIV/AIDS



THE CIVIL SOCIETY RESPONSE IN SA

A brief history of AIDS activism:

- 1987: First cases of HIV reported among Malawian mine workers;
- Govt tries to expel Malawians and stop migrant labour;
 - National Union of Mineworkers responds

- 
- 1990: Issue of HIV/AIDS addressed in conference held by ANC in Maputo:
 - “We cannot afford to allow the AIDS epidemic to ruin the realisation of our dreams. Existing statistics indicate that we are still at the beginning of the AIDS epidemic in our country. Unattended, however, this will result in untold damage and suffering by the end of the century”
 - Chris Hani

1990 – 1998: AIDS Law and Human Rights advocacy

- 1991: Charter of Rights
- 1992: AIDS Consortium formed
- 1993: AIDS Law Project formed
- 1994: The start of legal activism: *McGeary* judgment
- 1994: First democratic election and adoption of NACOSA National AIDS Plan

Policy commitments .. But practical marginalisation

- 1996: “Sarafina” scandal
- 1997: Virodene scandal (Thabo Mbeki, in Mayibuye)
- 1998: Proposal to make AIDS notifiable
- October 1999: beginning of malign denialism
 - Mbeki speech to NCOP
 - Formation of International AIDS Advisory panel



Law Wars:

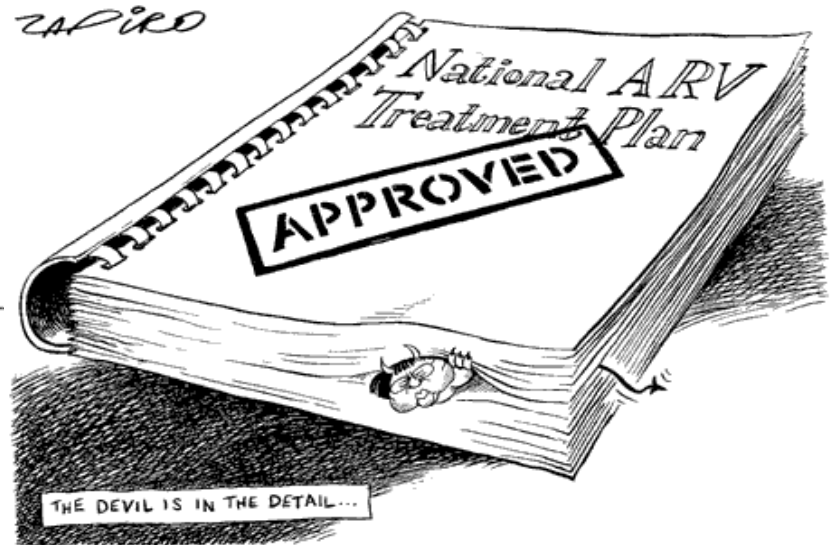
Pre-employment testing (SAA)

Access to PMTCT

Access to ARVs in prisons

Stopping quackery: Matthias Rath

The Government's AIDS Treatment Plan:



A short history of the TAC

- Formed December 1998
- Led by people with HIV
- Advocacy for **human rights** to treatment and health care services
- Targeting government, pharmaceutical companies and communities

Political law: the method of TAC

- Combining law, research, community based education, advocacy and protest to realise the right to health:
- Examples of successful campaigns:
 - MTCT prevention, 1999-2002
 - Medicine prices, Ongoing
 - Fluconazole
 - ARVs
 - National Treatment Plan, 2003
 - National Strategic Plan (2007-2011)



DRAWING CONCLUSIONS

Questions

- What is the relationship between public health, human rights and law?
- Health and democracy: What is the role of ‘civil society’?
 - How can an effective activist movement be sustained?
 - What may be the role of human rights law?

Human Rights vs Public health??

- De Cock et al:

- “Procedures that safeguard a patient’s autonomy at the expense of his or her health and well-being undermine the moral and logical basis of human rights themselves.” (i)

- See also: D. Miller et al., *The Gateway to Treatment: An increased role for provider initiated HIV testing and counselling in resource poor settings* (2004)

HIV/AIDS versus health generally?

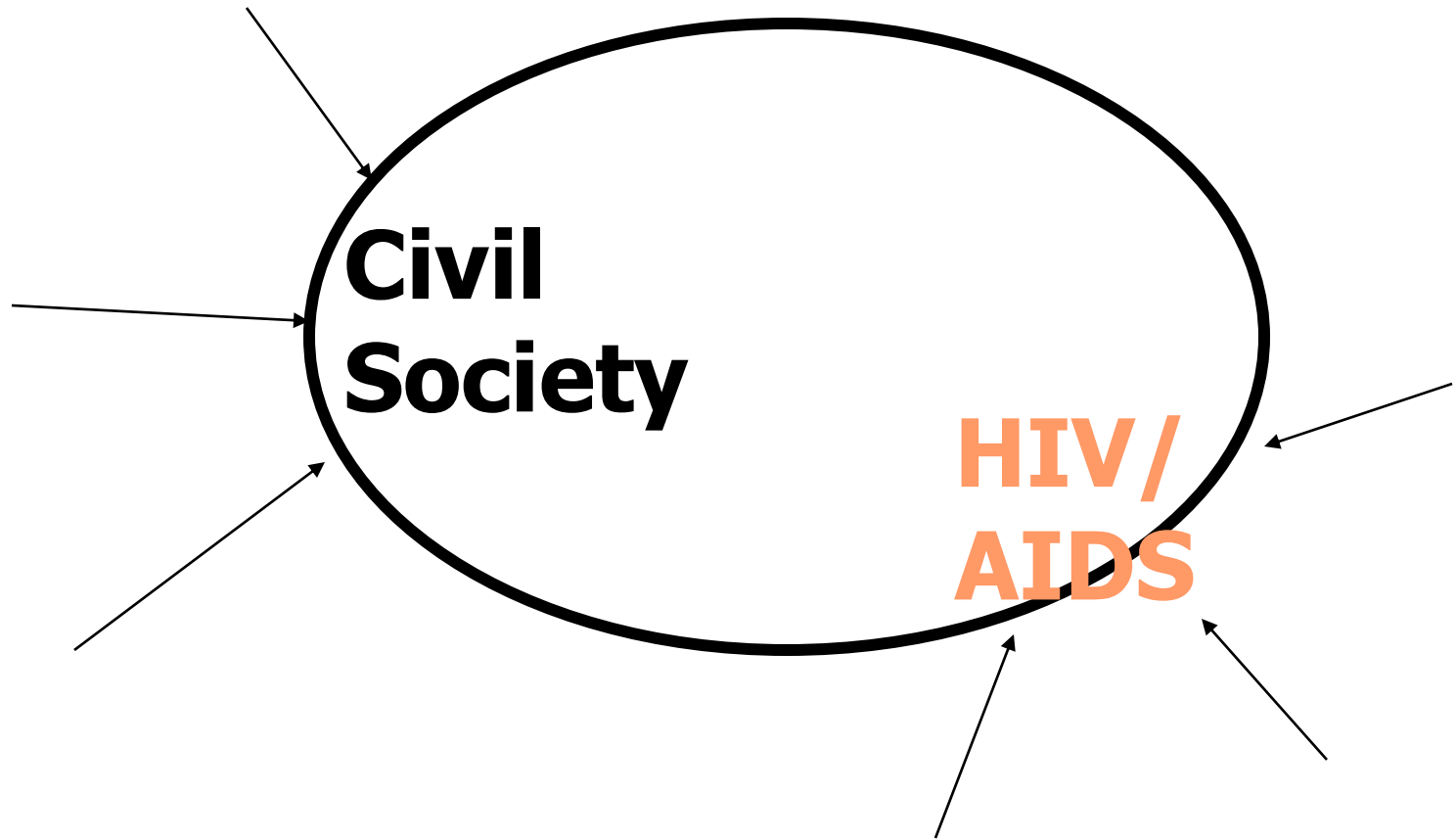
- “The current allocation of health assistance to developing countries is far from optimal. One would expect resources allocated to a particular disease to be roughly proportional to the potential ill health averted by those expenditures. But the proportion of development assistance for health that is allocated to HIV/AIDS reached 23% in 2007, whereas the proportion of deaths attributable to AIDS in the developing world is less than 5%.”
 - H Bongaarts, M Over, Global HIV/AIDS Policy in Transition, Science, VOL 328, 11 June 2010

Reorganising the architecture global health funding and delivery

- Recognising health as a human right
- Development of a UN Framework
Convention on Global Health?
 - See L O. Gostin, *Meeting Basic Survival Needs of the World's Least Healthy People: Toward a Framework Convention on Global Health*, 96 Geo. L.J. 331 (2008),
<http://ssrn.com/abstract=1014082>,
http://scholarship.law.georgetown.edu/ois_papers/1/.

AIDS as a builder of civil society, or AIDS as a destroyer of civil society

From vicious circle to virtuous circle ??



The many relationships between human rights, law stigma and discrimination

