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# **Human Rights and TB Time to demand Action**

**By Mark Heywood  
Executive Director, AIDS Law Project  
Presentation to South African TB  
Conference,  
3 July 2008**



- **Do human rights apply to TB?**
- **How rights violations have determined the course of the TB epidemic**
- **What is a human rights approach to TB?**
  - **State duties to devise and implement a reasonable plan**
  - **State duties towards health care workers**
  - **State duties towards people with TB, HIV and TB and HIV**



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# Health is a Rights: so, why not TB?

- **“All people have the right to the highest attainable standard of physical and mental health”**
  - **ICESCR, Article 12**
- **“Everyone has a right of access to health care services”**
  - **SA Constitution, s 27**
- **Governments must take steps for “The prevention, treatment and control of epidemic, endemic, occupational and other diseases”**
  - **ICESCR, Article 12**



- **HIV is a ‘human rights’ issue:**
  - **UN, International Guidelines on HIV and Human Rights;**
  - **UNGASS, Declaration of commitment, etc.**
- **So why not TB?**
  - **Less Stigma?**
  - **Not sexually transmitted?**
  - **“Treatable”?**
- **HIV galvanised a global activist movement - why not TB?**



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# Lessons of HIV:

- **Protection of human rights and good public health are connected:**
  - **Respect for dignity - better uptake;**
  - **Respect for patient autonomy - better adherence;**
  - **Promotion of equality and non-discrimination - greater openness;**



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# **Squabbling while Rome burns - letting TB happen**

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- **State duties - ignored in relation to TB (and HIV)**

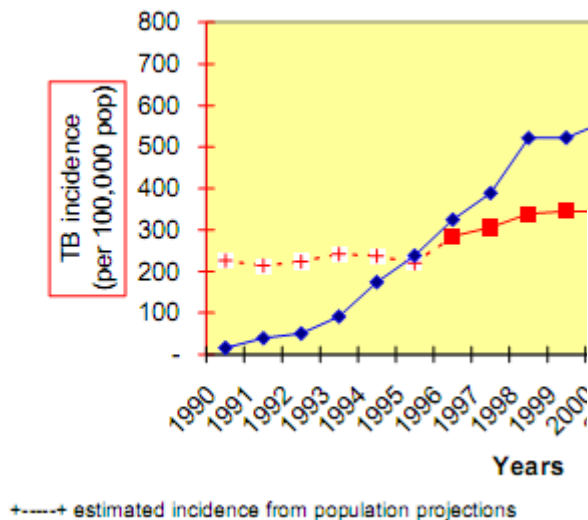
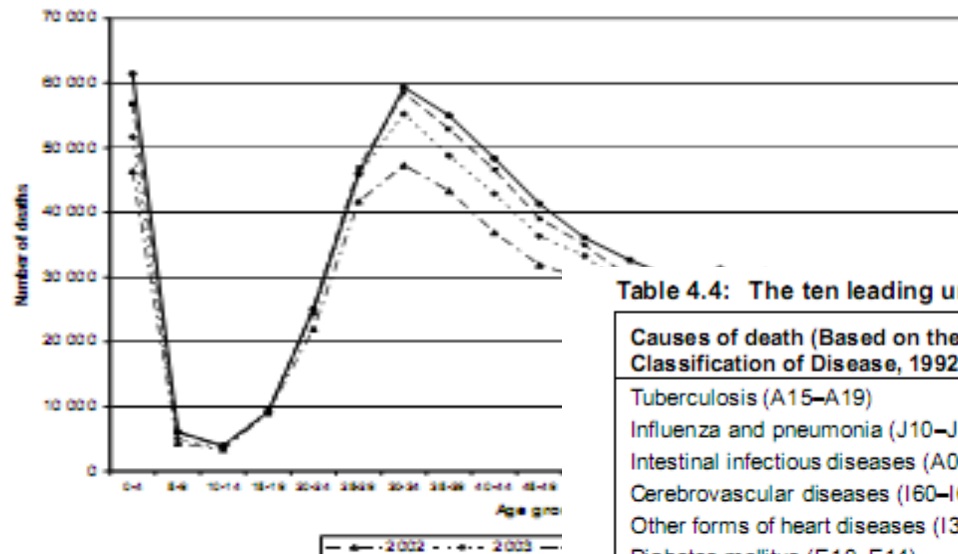


Table 5: MDR-TB cases per province 2004-2007

Province	2004	2005	2006	2007 (Q1)
E Cape	520	601	927	315
F State	131	171	226	47
Gauteng	662	711	794	168
KZN	308	1014	2806	1134
Limpopo	86	58	84	21
Mpumalanga	156	156	177	25
N West	126	180	201	38
N Cape	126	161	203	44
W Cape	1163	1253	1298	348
S Africa	3278	4305	6716	2140



Figure 3.2: Distribution of deaths by age, 2002–2005\*



\*Excluding deaths with unspecified age (2 029 deaths in 2002; 2 791 deaths in 2003; Data for 2002–2004 updated to include late registrations processed in 2006.

Table 4.4: The ten leading underlying natural causes of death, 2004 and 2005\*

Causes of death (Based on the Tenth Revision, International Classification of Disease, 1992)	Rank	2005		2004*	
		Number	%	Number	%
Tuberculosis (A15–A19)	1	73 903	12,5	70 355	12,3
Influenza and pneumonia (J10–J18)	2	45 596	7,7	45 580	8,0
Intestinal infectious diseases (A00–A09)	3	28 548	4,8	26 740	4,7
Cerebrovascular diseases (I60–I69)	4	24 437	4,1	25 226	4,4
Other forms of heart diseases (I30–I52)	5	23 963	4,1	23 925	4,2
Diabetes mellitus (E10–E14)	6	18 423	3,1	17 071	3,0
Certain disorders involving the immune mechanism (D80–D89)	7	16 171	2,7	16 226	2,8
Chronic lower respiratory diseases (J40–J47)	8	15 738	2,7	15 521	2,7
Respiratory and cardiovascular disorders specific to the perinatal period (P20–P29)	9	15 457	2,6	13 478	2,4
Human immunodeficiency virus [HIV] disease (B20–B24)	10	14 532	2,5	13 440	2,3
Other natural causes		261 317	44,2	251 819	44,0
Non-natural causes		53 128	9,0	52 969	9,3
<b>All causes</b>		<b>591 213</b>	<b>100,0</b>	<b>572 350</b>	<b>100,0</b>

\*Data for 2004 updated to include late registrations processed in 2006.



# Declining life expectancy

Figure 3: Provincial average life expectancy at birth, 2001–2006 and 2006-11 (females)

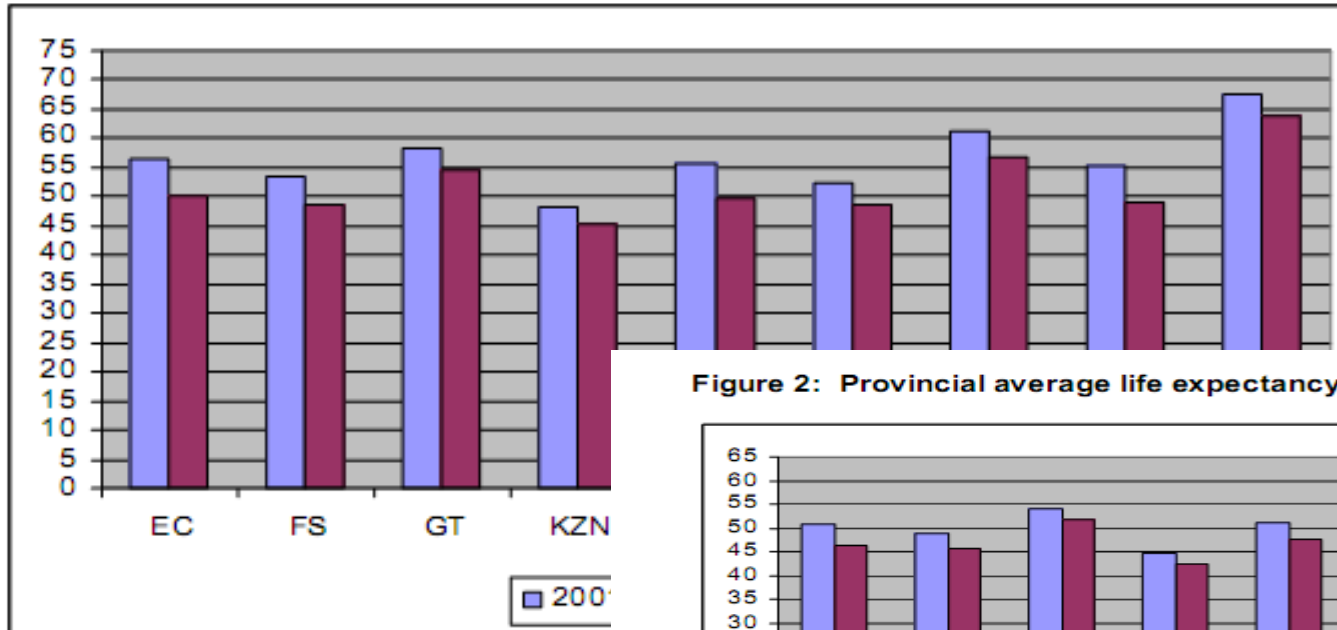
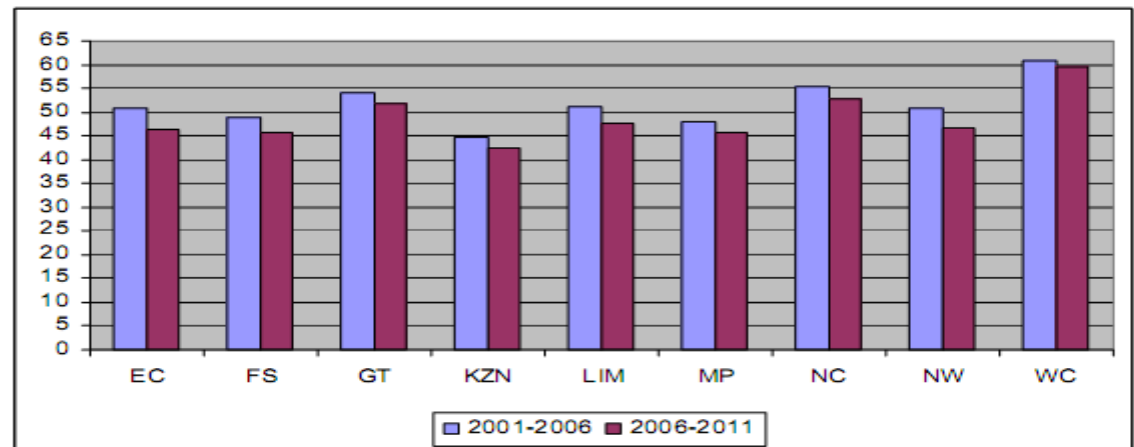


Figure 2: Provincial average life expectancy at birth, 2001–2006 and 2006-11 (males)





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# Political indifference

- **Letter to Deputy Chairperson of SANAC:**
  - **We could write books on our experiences and battles to get people onto TB treatment. There were talks of protocols changing but it remains a fact that people are dying because of this problem. Sadly, many have also lost the battle because the treatment came too late. We have gone through that pain too!**
  - **We appeal to you in your position as Deputy Chair of SANAC, Director of AIDS Law Project and National Secretary of TAC that you may do something or advise us as to the steps we can take. People are suffering, sometimes unnecessarily and our hands are tied. Even though we have ARVs people are still dying, especially because of TB/AIDS! What about the public health implications of people living in their communities and families with TB? What about all the TB contacts? How are we managing the problem of the spread of TB infection and this in the light of increasing drug resistance? We have been accused by 1 professional of exacerbating the problem of XDR TB. However, of all the people we got onto TB treatment most improved and went home. Of those who died, they were already far gone with the disease before treatment and it was too late. I apologise for the length of this letter. We are frustrated and sometimes angry because of this situation and have raised it in many forums with no satisfaction. We are in defence of human life and have no intention of belittling any person or organisation but we feel something has to be done!**

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- **Dear Mark**
- 
- **I was so pleased to see that you had raised the matter of the number of deaths in people living with HIV/AIDS from TB. We are faced with this tragedy every day here in the Free State, and I am at a loss as to know how to get some reaction from the DoH.**
- 
- **I lost a very dear friend of mine in Koffiefontein in September. There is a state of the art clinic building there with doctors sometimes in attendance and even the services of physiotherpaists, speach therapists, psychologists, on certain days a week that travel from Bloemfontein. They asses for ART and dispense ARV's. Maggie had been living with HIV for more than 10 years, and had been on ART very successfully for the last year. She developed a fever and severe night sweats and was convinced that if she could just have a chest X-ray they would find TB and then they could treat it and she would get better. After 10 weeks they still had not x-rayed her chest and although she kept going back and back and back to the clinic, they just said she had "Swart Griep". Eventually 5 days before she died they sent her through to Bfn for an X-ray and she died without ever getting TB treatment. I have subsequently learned that "Swart Griep" is one of the many derogatory terms people use for AIDS - can you believe it?**
- 
- **I tell you the story of Maggie because there are thousands of Maggies in every town in the Southern Free State where we have been holding workshops this year.**
- 
- **....**
- **If I report problems to the DoH, even in a constructive way, the whole thing turns into a witch hunt and achieves nothing positive. This is why I am writing to you.**
- 

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# Rhetoric -- and inaction

- 
- AU Abuja Declaration, 2001;
- TB unanimously declared an emergency by WHO-Afro, 2006;
- TB declared a national crisis by SA Minister of Health
- *Minister of Health, Introduction to the TB NSP*



- **NP Nkonyeni, KZN Health MEC, Budget speech, 29 April 2008**
  - “The lack of consideration in this regard in as far as budget allocations and progress in the upgrading of these facilities; together with other infrastructural projects in the pipeline, ***exacerbates the bed occupancy and the hospital stay of MDR & XDR TB patients in medical wards. This situation poses a threat of direct transmission of MDR and/or XDR TB to other patients who are otherwise admitted for other medical conditions.***
  - ***In other situations, we are facing challenges wherein our TB patients end up lumped together with a result that those with ordinary TB are in the danger of contracting MDR or XDR TB.”***



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- **Health and law**
  - **Duties of the state**

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## **Statement of the Constitutional Court, 2002:**

- “The magnitude of the HIV/AIDS challenge calls for a concerted, co-ordinated and co-operative national effort in which government in each of its three spheres and the panoply of resources and skills of civil society are marshaled, inspired and led.
- This can be achieved only if there is proper communication, especially by government. In order for it to be optimally implemented, a public health programme must be made known effectively to all concerned, down to the district nurse and patients. Indeed, for a public programme such as this to meet the constitutional requirement of reasonableness, its contents must be made known appropriately.”



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# Rights issues and TB - what are they?

## **1. Rights of patients and duties of the State:**

- **To dignity**
- **To autonomy**
- **To reasonable and justifiable limitations**
- **To access to treatment**

## **2. Rights of health care workers and duties of State:**

## **3. Rights of public and duties of State:**

- **To a 'reasonable' TB Plan**



## Justifiable limitations?



– Denial of freedom of movement:

- Nomasonto Shaba, 32, said the situation was “mentally frustrating and suicidal”. “I am on ARVs but these days I do not take them. “I think it is better to



## Denial of social security:



“ABOUT 30 MDR- and XDR-TB patients at the Jose Pearson TB facility in Port Elizabeth held a protest at the hospital gates. This follows a meeting with the South African Social Security Agency during which the patients rejected a government policy that suspends their welfare grants for the period they are in hospital.”



- **Growing evidence of nosocomial infection of health care workers?**
- **Managing HIV and TB in health workers**
- **What the NHA says:**

20. (2) Despite subsection (1) but subject to any applicable law, the head of the health establishment concerned may in accordance with any guidelines determined by the Minister **impose conditions on the service that may be rendered by a health care provider or health worker on the basis of his or her health status.**

(3) Subject to any applicable law, every health establishment must implement measures to minimise-

*(a) injury or damage to the person and property of health care personnel*

*(b) **disease transmission at that establishment;***



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**TUBERCULOSIS STRATEGIC PLAN  
FOR SOUTH AFRICA, 2007-2011**



health

Department:  
Health  
REPUBLIC OF SOUTH AFRICA

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# Tuberculosis Strategic Plan 2007-2011

The programme must be capable of facilitating the realisation of the right	X
The state must create conditions for access for people at all economic levels	X
Those whose needs are most urgent must not be ignored	X
If the measures, though statistically significant, fail to respond to the needs of the most desperate, they may not pass the test	X
The programme must safeguard rights	X
The programme must progressively realise access to treatment	X



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## Conclusions

**Our TB plan will fail,  
unless.....**

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# A human rights approach requires:

- **Identification of emergency measures:**
  - Infection control
  - Case tracing
  - IPT therapy for people, particularly in MDR/XDR high incidence nodes
- **Integration of TB and HIV services as envisaged by the NSP:**
  - Proper co-ordination and oversight through SANAC
- **Massive and co-ordinated information campaign:**
- **Isolation of MDR/XDR patients in humane conditions:**
  - Restoration of grants, introduction of chronic disease grant
  - Access to facilities, means of proper communication etc
- **Needs-based planning and budgeting for TB:**
- **A human resource plan for TB:**
  - Based on identification of needs
- **Political leadership**



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- **Thank you**
- **If you have comments on/disagreements/suggestions please contact me at:**
  - [heywoodm@alp.org.za](mailto:heywoodm@alp.org.za)
  - [www.alp.org.za](http://www.alp.org.za)
  - [www.tac.org.za](http://www.tac.org.za)

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