TUBERCULOSIS AND HUMAN RIGHTS
INFORMATION NOTE

Introduction

Tuberculosis is a disease of poverty and inequality that particularly affects key vulnerable populations[1] with little or no access to basic services. Many of the factors that increase people's vulnerability to tuberculosis (TB) or reduce their access to diagnostic, prevention and treatment services are associated with people's ability to realize their human rights.

Access to TB prevention, treatment, support and care services, as well as to basic necessities such as food, housing and social services, are fundamental human rights embedded in the right to health. A human rights-based approach to TB prevention, treatment and care can help overcome the legal, structural and social barriers to quality TB prevention, diagnosis, treatment and care services.

WHO Stop TB Strategy and Human Rights

An important objective of the WHO Stop TB Strategy[2] is to protect and promote human rights in TB prevention and care. Addressing HIV related TB (TB/HIV), multidrug resistant (MDR)-TB and the needs of poor and vulnerable populations[1]; and empowering communities and people with TB have been identified as core components in the *Stop TB Partnerships Global Plan to Stop TB (2011-2015[3])*.
These components emphasize patients‟ rights and responsibilities and the obligations of programs, policy-makers and donors to foster community participation in TB care, prevention and health promotion. The Patients' Charter for TB Care[4] is also referenced in the strategy.

The Global Fund supports the integration of human rights into health programming in order to maximize health outcomes.

Health and human rights

Human rights are a set of entitlements which apply to all human beings. They are interdependent and indivisible as all are necessary to ensure a person's dignity. The *right to health* is dependent on and contributes to the realization of many other human rights. It extends not only to adequate and appropriate care but includes also a wide range of factors, the underlying "*determinants of health"* such as safe drinking water, food, adequate nutrition, housing, non discrimination, healthy occupational and environmental conditions and education.

The right to health and other human rights are legally recognized and guaranteed through numerous national constitutions as well as international and regional treaties that the majority of countries have ratified. Under human rights law, States have the duty to respect, protect and fulfill human rights. These obligations require that States must refrain and prevent others from interfering with the enjoyment of the right and adopt appropriate measures towards the full realization of the rights.

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[1] Key TB vulnerable and at risk groups include: women, children, people working in settings that facilitate TB transmission (e.g. health care workers, miners, and prison officers), prisoners, migrants (including undocumented migrants), refugees and internally displaced people, indigenous peoples, people living with HIV and people who use drugs.
[2] WHO Stop TB Strategy http://www.who.int/tb/strategy/en/
[3] Global Plan to Stop TB, 2011-2015: http://www.stoptb.org/assets/documents/global/plan/TB_GlobalPlanToStopTB2011-2015.pdf
[4] Patients' Charter for TB Care,2010: http://www.worldcarecouncil.org/content/patients-charter-tuberculosis-care

The *right to health* further requires immediate and targeted steps to be taken to progressively ensure that health services, goods and facilities are *available, accessible, acceptable and of quality.* The right to non-discrimination, including on the grounds of social and health status, is an immediately enforceable obligation.

Why are human rights important in the TB response?

The integration of a human rights- based approach into TB programmes, policies and interventions can help achieve universal access to TB prevention, care and treatment through:

<u>Contributing to TB prevention.</u> Economic, social and cultural rights are strongly interlinked. For example vulnerability to TB infection and disease increases with a lack of access to: education; appropriate nutrition; quality housing and sanitation; health services and facilities; employment and social security. Being ill with TB also increases vulnerability to poverty. A human rights-based approach addresses the socio-economic determinants of health that impact TB by ensuring that the rights to food, education, housing and social security of vulnerable and marginalized groups are promoted and protected.

<u>Facilitating access to care.</u> Effective diagnosis is often hindered by costs, lack of social security or health services and other barriers associated with seeking care, such as stigma and discrimination, or lack of information and specific public policies. Accessing care can lead to catastrophic expenditures which may contribute to impoverishment for the individual and his or her entire family. These barriers can be removed if human rights implications of TB policy, legislation and programming are addressed within an integrated and multisectoral response to TB.

<u>Empowering patients and communities.</u> Patients and communities play an integral role in TB treatment literacy, social support, advocacy, communication and social mobilization. TB cannot be adequately addressed without meaningfully involving representatives of the most affected communities in the planning and implementation of polices and programs that impact on them. A human rights based approach to TB places affected persons and communities at the centre, as equal partners, driving health policy, providing them with the tools to participate and claim specific rights

<u>Reaching key vulnerable groups[1].</u> A rights-based approach to TB requires particular attention to ensuring that the specific needs and rights of vulnerable groups are recognized and adequately addressed. Stigma and discrimination against people with TB and those vulnerable to TB can prevent those most in need from accessing TB prevention, treatment and care services.

<u>Improving quality of services.</u> Poor quality of care hampers global TB control efforts. Inadequate training and supervision of health workers, inconsistent drug supplies, inadequate diagnostic tests and limited resources inhibit early detection and proper treatment resulting in increased transmission and poor health outcomes. By tailoring services to meet the needs of patients and communities, a human rights based approach will improve service delivery, ensure that resource use matches community priorities and provide evidence that can be used to mobilize additional resources.

<u>Addressing co-morbidities, including HIV</u>. Early diagnosis among people living with HIV is challenging but vital. Prevention, diagnosis and treatment of TB should be integrated or coordinated to meet the needs of patients with HIV, Hepatitis C, diabetes, those on opiate substitution therapy and other common co-morbidities. Integrating and coordinating services facilitate adherence and ensures patients are not forced to choose between the therapies they need.

<u>Preventing drug resistant TB and promote rights-respecting treatment.</u> Drug-resistant TB, including multi-drug resistant and extensively drug resistant TB, is associated with poor prescribing, irregular drug supply, inadequate access to quality care, mandatory treatment or

confinement and inability to complete treatment. Human rights approaches emphasize appropriate treatments that meet patients' needs to prevent the development of drug resistance, patients' right to be free from discrimination (including in health care settings) and to be free from forced or coerced treatment.

When drug resistant TB does develop, community-based treatment options that respect patients' rights, have excellent treatment completion rates, are cost effective and protect public health should be considered. Community based palliative care for some patients with drug resistant TB is also needed, including access to both effective opiate pain relief and social support. Treatment for drug resistant TB should be non- restrictive and avoid long in-patient hospitalization and detention of TB patients. It should be 'patient-centered', as outlined by the International Standards for Tuberculosis Care[5], the Patient's Charter for Tuberculosis Care[6] and the Guidelines for the Programmatic Management of drug resistant-TB[7], among other guidance documents.

How a human rights-based approach to TB can be integrated into Global Fund proposals

The Global Fund encourages applicants to include rights-promoting activities in proposals in order to improve access to TB prevention, treatment, care and support and increase the effectiveness of TB programmes. Human rights interventions to stop TB must be appropriately targeted to address the needs of key vulnerable and most at risk populations as well as the social and structural barriers to universal access to TB prevention, treatment, care and support.

Key activities to consider include:

Monitoring and analysis of vulnerabilities and rights issues related to TB:

- Development of disaggregated data - for example by sex and/or risk group; and development of indicators and research to identify and analyze TB socio- economic determinants, risk factors and vulnerable groups.
- Support to public monitoring bodies for monitoring human rights issues focusing on key vulnerable groups as noted above
- Patient support (peer) groups and local civil society organizations can also contribute to documentation of rights violations and identifying gaps in the implementation of laws and policies related to TB.

Programmes to ensure continuity of care for key vulnerable groups[1]:

- Economic and social support such as travel vouchers
- Food packages
- Conditional cash transfers
- Microcredit schemes
- Vocational training
- Health education

Policies and programs to integrate and/or coordinate services are key elements for ensuring continued access to quality care[8]. Such approaches need careful design, monitoring and documentation of best practice, and operational research can be encouraged in this and other areas. Applicants are also encouraged to plan for continuity of care beyond the lifetime of the

[5] International Standards for Tuberculosis care, 2006: http://www.who.int/tb/publications/2006/istc_report.pdf
[6] Patients' Charter for TB Care,2010: http://www.worldcarecouncil.org/content/patients-charter-tuberculosis-care
[7] WHO Guidelines for the Programmatic Management of drug resistant-TB, 2006: http://whqlibdoc.who.int/publications/2006/9241546956_eng.pdf
[8] The GFATM Board resolution , November 2008, reiterates that all TB proposal should explain how they will address HIV in TB patients and all HIV proposals should explain how they will address TB in PLHIV.

Global Fund grant.

Increase accessibility, availability, acceptability and quality of TB prevention and care:

- Community-based TB and MDR-TB case-finding and treatment programs that reduce the economic and social costs of seeking and staying in care
- Expansion of peer educators and community health workers role in TB
- Preventive therapy programs for people living with HIV

Programmes to reduce stigma and discrimination:

- Health education and information targeting key vulnerable groups[1]
- Training of health workers on non-discrimination, informed consent, confidentiality and duty to treat
- Human rights and TB treatment literacy such as ‘know your rights’ campaigns
- Law and policy reform
- Community -based treatment
- Patient support initiatives
- Advocacy and social mobilization campaigns
- Capacity building of affected communities to lead and manage interventions
- Use of new technology such as mobile phone messages for patient and adherence support.

Legal services for TB patients and vulnerable groups:

- Advice and support – including strategic litigation where appropriate - on legal issues, such as discrimination and problems in accessing care, privacy, confidentiality and informed consent issues
- Support for TB patients made redundant and/or facing deportation in relation to the completion of TB treatment

Support to empower communities:

- Social mobilization and campaigns to improve awareness of rights relevant to TB and capacity building of affected communities and vulnerable groups to claim their rights
- Meaningful and accountable involvement of patients and their community based organizations in the development of policies and programs that impact on them.

Law and policy review and reform:

- Review and reform of laws and policies that hamper effective TB responses (i.e. access to TB prevention services for key vulnerable groups) or those which encourage rather than discourage involuntary detention for patients. Policies should promote access to community based care models, patient economic and social support for TB and MDR-patients.
- Support to legal service providers (referred to above), Ombudsmen offices, and National Human Rights Institutions to engage in community outreach, campaigns, and advocacy with government for changes in law and policy.

Monitor and evaluate proposed interventions using human rights principles:

- The use of participatory research approaches that involve patients and communities in monitoring and evaluating interventions
- Establish evaluation indicators based on human rights criteria for example measuring levels of service access and involvement for marginalized groups
- Develop redress mechanisms for use when human rights are violated
- Share best practices and ensure lessons learned are transferred across programs

Key References

Human rights documents

- *Briefing Note on Tuberculosis and Human Rights, Stop TB Human Rights Taskforce (2011)* *http://www.stoptb.org/assets/documents/global/hrtf/Briefing%20note%20on%20TB%20and%20Human%20Rights.pdf*
- *Declaration of Human Rights (1948)* http://www.un.org/en/documents/udhr/
- *International Covenant on Economic, Social and Cultural Rights (1966)* http://www2.ohchr.org/english/law/cescr.htm
- *International Covenant of Civil and Political Rights (1966).* *http://www2.ohchr.org/english/law/ccpr.htm*
- *Committee on Economic, Social and Cultural Rights, General Comment No. 14* http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En
- *Committee on Economic, Social and Cultural Rights, General comment No. 20 on non discrimination in economic, social and cultural rights,* http://www2.ohchr.org/english/bodies/cescr/comments.htm
- *Convention on the Rights of the Child (1989)* http://www2.ohchr.org/english/law/crc.htm
- *Convention on the Elimination of All Forms of Discrimination Against Women (1979)* http://www.un.org/womenwatch/daw/cedaw/
- *International Convention on the Elimination of All Forms of Racial Discrimination (1963)* http://www2.ohchr.org/english/law/cerd.htm
- *Convention on the Rights of Migrant Workers (1990)* http://www2.ohchr.org/english/law/cmw.htm
- *Declaration of Alma Ata (1978)* http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf
- *Siracusa principles:* http://www1.umn.edu/humanrts/instree/siracusaprinciples.html
- *Special Rapporteur on the Right to Health (2002):* http://www2.ohchr.org/english/issues/health/right/

TB-related documents

- *WHO Stop TB Strategy:* http://www.who.int/tb/strategy/en/index.html
- *Updated Global Plan to Stop TB, 2011-2015:* http://www.stoptb.org/assets/documents/global/plan/TB_GlobalPlanToStopTB2011-2015.pdf
- *Global Plan to Stop TB, 2006-2015:* http://www.who.int/tb/features_archive/global_plan_to_stop_tb/en/index.html
- UNAIDS Strategy (including TB/HIV): http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2010/JC2034_UNAIDS_Strategy_en.pdf
- *Patients' Charter for TB Care:* http://www.who.int/tb/publications/2006/patients_charter.pdf
- *Social determinants and TB:* http://whqlibdoc.who.int/publications/2010/9789241563970_eng.pdf
- *Poverty and TB:* http://www.who.int/tb/challenges/poverty/en/index.html
- *TB in Prisons:* http://www.who.int/tb/challenges/prisons/en/index.html
- *TB care and control in refugees and displaced populations:* http://www.who.int/tb/challenges/refugees/en/index.html
- *Women and TB:* http://www.who.int/tb/womenandtb.pdf
- *Union statement on TB among undocumented migrants:* http://www.theunion.org/images/stories/download/guide/Undocumented-migrants-Statement_2008.pdf
- *Guidelines for social mobilization. A human rights approach to TB:* http://www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf
- *Community involvement in TB:* http://www.who.int/tb/people_and_communities/involvement/resources/en/index.html
- *Active engagement of civil society organizations*

http://whqlibdoc.who.int/hq/2010/WHO_HTM_TB_2010.15_eng.pdf

- *Policy guidelines for collaborative TB and HIV services for injecting and other drug users* *http://www.who.int/hiv/pub/idu/tb_hiv/en/index.html*
- *WHO guidance on human rights and involuntary detention for xdr-tb control* *http://www.who.int/tb/features_archive/involuntary_treatment/en/index.html*
- *Principles for the Greater Involvement of People with TB (GIPT)* *http://www.worldcarecouncil.org/content/greater-involvement-people-tb-gipt*
- *Guidance on ethics of tuberculosis prevention, care and control* *http://whqlibdoc.who.int/publications/2010/9789241500531_eng.pdf*

Health and Human Rights documents

- *WHO Health and Human Rights/Department of Ethics, Equity, Trade and Human Rights*: www.who.int/hhr/
- *HIV and human Rights:* http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf http://www.unaids.org/en/PolicyAndPractice/HumanRights/20070601_reference_group_
- *TB/HIV and human Rights*: http://data.unaids.org/pub/ExternalDocument/2010/20100324_unaidsrghrtsissuepapertbhrts_en.pdf

TB and Human Rights Task Force

The Stop TB Partnership has established a TB and Human Rights Task Force.

The aim is to protect and promote human rights, in pursuit of universal access to TB prevention, diagnosis and treatment.

The purpose of the Task Force is to develop:

- a joint WHO, UNAIDS and Stop TB Partnership policy framework for a rights-based approach to Stop TB so as to advance health, development and effective TB prevention, diagnosis and treatment
- a strategic agenda for 2010-2012 to be taken up and implemented by a wide range stakeholders within and beyond the TB community.

The Task Force is composed of major stakeholders constituencies from affected communities and risk groups, UN agencies, human rights and civil society organizations, health and human rights experts and development partners.

The WHO Stop TB Department and UNAIDS jointly provide Secretariat support for this Task Force. Open Society Institute and Human Rights Watch are part of the core planning team for the Task Force.

More information is available at: http://www.stoptb.org/global/hrtf