

A human rights approach to tuberculosis



- TB and poverty
- TB and children
- TB and women
- TB, migrants and refugees
- TB and prisons



A human rights approach to TB

Stop TB Guidelines for Social Mobilization

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Tuberculosis (TB) is deeply rooted in populations where human rights and dignity are limited. While anyone can contract TB, the disease thrives on the most vulnerable—the marginalized, discriminated against populations, and people living in poverty.

Executive summary

This guide examines the human rights dimensions of issues affecting people's vulnerability to contracting TB and their access to TB cure. It looks at specific groups and settings where people are particularly vulnerable to TB and its impacts; and where, if they become sick with TB, are limited in their access to treatment—limitations created by stigma, lack of adequate information, and inadequate resource allocations to those most in need.

The principle of nondiscrimination is fundamental to public health and human rights thinking and practice. Gender discrimination, for example, in addition to directly affecting vulnerability to TB and access to TB services, can deny girls and women access to education, information, and various forms of economic, social, and political participation that can increase health risk.

Neglect of the right to information can also have substantial health impacts. Misinformation about what causes TB, how the disease is transmitted and whether it can be cured is linked to the stigmatization of TB and of people with TB. Children in households with TB may also be taken out of school or sent to work. Both situations deprive children of their right to education and put them in situations that may expose them to more prolonged contact with persons with active TB.

Prisons are examined as an environment that increases vulnerability to TB. It is argued that “because tuberculosis is easily diagnosed, treatable, and curable but may lead to death if neglected, contracting tuberculosis and not getting treatment because of poor prison conditions may be considered to be a violation of human rights.”* Both the prison population and the general community have the right to protection from TB generated in prisons and other institutions.

The need to address TB and HIV together in light of the human rights dimensions is urged. Conditions that enhance vulnerability to TB—poverty, homelessness, substance abuse, psychological stress, poor nutritional status, crowded living conditions—also enhance vulnerability to HIV. Both epidemics register their highest rates of infection among populations that are typically disadvantaged or marginalized in their own societies.

The dual epidemic of HIV and TB raises issues of individual choice and confidentiality. Individuals have a right to privacy that protects them against both mandatory testing and disclosure of their health status. Individuals also



* Levy M, Reyes H, Coninx R. Overwhelming consumption in prisons: Human rights and tuberculosis control. *Health and Human Rights*, 1999, (1): 166–191

Women, children, migrants and refugees, people in prison, and people living with HIV are some of the groups whose vulnerability to TB is discussed.

*“A health and human rights approach can strengthen health systems by recognizing inherent differences among groups within populations and providing the most vulnerable with the tools to participate and claim specific rights.”**

have a right to education and information about TB, HIV, and the synergy between the two infections so that they can make informed choices about testing and treatment options.

Human rights is also presented in the document as a tool for data collection and analysis. Human rights principles and norms are relevant when choosing which data are collected to determine the type and extent of health problems affecting a population. Decisions on how data are collected (e.g. disaggregated by age, sex) also have a direct influence on the policies and programmes that are put into place. Collection of data should be disaggregated and analyzed to draw attention to subpopulations, particularly those vulnerable to TB, in order to ensure that discrimination can be detected and action taken. Attention must be paid to involving the most vulnerable and marginalized sectors of society in setting priorities, making decisions, and planning, implementing and evaluating programmes that may affect their development.

A human rights approach to TB is proposed as an avenue for social mobilization to stop TB. Social mobilization is defined as a broadscale movement to engage people’s participation in achieving a specific goal. It involves all relevant segments of society: decision and policy-makers, opinion leaders, nongovernmental organizations such as professional and religious groups, the media, the private sector, communities, and individuals. Social mobilization is a process of dialogue, negotiation, and consensus for mobilizing action that engages a range of players in interrelated and complementary efforts, taking into account the felt needs of people. The interdependence of human rights, for example the right to nondiscrimination and the right to information as integral to achieving the right to health, and the need for all levels of society to be mobilized around the core principles of human rights, calls for a social mobilization approach.

Health systems and health care delivery are increasingly taking human rights norms and standards into account. This is reflected in a new focus on questions such as: is there equality of access? Are privacy and confidentiality maintained? Do the providers practice nondiscrimination? Is there sufficient attention to vulnerable groups? Experience has demonstrated that when health systems take these and other human rights issues into account, patients and public health are both far better served.

This document is not intended to be a comprehensive account of all aspects of human rights that can affect people’s vulnerability to TB and the related risks and impacts. Rather, it examines equity and some key human rights principles such as freedom from discrimination and the right to information and education in order to generate new thinking and action in the global response to stop TB. It is acknowledged that considerably more work needs to be done to further develop the understanding and mobilize action on TB in relation to human rights.

* *HSD Working Paper: Health and Human Rights.* Geneva, World Health Organization, 2000 (unpublished document; available on request from Sustainable Development and Healthy Environments, Department of Health in Sustainable Development (SDE/HSD), World Health Organization, 1211 Geneva 27, Switzerland).

Human rights puts the individual at the centre of any health policy, programme or legislation. Active, free, and meaningful participation of individuals is an integral component of a rights-based approach.

“Tuberculosis is not (only) a health problem. It is a social, economic, and political disease. It manifests itself wherever there is neglect, exploitation, illiteracy and widespread violation of human rights.”¹

Director, South Asia Panos Institute

Introduction

Tuberculosis (TB) is spread by an airborne microorganism, *Mycobacterium tuberculosis*. It can be argued, however, that the real cause of the spread of TB—particularly of TB epidemics in specific populations—is not so much the microbe as it is a complex set of socioeconomic and political factors outside the realm of human biology. These factors affect people’s vulnerability to contracting TB and limit their access to treatment and cure.

TB is deeply rooted in populations where human rights and dignity are limited. While anyone can contract tuberculosis, the disease thrives on the most vulnerable—the marginalized, discriminated against populations, and people living in poverty.

Every year, eight million people become sick and nearly two million people die of TB. TB kills over 250 000 children each year and is the leading infectious cause of death among young women. People living with HIV are especially vulnerable to TB, and the HIV/AIDS pandemic is fueling an explosive growth of new TB cases. TB is the leading killer of people with HIV. The direct and indirect costs of TB can be devastating to individuals as well as to families. The cost to high TB burden countries is overwhelming. Worldwide, every year, TB-related illness and deaths cause the loss of millions of potentially healthy and productive years of life. This is all in the face of an available, cost-effective cure.

Vulnerable and marginalized populations bear an undue proportion of health problems. Overt or implicit discrimination violates one of the fundamental principles of human rights. It often lies at the root of poor health status and results in the lack of targeted policies and programmes and of access to services and other government structures relevant to health.

Many factors can contribute to one’s vulnerability to TB. Being poor, of a minority group, a migrant or refugee, a child, a prisoner, or having a weak immune system due to HIV or substance abuse are all factors that can make someone more likely to become sick with TB.

This document looks at the human rights dimensions of issues affecting people’s vulnerability to contracting TB and their access to TB cure. It examines particular groups and settings where people are particularly vulnerable to TB and its impacts and, if they become sick with TB, are limited in their access to treatment—limits created by stigma, lack of adequate information, and inadequate resource allocations to those most in need.



1. Kunda Dixit, Director, Panos Institute, South Asia. Speech at 1999 *tb.net* Conference on “TB and Human Rights”, Kathmandu

Why does there continue to be so much illness and death due to TB despite the fact that as little as US\$ 11 per person can buy six months of TB drugs needed to cure TB?

Vulnerability can begin to be reduced by modifying laws, policies, regulations, or practices that discriminate against specific populations.

This document is not intended to be a comprehensive account of all aspects of human rights that can affect people's vulnerability to TB and the related risks and impacts. Rather, it examines equity and some key human rights principles, such as freedom from discrimination and the right to information and education, in order to stimulate new thinking and action in the global response to stop TB. It is understood that considerable more work needs to be done to further develop the understanding and mobilize action on TB in relation to human rights.

Why TB and human rights in guidelines for social mobilization?

Human rights "necessitates a cross-sectoral approach... Increasing synergy amongst the various sectors relevant to health and development should be promoted and fragmented interventions avoided."² The interdependence of human rights—i.e. the right to nondiscrimination and the right to information as integral to achieving the right to health—and the need for all levels of society to be mobilized around the core principles of human rights call for a social mobilization approach. Human rights emphasizes empowerment, participation, and nondiscrimination.

Social mobilization is defined as a broadscale movement to engage people's participation in achieving a specific goal. It involves all relevant segments of society: decision and policy-makers, opinion leaders, nongovernmental organizations such as professional and religious groups, the media, the private sector, communities and individuals. It is a process of dialogue, negotiation and consensus for mobilizing action that engages a range of players in interrelated and complementary efforts, taking into account the felt needs of people.

Social mobilization recognizes that sustainable social and behavioural change requires many levels of involvement—from individual to community to policy and legislative action. Isolated efforts cannot have the same impact as collective ones. *Advocacy* to mobilize resources and effect policy change, *media* and *special events* to raise public awareness, *partnership building* and *networking*, and *community participation* are all key strategies of social mobilization.

Social mobilization starts with an honest recognition of the problem to be addressed. The state of the epidemic and an awareness of contributing factors all need to be assessed and acknowledged. The public needs to know their own vulnerability as well as what can be done in order to support, for example, positive acceptance of people with TB and support for appropriate policies and programmes. Once there is an understanding of the issues, potential partners need to know what role they can play. **Promoting specific practical ways to participate, relevant to the strengths and mandates of organizations, communities and individuals, is key to successful mobilization.**

2. *HSD Working Paper: Health and Human Rights*. Geneva, WHO, 2000 (unpublished document; available on request from Sustainable Development and Healthy Environments, Department of Health in Sustainable Development—SDE/HSD—, World Health Organization, 1211 Geneva 27, Switzerland), p. 3, 13
3. *Ibid.*, p. 9

"A health and human rights approach can strengthen health systems by recognizing inherent differences among groups within populations and providing the most vulnerable with the tools to participate and claim specific rights."³

Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR): *The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.*⁴

What are human rights?⁵



Human rights refers to an internationally agreed upon set of principles and norms by governments that are contained in treaties, conventions, declarations, resolutions, guidelines, and recommendations at the international and regional levels. In the 50 years since the adoption of the Charter of the United Nations, specificity has been given to the term “human rights” by the adoption of the Universal Declaration of Human Rights (UDHR) and numerous treaties, conventions, declarations, resolutions, guidelines, and recommendations.

Governmental obligations with regard to human rights fall under the broad principles of *respect, protect, and fulfil*.⁶ In practical terms, international human rights law is about defining what governments *can do to us, cannot do to us and should do for us*. In the context of TB, this is relevant because it can bring new criteria to assessing the effectiveness of existing TB interventions and programmes in reaching the most vulnerable populations. Creating widespread awareness about government obligations can also be a means to mobilize increased resources. It also provides a framework for governments to document their own progress towards realizing their commitments.

Individual rights and public health.

Public health is sometimes used by States as a ground for limiting the exercise of human rights. Limitation and derogation clauses in the international human rights instruments recognize that States at certain times may need to limit rights. Such clauses are primarily intended to protect the rights of individuals when States perceive that such limitations must take place.

These restrictions must be in accordance with the law, in the interest of legitimate aims pursued, and strictly necessary for the promotion of the general welfare in a democratic society. In addition, where several types of limitations are available, the least restrictive alternative must be adopted. Even where, on grounds of protecting public health, such limitations are basically permitted—based on a set of principles called the Siracusa Principles—they should be of limited duration and subject to review.

The rights of individuals and groups to active, free and meaningful participation in setting priorities, making decisions, planning, implementing and evaluating programmes that may affect their development is an integral component of a rights-based approach.

4. The steps to be taken by the States Parties to achieve the full realization of this right include:
 - c. *The prevention, treatment and control of epidemic, endemic, occupational and other diseases.*
5. *HSD Working Paper: Health and Human Rights.* Geneva, WHO, 2000 (unpublished document), op. cit., Annex 2
6. In turn, the obligation to fulfil contains obligations *to facilitate, provide and promote* (footnote 33 of General Comment on the right to the highest attainable standard of health)

Siracusa Principles

- 1. The restriction is provided for and carried out in accordance with the law;**
- 2. The restriction is in the interest of a legitimate objective of general interest;**
- 3. The restriction is strictly necessary in a democratic society to achieve the objective;**
- 4. There are no less intrusive and restrictive means available to reach the same goal; and**
- 5. The restriction is not imposed arbitrarily, i.e. in an unreasonable or otherwise discriminatory manner.**

“Progressive” realization of rights.

In all countries, resource and other constraints can make it impossible to fulfil all rights immediately and completely. The principle of progressive realization provides that States may proceed “progressively” with attention to “the maximum of its available resources.” Lack of resources cannot be used to justify **not** implementing human rights. This applies equally to all countries, rich or poor. The international community has an obligation to support the fulfilment of basic human rights and services in resource poor areas.

Governmental obligations with regard to human rights fall under the broad principles of respect, protect, and fulfil.⁷

Respect human rights, which requires governments to refrain from interfering directly or indirectly with the enjoyment of human rights.

States have the obligation to strive to ensure that no government practice, policy or programme violates human rights, ensuring provision of services to all population groups on the basis of equality and freedom from discrimination, paying particular attention to vulnerable and marginalized groups.

Protect human rights, which requires governments to take measures that prevent third parties from interfering with human rights.

States have the obligation to prevent other actors in the field of health, for example biomedical research institutions, health insurance companies, care providers, health management organizations, and pharmaceutical industry from infringing human rights by supporting measures which progress towards equal access to health care, health technologies, goods and services or quality information provided by third parties.

Fulfil human rights, which requires States to adopt appropriate legislation, administrative, budgetary, judicial, promotional and other measures towards the full realization of human rights.

States have the obligation to take all appropriate measures—including but not limited to legislative, administrative, budgetary, and judicial—towards fulfillment of human rights, including the obligation to provide some sort of redress that people know about and can access if they feel that their health-related rights have been impinged on.

Governmental responsibility for the principle of nondiscrimination includes ensuring equal protection under the law, as well as in relation to such issues as housing, employment, and medical care.

The principle of nondiscrimination is fundamental to public health and human rights thinking and practice.

Freedom from discrimination is a key principle in international human rights law and has been interpreted, in regard to the right to health, as prohibiting “any discrimination in access to health care and underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation, civil, political, social or other status, which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health.”⁸

Like leprosy and HIV, TB is a highly stigmatized disease. Widely held, and usually mistaken, beliefs about what causes TB, how it is transmitted, and whether it can be cured are linked to that stigmatization and to discrimination against people with TB. Patients may go to great lengths to escape stigma and discrimination, lengths that may prolong both their own suffering and the length of time they remain infectious: they may reject a diagnosis of TB and “shop around” for another, more acceptable one; hide their diagnosis from employers, family and/or community; or simply avoid diagnosis entirely.

TB patients may avoid going to nearby health centres associated with TB diagnosis for fear of exposure, instead seeking diagnosis and treatment in a different community. This may afford more privacy, but it also makes travel, and thus completion of treatment, more difficult. In Pakistan, TB patients mentioned that they face difficulties in obtaining sick leave, and even in government service they are at risk of losing their jobs.⁹

Neglect of the right to information can have substantial health impacts.

No health programme can be successful if those who could potentially benefit from it lack the information they need. Misinformation about what causes TB, how it is transmitted, and whether it can be cured is linked to the stigmatization of TB and of people with TB. Various cultures associate TB with socially and morally unacceptable behaviour, witchcraft, and curses. TB is also widely believed to be inherited, and people who have TB are sometimes considered unmarriageable. Such beliefs due to misinformation have led people to be physically isolated, discriminated against, and terminated from work. For women, the results have been particularly severe: divorce, desertion, and separation from their children¹⁰. Children can be deprived of their right to education, ostracized by their peers and sometimes by teachers, due to having a family member sick with TB.

- 8. General comment on the right to health adopted by the Committee on Economic, Social and Cultural Rights on 11 May 2000 paragraph 18
- 9. Hurtig AK, Porter JDH, Ogden JA. Tuberculosis control and directly observed therapy from the public health/human rights perspective. *International Journal of Tuberculosis and Lung Disease*, 1999, 3(7):553–560
- 10. Rangan W, Uplekar M. “Socio-cultural dimensions in tuberculosis control” in Porter JDH and Grange JM, eds. *Tuberculosis: An Interdisciplinary Perspective*. London, Imperial College Press, 1999, p. 265–281

**Everyone “shall have the right to... seek, receive and impart information and ideas of all kinds...”.
Article 19 of the Universal Declaration**

**The provision of and access to health-related information is considered an “underlying determinant of health” and an integral part of the realization of the right to health.
General Comment, No.14**

*Dissemination of information is emphasized
as a strategy to eliminate health-related discrimination.
The right of women, children and adolescents to such
information is particularly stressed.*

Lack of practical information about available treatment for TB is common. In one study in India, more than half of surveyed households knew that government-run primary health centres existed, but only 15 per cent knew that free TB treatment was available there.

Lack of accurate knowledge and understanding about TB itself is also common. Individuals' socioeconomic status has been found to determine their access to information about TB as well as the treatment available. Another study in India found that people who are illiterate have the most misconceptions about TB. Other Indian studies found that many physicians who treat TB themselves lack knowledge.¹¹ In the United States of America, a study of homeless adults found that over 60 per cent had misconceptions about TB transmission;¹² a study of drug users found that less than half knew that HIV-related TB could be treated and 70 per cent thought that a reactive skin test meant they were infected.¹³

Education and information can promote understanding, respect, tolerance, and nondiscrimination in relation to persons with TB. Public programming explicitly designed to reduce the stigma attached to HIV/AIDS by challenging beliefs based on ignorance and prejudice has been shown to help create a more tolerant and understanding supportive environment.¹⁴ Visibility and openness about HIV/AIDS was shown to be key to successfully mobilizing government and community resources to respond to the epidemic. An understanding that TB is curable, not hereditary, and, after a short period of treatment, no longer contagious, can also help alleviate the stigma around TB, increase acceptance of people with TB, and create a supportive environment to encourage diagnosis, continuous treatment, and effective cure.

Studies have shown that public health education contributes to the success of TB programmes, especially when peers and family members are involved. But, while greater knowledge of the symptoms, treatment available, and health impact of TB is crucial, addressing the right to information is only one part of a broader response needed to address the interdependency of human rights to improve health, reduce vulnerability to TB, and increase access to treatment for all.

11. Pathania V, Almeida J, Kochi A. *TB Patients and Private For-Profit Health Care Providers in India*. Geneva, World Health Organization, The Global TB Programme, 1997. (Unpublished document WHO/TB/97.223) (These problems are not at all unique to India, but that country has been the site of most of the few comprehensive studies on TB patients' health seeking behaviour.)
12. Peterson Tulskey J, Castle White M, Young JA, et al. "Street talk: knowledge and attitudes about tuberculosis and tuberculosis control among homeless adults." *International Journal of Tuberculosis and Lung Disease*, 1999, 3(6):528-533
13. Salomon N, Perlman DC, Friedmann P, et al. "Knowledge of tuberculosis among drug users. Relationship to return rates for tuberculosis screening at a syringe exchange." *Journal of Substance Abuse and Treatment*, 1999, 16(3):229-235
14. *HIV/AIDS and Human Rights: International Guidelines*. Second International Consultation on HIV/AIDS and Human Rights. Geneva, 23-25 September 1996. New York and Geneva, United Nations, 1998, HR/PUB/98/1, p. 27

“All UN agencies are parts of a broad alliance for human rights. Based on our mandates we are pursuing different paths towards that goal. But one observation is common to all: poverty is the main obstacle.”¹⁵
Dr Gro Harlem Brundtland, Director-General, World Health Organization

TB & human rights



TB and poverty

The socioeconomic status of individuals can affect their access to information about TB as well as their access to the diagnostic and treatment facilities available. It can also influence their choice of provider and their ability to meet the demands of the TB treatment regimen.

Poverty can increase people’s vulnerability to TB.

Studies have only recently been undertaken to identify the socioeconomic burden of illnesses such as TB, but the linkage between TB and poverty has long been noted. Increased probability of becoming infected with TB and of developing active TB are both associated with malnutrition, crowding, poor air circulation, and poor sanitation—all factors associated with poverty.¹⁶ In developed countries, there was a significant decline in tuberculosis between the mid-19th and mid-20th centuries, before the advent of drug treatment. This was largely brought about by factors that reduced transmission—improved working conditions and less overcrowding for example. Because effective drug treatment for TB was introduced in developed countries at a time when the incidence of tuberculosis was already rapidly declining, this may have led to an over appreciation of the role of chemotherapy in the decline and an underestimation of the impact of changing socioeconomic conditions. As one researcher observed, “without [Robert] Koch’s discovery [of the TB bacillus in 1882], the socioeconomic character of tuberculosis would have been clearer, and a demand for redistribution of the wealth of the community would have become a much more important issue.”¹⁷

A series of studies in India¹⁸ have strongly correlated income with TB. In one district, those who earned less than US\$ 7 per month had twice the prevalence of those earning more than US\$ 20 per month. In urban areas, prevalence among those with no schooling was four times that of tertiary graduates. In the developed world as well, people living in poverty experience conditions that are more conducive to TB, have little access to health care, which delays diagnosis, and if they get treatment it is more likely to be inconsistent or partial.¹⁹

15. Fiftieth Anniversary of the Universal Declaration of Human Rights, Paris, France, 8 December 1998
16. Kamolratanakul P, Sawert H, Kongsin S, et al. “Economic impact of tuberculosis at the household level.” *International Journal of Tuberculosis and Lung Disease*, 1999, 3(7):596–602
17. Waaler, HT. Tuberculosis and socio-economic development. *International Journal of Tuberculosis and Lung Disease*, 1982, 5(7):202–205
18. Pathania V, et al. Op. cit.
19. Grange JM. The Global Burden of Tuberculosis. In Porter JDH and Grange JM, eds, op. cit., p. 13

*“Human rights principles and norms are relevant when choosing which data are collected to determine the type and extent of health problems affecting a population ... decisions on how data are collected (e.g. disaggregated by age, sex) also have a direct influence on the policies and programmes that are put into place.”*²⁰

Not only does poverty predispose one to TB, but also TB can increase poverty.

The socioeconomic burden of TB is particularly acute as it has its greatest impact on adults in their most economically active years. Three quarters of the new cases of TB each year are among men and women between the ages of 15 and 54. The results of the India studies reflect averages throughout the developing world: three to four months of work time, the equivalent to 20–30 per cent of annual household income, are typically lost to TB. The cost is higher if patients have delayed seeking treatment and remain ill longer. Incurred debt, combined with lost income, may trigger sale of assets such as land or livestock, pushing the family deeper into poverty. If budgets become tight enough, both adults and children may begin to feel the effects of malnutrition, which can have a permanent impact on a child’s health. Children may be removed from school because there is no money for uniforms or fees or because they must begin work to help support the family. In the India study, one fifth of schoolchildren discontinued their studies.

International laws make governments and intergovernmental organizations publicly accountable for their actions in planning and implementing public health policies and programmes. It makes them responsible for creating environments that facilitate or prevent the further spread of TB as well as for their actions towards people who have TB.

Everyone has the right to a standard of living adequate for health and well-being, including food, clothing, housing, medical care and necessary social services and the right to security in the event of sickness. (Article 25 Universal Declaration of Human Rights, 1948)

TB and children

There has been a perception, particularly in the industrialized world, that TB is a disease of the old. Fifty years ago, however, hospital services for children in the North dedicated entire wards for infants and children with TB. When TB was common in those countries during the 19th century, young people were heavily affected. In developing countries, and in some of the most vulnerable communities in the developed world, young children have high TB rates. In developing countries where a large proportion of the population is under the age of 15 years, as many as 40 per cent of tuberculosis notifications may be children; tuberculosis may be responsible for 10 per cent or more of childhood hospital admissions, and 10 per cent or more of hospital deaths. Furthermore, with an annual risk of infection of 2–3 per cent, close to 40 per cent of the population may be infected by age 15 years.²¹ Like adults, children

20. Ibid., p. 7

21. Donald PR. Children and tuberculosis: protecting the next generation? (Tuberculosis Progress Report). *The Lancet Interactive*. 20 March 1999

with HIV are more vulnerable to TB. In Lusaka, Zambia, 37 per cent of children admitted to hospital with TB in 1990 were HIV-positive. This had increased to 56 per cent in 1991 and 68.9 per cent by 1992.²²

TB is difficult to diagnose in children because it is hard to confirm the diagnosis by culture even where laboratory facilities are good. The presence of HIV makes the task even more difficult, resulting in some children being misdiagnosed as having TB and given treatment, while others with TB may be falsely negative and not receive treatment.

The current international TB control strategy focuses on active pulmonary TB—the source of most TB infection in children—but does not address children and adolescents as vulnerable sub-groups. Furthermore, vaccination of infants with BCG is no longer believed to prevent active TB in adulthood, although it can protect children from the disseminated forms of the disease, for example, tuberculosis meningitis.²³

Children are exposed to TB primarily through contact with infectious adults—with special risk in high TB-HIV settings—and will continue to be at risk for TB as long as those adults remain untreated. Curing TB and preventing its spread in the wider community is thus one important strategy to reducing children's vulnerability to TB.

Children are also vulnerable to the direct and indirect impacts of other family members having TB. Already marginal households that lose income or incur debt due to TB will experience even greater poverty as budgets are cut and assets sold. If their primary care giver is ill or is preoccupied with caring for other ill family members, the child's care and education may be neglected. If the principal family provider is ill and cannot work, children risk malnutrition, which increases susceptibility to TB and brings with it lifelong deleterious effects on both health and education. Children are especially vulnerable if their mother becomes sick and dies. There is a strong correlation between maternal survival and child survival to age 10. One study in Bangladesh revealed that whereas a father's death increased child mortality rates by 6 per 100 000 for both boys and girls, a mother's death was associated with increases of 50 per 100 000 in sons and 144 per 100 000 in daughters.²⁴

Children in households with TB may also be taken out of school or sent to work. Both scenarios deprive them of their right to education and put them in situations that may expose them to more prolonged contact with persons with active TB. In rural Uganda, for example, 32 patients were interviewed about the economic costs of TB. Five of their children had had to be withdrawn from school because fees could not be paid.²⁵ Even if not removed from school, children from poor or marginalized communities where poor nutrition and ill-health prevail have a below-average school enrolment and attendance rate and,

22. Grange JM. The global burden of tuberculosis. *In* Porter JDH and Grange JM, op. cit., p. 16

23. <http://www.who.int/vaccines-diseases/history/history.htm>

24. Hudelson P. Gender issues in the detection and treatment of tuberculosis. *In* Porter JCH and Grange JM, eds., op. cit., p. 349

25. Croft RA and Croft RP. Expenditure and loss of income incurred by tuberculosis patients before reaching effective treatment in Bangladesh. *International Journal of Tuberculosis and Lung Disease*, 1998, 2(3):252–254

No vaccine yet exists that is truly effective against pulmonary disease. BCG vaccine (Bacillus Camille Guerin) was invented in 1921. It is useful in preventing certain types of TB, namely military and meningeal tuberculosis occurring in the first year of life, but is not effective in preventing the development of pulmonary TB in adulthood.

as a result, lower-than-average educational attainment. Lack of education correlated negatively with access to health services, and the neglect of the right to education on children's current and future health can be profound.

Children are entitled to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. Nearly every country in the world has ratified the Convention on the Rights of the Child which obligates States to take appropriate measures to diminish infant and child mortality; to combat disease and malnutrition; and ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care. (Article 24 Universal Declaration of Human Rights, 1948)

TB and women

In 1998, about three-quarters of a million women died of TB and over three million contracted the disease. Worldwide, TB is the greatest single infectious cause of death in young women. While fewer women than men are diagnosed with TB, a greater percentage of women die of it—and the stigma attached to having TB falls far more heavily on women.

Discrimination on the basis of sex was endorsed in the Universal Declaration of Human Rights in 1948 and permeates all international and regional human rights instruments. In 1979, a specific instrument addressing the broad spectrum of women's issues was adopted. The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) notes, in its preamble, that "in situations of poverty, women have the least access to food, health, education, training and opportunities for employment and other needs." Ratifiers of this convention agree that they will "take all appropriate measures to eliminate discrimination against women in the field of health care" in order to ensure that men and women have equal access to health services.

The stigma associated with TB may be greater for women than men and the consequences can include ostracism, abandonment by the husband and/or his family, divorce or the husband's taking of a second wife, and consequent loss of social and economic support, lodging, access to one's children, etc. Marriage chances may be affected if women are known to have TB, or even if they have a family member with TB, since the stigma associated with the disease may affect all household members. Women with TB have particular difficulty finding a marriage partner, and some families go to great lengths to deny or hide an unmarried daughter's illness. In-depth interviews with TB patients in

Bombay indicated that married women were concerned about rejection by husbands and harassment by in-laws and unmarried women worried about their reduced chances of marriage and being dismissed from work.

The concerns for women generally relate to discrimination and other issues that could, ideally, be redressed. Health volunteers with the Bangladesh Rural Advance Committee (BRAC), a nongovernmental organization involved in community TB care, for example, report that the level of stigma around TB has reduced considerably because TB is now understood to be curable and free, and good quality treatment is available in the villages. Indeed, the growth of community care programmes for people with TB and/or HIV indicates that stigmatization is not universal and can be overcome.²⁶

A vital area where information is lacking concerns the relationship between TB and pregnancy.

The available literature on the subject, much of it dating from the pre-chemotherapy era, is “confusing and controversial.” Yet up to 70 per cent of deaths due to TB occur during the childbearing years. The lack of data on diagnosis of TB in pregnant women, on the effects of TB on the health of the mother, foetus and infant, on the complications of treatment, on barriers to treatment, etc. means that there are no guidelines available for health professionals on the diagnosis and management of TB in pregnancy.²⁷ Commonly held beliefs among women, such as that pregnancy increases intolerance of TB drugs or makes them ineffective, have been linked to women interrupting their TB treatment when they became pregnant.²⁸ Women are entitled to appropriate services in connection with pregnancy, granting free services where necessary, according to the Women’s Convention (CEDAW).

Gender discrimination, even when not directly related to health care—for example denying girls and women access to education, information, and various forms of economic, social and political participation—can create increased health risk. Even if the best public health services are available, a woman has to be able to decide when and how she is going to access them, and that implies that she has to have the ability to control and make decisions about her life.

While in treatment, for example, women may be dependent on men for successful compliance. In Bangladesh, for example, as in some other cultures, women must be accompanied by a male relative when they go to a health facility. The men consult with the provider outside the women’s presence, and women may be dependent on the men for their supply of TB drugs.²⁹ Cultural barriers such as these can deprive women of their rights to information and participation, freedom of movement, privacy and individual autonomy, and impair their right to health.

26. Blinkhoff P, Bukanga E, Syamalewve B, et al. Under the mupundu tree: Volunteers in home care for people living with HIV/AIDS and TB in Zambia’s copperbelt. *Strategies for Hope*, Series No. 14. ACTIONAID, Oxford, 1999

27. Grange J, Ustianowski A, Zumla A. Tuberculosis and pregnancy. In Diwan VK, Thorson A, Winkvist A, eds. *Gender and Tuberculosis: An international Research Workshop*. Goteborg, Sweden, Nordic School of Public Health, 1998

28. Liefoghe R. Gender differences in beliefs and attitudes towards tuberculosis and their impact on tuberculosis control: What do we know? In Diwan VK, Thorson A, Winkvist A, eds. *Gender and Tuberculosis: An international Research Workshop*. Goteborg, Sweden, Nordic School of Public Health, 1998

29. Ibid.

TB, migrants and refugees

Migration is a social phenomenon caused by a constellation of factors, including poverty, conflict and war, policies of structural adjustment and globalization and, in Europe, an increasingly ageing workforce. It predominantly affects developing countries where two-thirds of migration flows occur.

Health risks are increased because of migrants' vulnerability due to lack of full enjoyment of human rights, including access to housing, education and food because, at their destination, however affluent it may be in general, many migrants are likely to move into social and economic conditions characterized by overcrowded, substandard housing, poor sanitation, and lack of access to medical services. Discrimination in the host country as regards access to information, health services, and health insurance creates a precarious environment exacerbated by social dysfunction (lack of social control and disruption of social norms). Even when health services are available and affordable, language difficulties, unfamiliarity with the new country's customs and culture, and fear of immigration authorities can be significant barriers to getting needed care. In addition, migrants can face discrimination linked with racism and xenophobia. To reduce the vulnerability of migrants, and thus the risk and impact of ill-health, their health and human rights protection in national health policies and legislation needs to be enhanced.

Access to TB treatment is particularly difficult for seasonal migrant workers.

The transient nature of their work and the long duration of TB treatment make it difficult for seasonal migrant workers to balance their economic needs with their health needs. Some states in the United States of America have set up effective voluntary screening programmes for farm workers in the fields. Virginia, for example, made a considerable effort to obtain reliable follow-up information (travel itineraries, winter addresses, relatives addresses) for those who started preventive or treatment therapy following screening.³⁰

There is little information on TB in migrants moving from one developing country to another, although considerable attention has been paid to TB in migrants moving from developing to developed countries. TB case-loads in a number of developed countries have increased due to migration. In 2000, almost one quarter of the people with TB in east London arrived in the United Kingdom in the previous year.³¹ Thirty-one to 47 per cent of migrant farm workers tested on the east and west coasts of the United States of America were TB positive, and those groups were six times more likely to develop TB than the general population of employed workers.³²

30. "Epidemiologic Notes and Reports Tuberculosis among Migrant Farm Workers—Virginia." *MMWR*. 35(29):467–469, July 25, 1986

31. Bothamley GH. "Failure to register with a general practice compounds the problem." *Letters BMJ*, 321:569 (2 September 2000)

32. "Tuberculosis among migrant farm workers in northeastern Colorado." Juanita Synder (<http://www.bernardino.colostate.edu/HICAHS/Research/Tuberculosis.htm>)

Refugees and internally displaced persons being resettled share many of these problems, although in camp situations they may have some advantages in the form of health care assistance from the United Nations and international relief organizations. However, because of the refugees' immediate needs for shelter, food and water, the need for TB control is often underestimated—for example, TB caused 25 per cent of all adults deaths in refugee camps in Somalia. Authorities undertaking displacement of persons shall ensure, to the greatest practicable extent, that proper accommodation is provided to the displaced persons and that such displacements are effected in satisfactory conditions of safety, nutrition, health, and hygiene. (Guiding Principles of Displacement)

Since 1950, refugees are protected under a specific treaty, the Convention Relating to the Status of Refugees. In the case of migrant workers, a specific instrument and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families has been developed, which has not yet entered into force. Such instruments are important tools and enhance protection of these vulnerable groups against discriminating treatment or simply inadvertent neglect. The high incidence of TB among immigrants and migrant workers has given rise in many developed countries to calls for stricter, more effective screening of new arrivals and better treatment and follow-up of positive cases. Screening new arrivals may not be strictly necessary, effective or cost efficient. In the United Kingdom, for example, the number of cases of active TB thus detected is low and there is little evidence that port of arrival screening has been effective in detecting TB.³³ Further evidence shows that despite the levels of TB among migrants in developed countries, it does not necessarily affect the risk of TB in the general population, nor warrant mandatory screening. Both Britain and the Netherlands, for instance, reported that in the late 1990s immigration had not substantially affected the annual risk of TB infection. Similarly, in New South Wales, Australia, despite very high rates among the immigrant population, the rate of infectious TB has remained low at 1.4 per 100 000.³⁴

States are under the obligation to respect the right to health by refraining from denying or limiting equal access for all persons, including asylum seekers and undocumented immigrants, to preventive and curative health services.³⁵

TB and prisons

TB is transmitted by the airborne spread of infectious droplets, usually when an infectious person coughs. Crowding and poor ventilation favour its transmission. People in institutions cannot choose to walk away from these conditions in order to protect themselves from TB. Whether the setting is prisons,

33. Surinder Bakhshi. "Screening is of doubtful value." *Letters. BMJ*, 321:569 (September 2, 2000)

34. Heath TC, Roberts C, Winks M, Capon AG. "The epidemiology of tuberculosis in New South Wales 1975–1995: the effects of immigration in a low prevalence population." *International Journal of Tuberculosis and Lung Disease*, 1998, 2(8):647–654

35. See General Comment on the Right to Health

*States are obliged to provide minimum levels of health care, accommodation and diet for every prisoner. These principles are clearly laid out in the United Nations Standard Minimum Rules for the Treatment of Prisoners and in other instruments stating the rules governing the treatment of prisoners.*³⁶

detention centres for asylum seekers, penal colonies, prisoner of war camps, or secure hospitals, institutionalization greatly increases vulnerability to TB.

The institutional system with the greatest impact on TB is the world's prison system.

Though no judge would condemn a wrongdoer to “infection with tuberculosis,” that has become the sentence for many prisoners. It has been argued that “because tuberculosis is easily diagnosed, treatable, and curable but may lead to death if neglected, contracting tuberculosis and not getting treatment because of poor prison conditions may be considered to be a violation of human rights.”³⁷

While these minimum level goals should be pursued by every State, it is clear from the burgeoning of TB, multidrug-resistant TB (MDR-TB), and HIV within the world's prison systems that it will take considerably more political will to ensure care for prisoners' health and, by extension, that of the prisoners' home communities.

On any given day, there are an estimated 8 to 10 million people incarcerated worldwide³⁸ and their numbers are increasing. The prevalence of TB in prisons is higher, sometimes considerably higher, than in the general population. Mortality rates for TB among prisoners are high. For every person in prison on any given day, four to six more will pass through the system that year. Released prisoners, as well as prison staff and visitors can, in a sense, bring the prison home.

In the U.S. State of Texas, for example, an inmate was found to have had undiagnosed TB for several months. Screening revealed that 106 of his fellow inmates and 11 jail employees were infected with *M. tuberculosis*. Alarmed, jail authorities contacted 3 000 released inmates who might have been infected over those several months. Only 50 appeared for screening, of whom 12 had positive skin tests; 2 950 remain somewhere in the community and are likely unaware that they may be infected with TB.³⁹

Prisoners are predominantly male (90–95 per cent worldwide), young (15–44 years old), from socioeconomically disadvantaged populations, and belong to minority groups. Independent of these pre-existing vulnerability factors, prisons conditions themselves foster transmission of TB and increase the likelihood of an inmate developing active TB. Prisons worldwide are characterized by overcrowding and poor ventilation, hygiene and nutrition. All these factors directly contribute to TB transmission and may promote reactivation of latent infection and progression to disease. Prisons are also a locus of HIV infection, a significant risk factor for acquiring and developing TB.

36. These include the United Nations Body of Principles for the Protection of All Prisoners under Any Form of Detention or Imprisonment; United Nations Basic Principles for the Treatment of Prisoners; Council of Europe Recommendation Concerning the Ethical and Organisational Aspects of Health Care in Prison; and the United Nations Rules for Protection of Juveniles Deprived of their Liberty, 1990 [see: www.unhcr.ch/html/intlnst.htm]

37. Levy M, Reyes H, Coninx R. Overwhelming consumption in prisons: Human rights and tuberculosis control. *Health and Human Rights*, 1999, 4(1):166–191

38. Levy M, et al., op. cit., p. 168

39. Wallace CE, Tyree A, Cruise P. Texas targets prisoners' TB. *The TB Treatment Observer*. Published by the Communicable Diseases Cluster, World Health Organization, Geneva. No. 8, 15 May 1999, p. 11

Pre-trial detention centres are often of worse quality than the prisons proper, and may pose special problems for TB transmission. In addition, individuals detained in such centres can be among the most mobile within the prison system, transferring often from holding centre to court room to jail or back into the community.

Control of TB inside prisons is critical for control of TB in the general population, but designing effective policies and programmes requires information. It is important that data on TB in prisons be reported in a transparent way that will allow it to be separated out from data on cases within the general community. Though countries are encouraged to report on TB in prisons, data from ministries in charge of prisons, usually the Ministry of Justice, are rarely incorporated into health statistics. It is feared that this results in “underestimates of the severity of the problem of tuberculosis both in prisons and in the general community.”⁴⁰

Both the prison population and the general community have the right to protection from TB generated in prisons and other institutions. Yet “recognition of tuberculosis as a specific health problem in prisons does not necessarily lead to action.”⁴¹ Prisoners are not cured, remain infectious, and may develop drug resistance. Prisons have become “both amplifiers and propagators of a problem created within the larger community”—MDR-TB.⁴²

Prison health services may be reluctant to begin treatment for a chronic illness for inmates they feel may be released soon, e.g. pre-trial prisoners or those nearing the end of their sentences. Prisons also do not provide a particularly supportive environment for prisoners who do begin treatment to complete it, and many may stop as soon as their symptoms abate. Some prisoners may also avoid diagnosis because they are afraid their release may be held up until they complete treatment. (Paradoxically, some prison inmates may try to get on TB programmes even if they do not have the disease, or may deliberately expose themselves to infection, because of the perceived—and in some cases quite real—benefits of better care in the hospital.)

An effective national TB programme must include prisons and institutions if it is to provide universal access to effective TB diagnosis and treatment. In 1997 in Baku, Azerbaijan, at a meeting on TB control in prisons, participants called on States to exercise the political will to take the necessary steps without which “tuberculosis will increase death among prisoners and their families, and the prison staff and the community.”⁴³

Holding a prisoner beyond his or her release date in order to complete TB treatment, or refusing treatment because the person may not be in prison long enough to complete it, need to be considered in light of the Siracusa Principles. Certainly, in both cases, a “less intrusive and restrictive means to reach the same

40. Levy M, et al., op. cit., p. 172

41. Maher D, Grzemska M, Coninx R, et al. *Guidelines for the Control of Tuberculosis in Prisons* WHO/TB/98.250. Geneva, World Health Organization, 1998, p. 25

42. Levy M, et al., op. cit., p. 177

43. The Baku Declaration. See Maher D, et al., 1998. Op. cit., p. 73

As with data on other subpopulations that are particularly vulnerable to TB, collection and analysis of prison data should be disaggregated so that discrimination can be detected and action taken.

goal” is available—the orderly integration of released prisoners into a TB programme in the public health system. In the absence of such an alternative, “public health and prison health officials face many dilemmas in delivering services that risk challenging, or even impinging on, the rights of prisoners. The poorer the country and the fewer the resources allocated to prison health, the more extreme may be those dilemmas.”⁴⁴ No matter how limited the country’s resources, however, prisoners have the right to health care that meets community standards and is equivalent to what is available to the general population.

TB and substance abuse

Substance abuse is a significant risk factor for acquiring TB infection and progressing to active TB. Abuse of drugs and alcohol are often cofactors alongside poverty, unemployment, homelessness, and a lack of access to social services. Injecting drug use is also a primary risk factor for HIV transmission, and HIV increases the risk of getting sick with TB.

In Odessa, Russia, testing in 1995 revealed that nearly three-quarters of that city’s injecting drug use population was HIV-positive, and in the former Soviet Union, the great majority of injectors are young people who share needles.⁴⁵ Because drug use, in particular, is almost universally criminalized, users frequently end up in prison—with its added risk factors for TB transmission.

In a study in Atlanta, Georgia, of 151 TB patients at a public hospital, 44 per cent reported having been incarcerated within the five years prior to their TB diagnosis. Risk factors for previous incarceration included being male, African American, aged under 45 years and having identified substance abuse problems with alcohol, intravenous drugs or crack cocaine. Substance abuse was identified as a problem by 71 per cent of all the patients in the study.

In addition to the links between drug abuse and other factors that increase vulnerability to TB such as poverty, poor nutrition, homelessness, and infection with HIV, drug use sites such as shooting galleries and crack houses can foster the spread of TB.

Because drug using populations are both marginalized and criminalized, their trust and cooperation may be particularly difficult to gain. Innovative and expanded TB outreach and services, especially those that respect individual rights and dignity, are necessary to reach these populations. Public health authorities working to control the crack house outbreak in California, for example, used a mobile health van to facilitate access to testing and treatment, bringing services directly to the affected neighbourhood.

44. Levy M, op. cit., p. 178

45. Garrett L. *Betrayal of Trust: The Collapse of Global Public Health*. New York: Hyperion, 2000, p. 212

Stigmatized and criminalized, people who abuse substances are pushed to the margins of most societies. This does not, however, obviate their right to equal and non-discriminatory access to TB information and treatment services, as well as to social services that would address the underlying conditions that increase their vulnerability to TB.

Another instance of substance use that contributes to increased vulnerability to TB is tobacco use. Smoking is associated with almost every population worldwide and is rapidly expanding. A recent study in China indicates that of all deaths in that country that can be attributed to tobacco, between 5 per cent and 8 per cent of those deaths were due to TB. Among Chinese men, 11.3 per cent of the deaths from TB can be attributed to smoking; and men in urban China who smoked more than 20 cigarettes a day had double the death rate from TB of non-smokers.⁴⁶ Tobacco consumption is steadily increasing in low-income countries, fueled by population growth, the self-perpetuating nature of smoking prevalence, and the lowering of social taboos against women smoking. It is also fueled by a lack of awareness among the general population of the health risks of smoking and intensive marketing campaigns by the tobacco industry directed at women and young people.⁴⁷ Populations exposed to tobacco industry advertising have a right to information on the health risks of smoking and to public health messages countering denials by the tobacco industry of those health risks. Where vulnerability to TB is already high due to a lack of basic human needs such as adequate nutrition, housing, and clean water, the expense and health risks associated with tobacco consumption can only further lower living standards, degrade health, and increase vulnerability to TB.

TB and HIV: dual epidemic, double discrimination

HIV may be the most potent risk factor for TB yet identified. The two infections have a symbiotic relationship: HIV infection is fueling the TB epidemic and TB is escalating the HIV mortality rates. People infected with HIV have a 50 per cent risk of developing active TB, though the risk for HIV-negative people is only 5–10 per cent. TB is the most common cause of death in persons with HIV infection throughout the world.

Clearly, any effort to control TB must take HIV into account.

Conditions that enhance vulnerability to TB—poverty, homelessness, substance abuse, psychological stress, poor nutritional status, crowded living conditions—also enhance vulnerability to HIV. Both epidemics register their highest rates of infection among populations that are typically disadvantaged or marginalized in their own societies.

HIV has received far more human rights focus than has TB. HIV has been recognized and addressed specifically in numerous rights-related documents throughout the world. The HIV/AIDS pandemic was a catalyst for beginning

46. Bo-Qi Liu, Peto R, Sheng-Ming Chen, et al. "Emerging tobacco hazard in China: 1. Retrospective proportional mortality study of one million deaths." *BMJ*, 1998, 317:1411–1422

47. Dagli E. "Are low income countries targets of the tobacco industry?" *International Journal of Tuberculosis and Lung Disease*, 1998, 3(2):113–118

to define some of the structural connections between health and human rights. The first WHO global response to AIDS in 1987 called for human rights for people living with HIV/AIDS. This was the first time human rights were explicitly named in a public health strategy.

Throughout the course of the HIV/AIDS pandemic it has been shown “that public health efforts to prevent and control the spread of HIV/AIDS are more likely to succeed in public health terms if policies and programmes promote and protect human rights.”⁴⁸

The dual epidemic of HIV and TB raises issues of individual choice and confidentiality.

In many countries, preserving confidentiality about one’s HIV or TB status is difficult. Merely visiting a TB- or HIV-associated clinic can arouse community suspicion and begin a cycle of stigmatization. This can act as a deterrent to diagnosis. Individuals have a right to privacy that protects them against both mandatory testing and disclosure of their health status. They also have a right to education and information about TB, HIV, and the synergy between the two infections so that they can make informed choices about testing and treatment options.

Informed, voluntary testing of TB patients for HIV is being encouraged by a community-based initiative implemented at several district-level sites in Africa called ProTEST. ProTEST attempts to reach some of the 90 per cent of people with HIV who do not know they are HIV-positive, and provide them with access to preventive treatment for TB if they have not yet developed it. ProTEST’s goal is to create an environment in which more people will choose to be tested for HIV. This is being done, in part, by taking a rights-based approach that emphasizes counselling and education. The name reflects the dual aims of promoting voluntary testing and mobilizing communities to protest for better TB and HIV care. It is hoped that when patients understand that if they know they are HIV-positive they will have access to a full range of HIV care and treatment services—including TB screening, prevention, and treatment—this new knowledge will counterbalance the stigma associated with HIV.

48. Gruskin, S. and D. Tarantola, HIV/AIDS, Health and Human Rights, chapter 29. In: *Handbook on HIV/AIDS*. Family Health International (in press)

Conclusion



Recognizing TB as a social, economic, and political disease, and not just a medical problem, prompts the need to explore new avenues through which efforts to ensure TB prevention and access to TB cure can be strengthened.

Human rights span civil, political, economic, social, and cultural dimensions of life. This calls for a cross-sectoral approach in which increased synergy among the various sectors relevant to health and development should be promoted and fragmented interventions avoided.

Human rights puts the individual at the centre of any health policy, programme or legislation.

Active, free, and meaningful participation of individuals is a key component of a rights-based approach. Attention must be paid to involving the most vulnerable and marginalized sectors of society in setting priorities, making decisions, planning, implementing, and evaluating programmes that may affect their development.

Hand-in-hand with participation are a range of key rights integral to applying human rights to public health. The rights to information and freedom from discrimination are such examples. Dissemination of information, paying attention to specific vulnerable population groups, is an important strategy to eliminate health-related discrimination.

Human rights as a tool for analysis.

Public health workers can use human rights instruments to support complex analysis of the multidimensional public health challenges we face in society today. Human rights can help identify key societal determinants of health that affect the vulnerability of specific population groups. Human rights can then be used to reduce vulnerability by modifying laws, policies, regulations, or practices to be consistent with human rights, for example, by ensuring freedom from discrimination in all spheres of society for vulnerable populations.

Human rights are also an important standard of assessment of governmental performance in the area of health. For example, nearly every

Human rights has implications for data collection, recognizing that human rights principles and norms are relevant when choosing which data are collected to determine the type and extent of health problems affecting a population. Decisions on how data are collected (e.g. disaggregated by age, sex) also have a direct influence on the policies and programmes that are put into place. Collection and analysis of data on subpopulations that are particularly vulnerable to TB should be disaggregated so that discrimination can be detected and action taken.

49. Tarantola D. "Building on the synergy between health and human rights: A global perspective." (unpublished paper) 14 August 2000

Health systems and health care delivery are increasingly taking human rights norms and standards into account. This is reflected in a new focus on questions such as: Is there equality of access? Are privacy and confidentiality maintained? Do the providers practice nondiscrimination? Is there sufficient attention to vulnerable groups? Experience has demonstrated that when health systems take these and other human rights issues into account, patients and public health are both far better served.

country in the world, by ratifying the Convention on the Rights of the Child, has pledged to ensure that children are entitled to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. This obligates states to take appropriate measures to diminish infant and child mortality; to combat disease and malnutrition; and ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care. (Article 24) Raising awareness of these obligations can mobilize action and support from various sectors of society and enhance governmental accountability.

Attention to human rights also brings a focus on less "popular" vulnerable groups that tend to be forgotten. Prisoners are such an example, and human rights reminds us that prisoners have rights like everyone else, including rights to health care, adequate accommodation, and nutrition. People who abuse substances belong to another marginalized group that is often stigmatized and criminalized. They have human rights to equal and nondiscriminatory access to TB information and treatment services, as well as to social services which would address the underlying conditions that increase their vulnerability to TB.

Until recently, public health and human rights were considered as almost antagonistic sets of principles and practices.⁴⁹ Public health was understood to promote the collective health of society even if individual freedoms were curtailed, such as through quarantine and excessive institutionalization.

In the 1980s, those with a focus on reproductive health, and later on HIV/AIDS, started to recognize public health and human rights perspectives as mutually reinforcing and synergistic. A new understanding emerged that acknowledged that a lack of respect for human rights can affect people's vulnerability to disease and ill-health.

Today there is an increasing recognition that public health and human rights are complementary and mutually reinforcing approaches to human well-being and development. The potential of human rights to contribute to advancing global health objectives, such as TB treatment and cure has, however, only recently begun to be explored. It is hoped that this document will heighten interest in exploring human rights as a potentially useful avenue for public health workers to tackle the challenges posed by one of the world's biggest killers.

As Archbishop Desmond Tutu highlighted the link between TB and human rights in a keynote address: "The majority of tuberculosis patients throughout the world do not have the basic medical care that they need and deserve. Why? Because it is not free and they have no money to buy it, because it is not available in their community, because there is an unreliable supply of

medication or a lack of health care workers to monitor their treatment, or because such strong social stigma is attached to tuberculosis in their community that they feel they should hide their illness.

Tuberculosis has long been linked with social stigma and discrimination. We can change this by recognizing TB as a curable disease just like any other.

Every person with tuberculosis has the right to be treated for his or her disease. No one can deny that. So let us stop denying them this basic human right.”⁵⁰

50. Inaugural address by His Grace Archbishop Desmond Tutu, 30th World Conference on Lung Health, Madrid, Spain, 15 September 1999

The Committee on Economic, Social and Cultural Rights recently adopted a general comment on the right to health, which is intended to clarify the nature and scope of this complex right. A key guiding principle put forward—which may help ensure that all individuals can access treatment—was “availability,” meaning that functioning public health and health care facilities, goods, services, and programmes have to be available in sufficient quantity within the State party. Essential drugs, as defined by WHO’s Action Programme on Essential Drugs, is explicitly mentioned herein which means that the governmental obligation to fulfil the right to health must include efforts to ensure that essential drugs are made available to all population groups.

Annex

Additional contact information

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The Stop TB Initiative
A partnership hosted by WHO
<http://www.stoptb.org>

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(includes list of international human rights instruments)

Amnesty International (see list of country contacts in website)
<http://www.amnesty.org>

Human Rights Watch
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(includes list of other Human Rights NGOs)

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