

HUMAN RIGHTS & GOVERNANCE FOR **TB** PATIENTS IN SUDAN

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National **STOP TB** Board & **TB** Patients Association

SUDAN

37th Union World Congress on Lung Health, Paris November 2, 2006.

METHODOLOGY

- Desk review of documents: MoH, NTP, Sudanese TB Patients Association, Sudan Stop TB Partnership, NAP, HAC, JAM, PRSP, MDG, MICS 2000, CPA and the Interim Constitution.
- Literature reviews: on International Human Rights, TB and Human Rights, the International Standards for TB Care, The Charter, stigma & discrimination, developmental and poverty Reduction, access barriers, HIV co-infection.
- Consultations with key informants.

OVERVIEW OF FINDINGS

Country Context

- Poor country
- Conflict & post-conflict
- Human rights concerns
- Weak health system

TB Control: the Breakthrough

- The NTP and the success story
- Formulation of the **TB** Patients association
- Formulation of the national Stop **TB** Board

Human Rights of Patients and the way forward

- What are basic human rights
- Patients' rights concerns
- TB patients in action
- Summary and recommendation
- The way forward

COUNTRY CONTEXT

- Total population 36 million
- Civil war for >20 years. Peace Agreement 2005
- Highly indebted poor country
- GDP growth rate: 5% (2002), GNI/Capita: \$460(2003)
- % population <\$1 /day – 50-60
- Illiteracy rate >15yrs: Males 27%, Females 47%
- TB annual infection rate: ?1.8%
- HIV/AIDS Prevalence among Adult population: 2.6%
- HIV/AIDS prevalence in adult incident TB cases: 11%.

COUNTRY CONTEXT contd

- Conflict and post-conflict issues:
 - The civil war(s) caused massive population movement.
 - chronic deprivation, violence,
 - contributed to spread of TB and HIV.
 - the conflict in Darfur:
 - Further stress on the already weak health structures.
 - Increase in HIV, consequent impact in TB control.
 - IDPs & Refugees: lack of clear policy health care needs, protection of women, reliance on international aid.

COUNTRY CONTEXT contd

- Human rights concerns
 - Interim constitution with several fundamental rights,
 - Social, cultural & economic marginalization.
 - stigmatization & discrimination,
 - limited access to information: Health issues (HIV/AIDS)
 - limited access to social services.
- Gender inequality
 - obstacle to poverty reduction & protection of human rights.
 - Stigmatization, discrimination, and divorce.
 - women make up significant % of small scale market traders.

Slide 6

Dr.7

list of international treaty ratified

Eisa, 10/22/2006

COUNTRY CONTEXT contd

- Poor Health system. Limited availability, accessibility, acceptability, and quality of health care:
 - Inadequate human, technical and financial resources.
 - insufficient infrastructure, uneven distribution & lack of proximity.
 - Social restriction on women mobility(higher Eastern Sudan).
 - User fees and out of pocket expenses.
 - behavior of health personnel towards TB and HIV patients, medical negligence, lack of acceptable treatment options & follow-up
 - Quality of services: confidentiality, privacy, nondiscrimination

TB Control: the Breakthrough

- TB control success
 - DOTS Pilot project started 1993
 - DOTS all over by end of 2002
 - Case detection rate 39 %
 - Treatment success rate 82%
- Partners in TB control
 - TB Patients association 2000
 - DOTS Committees, TB in Schools, TB clubs
 - National stop TB board 2005.

Sudan **TB** Patients Association

- Established 2000, registered as charity in 2002.
- Composed of TB patients and other members
- Chaired by women
- Active branches in 20 out of 25 states.
- Main source of funding: LHL, Private sector, Poverty reduction, government in Red sea (Eastern Sudan)
- National, regional and international link

Mission-Objectives- Activities

Mission:

- Bring TB patients back into the social life, empower & encourage them to combat social stigma.

Objectives:

- Raise awareness of rights among TB patients.
- Enable TB patients to play leading role in TB control
- Advocate for TB treatment as a human right
- Improve the economic and social status of patients
- Minimize social stigma of TB

Activities

- Establish patients association at state level
- Conduct surveys on the status of TB patients
- Enhance the DOTS strategy
- Train and build capacity of TB patients
- Educate patients and care providers together
- Increase participation in national, regional & international forums
- Engage communities in TB control activities

Sudan **TB** Patients Association

Activities 2002 -2003- 2004	Planed	Achieved
Opening branches in different states	22	20
Training of the central office on health education	20	20
Formation of subcommittees in different social sectors.	100	47
Participate in advocacy days and events.	2	2 WTD& Union Cong
Periodical bulletins on magazines and local media	10	4
To enlighten the community to be aware about the ways that transmits TB.	Group discussions & booklet on true stories	
Food assistance in collaboration with WFP	3 States (East & West)	
Donation of food supply from private sectors	Khartoum, Darfur, South	
Small enterprise cooperative (Sandooq), 15 women co-own 5 food processing machines.	IDPs in Khartoum	

National **STOP TB** Board, Sudan

- Established 2005
- Autonomous network of partners: Ministries, NGOs, UN, CBOs, Universities and research, schools, uniformed, individuals,
- TB patients in executive committee
- Aim: Reduction of social and economic burden of TB
- Strategies: Social mobilization and communication, Resource mobilization, partnerships.
- National, regional and international link

What are basic Human Rights?

- A range of **personal freedoms**, and access to **vital material requirements**
- 1st generation (**political and civil rights**) and 2nd generation (**socio-economic**) human rights.
- Examples of freedoms: from discrimination and mistreatment, to live together with one's family, to participate in community life and decision-making.
- Examples of vital material requirements: food, clean water, shelter, **Health care** and primary education.
- The Patients' Rights (charter2006): Care, Dignity, Information , Choice, Confidence, Justice, Organization, Security.

What are basic Human Rights? cont

- Human Rights Inherent to all people.
- Ensured collectively, by individuals, communities, local and national government bodies , and international entities.
- National laws and international treaties, conventions and declarations.
- Adherence to international human rights principles is uneven around the world.
- Women's and children's rights are poorly accepted in many countries.
- causal link from first generation human rights to improved socio-economic outcomes (Kaufmann 2004)

Human Rights in Sudan

- Ratified and enacted International Human Rights
- Right to health
 - Health laws & protocols: Public health law (1912, modified 1914, 1939, 1975!), quarantine law 1974
 - Local governance law 1951, 1970 & 1993: decentralization of health services
 - Basic standards of care, liability for negligence,
 - Mechanisms: General Health Council, Medical council,
 - No specialized unit for health legislations,
 - no bill of patients' rights.

TB patients Human Rights, Sudan

Five stories of TB patients who sought 'protection' :

1. Misdiagnosis & neglect: a Chest specialist talking to Head of STBPA:
" don't waste your time, it is my last priority is to invest in health education, give me the money & I will know how manage our patients".
2. Marriage: a family was worried **the groom will 'fly away' if he knew that the mother- in -law had TB**. Concerned about the health of crowds.
3. Work: director of governmental unit, informed his subordinates he got TB, all avoided him. He **developed depression and resigned**
4. Study: a female university student was deserted by her colleagues and more: **students' affairs band her from going to class!** the affairs office advised SNTBPA not intervene as **" we know TB from generations"**
5. Housing: in eastern Sudan **the house of people with the "bad disease" is burned for hygienic purposes**. The family moves to new place.

TB patients Human Rights, Sudan

- Recent study on TB and HIV **Patients concerns**
 - Socio-economic status, stigma, education, medical care, **RIGHTS**, psychosocial well being. Other issues raised: finance and policy making.
- Tools and measures suggested by patients
 - Awareness and educational programs
 - Skills training & Income generation
 - **Laws addressing rights issues (PLHA)**
- IGAD Mapping Study: policies do not address the cross border mobile populations, lacked information,. The health services and facilities inadequate and of poor quality.

Summary of Rights concerns

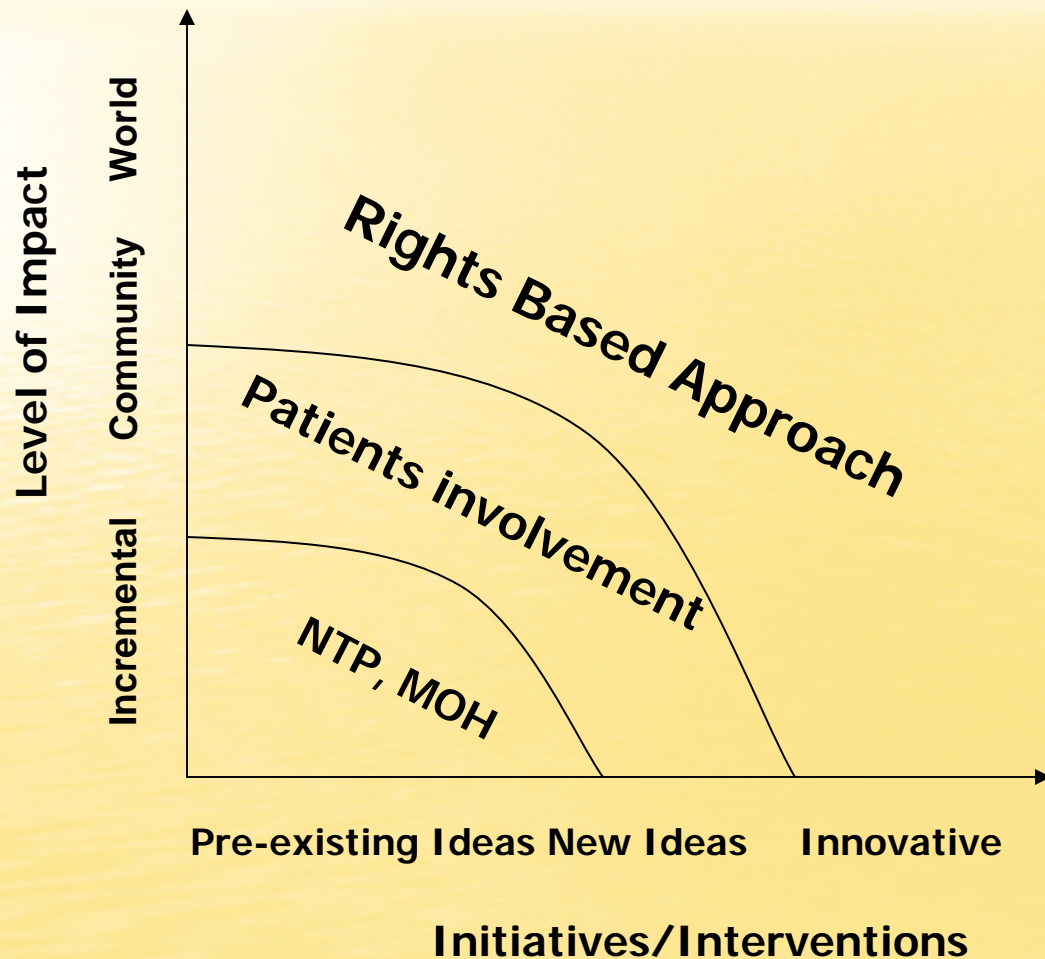
- Inequalities and denial of access to health facilities
– especially in Eastern and Western Sudan.
- limited access to HIV care.
- Lack of accesses to & misrepresentation of information
- Failure to enact laws: such as mandatory testing of IDPs, refugees.
- Outdated health laws.
- Insufficient expenditure or misallocation of resources:

The recommendations

The **TB** Patients Association, the STOP **TB** Board & NTP:

- Principle of non-discrimination.
- Mechanisms to monitor health-related rights.
- Engage CBOs, NGOs and CSOs.
- Engage the patients groups.
- Develop strong leadership at all levels
- ensure protective laws (women & children).
- Provide free legal services.
- link international partners: the charter and the standard of care

Way forward: transformation



OPPORTUNITIES

- Devolution of power & resources
- Poverty Reduction Budget
- Link with Human Rights groups: cooperative women lawyers & Khartoum Human Rights centre.
- International link with activists' groups, focused on Patients' Charter and Standard of Care
- Tap on global resources: Global stop TB Plan, GFATM.