

# A HUMAN RIGHTS-BASED APPROACH TO NEGLECTED TROPICAL DISEASES



World Health  
Organization



## Neglected tropical diseases

Approximately one billion people in the world are affected by neglected tropical diseases (see last page for list of diseases). Most of them are poor and marginalized people living in rural parts of low-income countries.

Neglected tropical diseases have received little attention and resources despite their magnitude and impact on both economic development and quality of life. However, in recent years, growing attention has been focused on neglected tropical diseases as both a public health issue and a human rights issue.

Neglected tropical diseases often result in lifelong disabilities and deformities and sometimes even cause death. Neglected tropical diseases fall into two main categories:

1. **Endemic, chronic and disabling diseases** like river blindness for which effective low-cost treatments exist, but are often not accessible to all affected populations.
2. **Deadly diseases** like sleeping sickness for which the only option is systematic case finding and treatment at an early stage. Research and development has been insufficient and for some of these diseases there is no modern effective treatment.

The prevention, control, elimination and eradication of neglected tropical diseases face several challenges:

### International level:

- Limited visibility since the diseases are tied to specific geographical and environmental conditions and do not spread easily to industrialized countries;
- Not on the radar screen of most decision makers, mainstream research and funding agencies;
- Little market incentive to develop medicines and vaccines as mainly poor people are affected.

### National level:

- Often hidden as they affect poor populations with little political voice;
- Rarely given priority in poverty reduction strategies and health sector plans;
- Require inter-sectoral collaboration to address underlying determinants of health;
- Interventions often not part of existing national health systems.

### Community level:

- More likely to occur where people do not have access to health care, clean water, adequate sanitation, housing, education and information;
- Limited access to preventive measures and treatments;
- Lack of information and education;
- Constitute a source of social stigma, discrimination and poverty.

The former United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health ('right to health'), Prof. Paul Hunt, has addressed neglected tropical diseases in several reports. In 2004, the Commission on Human Rights invited the Special Rapporteur to continue his analysis of the national, international, and human rights dimensions of neglected diseases, and diseases particularly affecting developing countries (Resolution 2004/27). In 2005, Prof. Hunt carried out a mission to Uganda in collaboration with the WHO, which addressed neglected tropical diseases from a human rights perspective. He submitted a report with recommendations to the Commission on Human Rights in 2006 (E/CN.4/2006/48/Add.2).

### A human rights-based approach

Human rights are a set of entitlements, which apply to all human beings. A human rights-based approach is guided by human rights standards and principles. It requires that health interventions support the capacity of duty bearers (primarily government authorities) to meet their obligations and of affected communities to claim their rights.

The right to the highest attainable standard of health ('the right to health') is recognized in several human rights treaties and national constitutions. Moreover, the right to health is closely related to and contingent on several other human rights. Development efforts often need to be cross-sectoral and include economic, social and political interventions.

The contents of the right to health have been clarified by the UN Committee on Economic, Social and Cultural Rights in General Comment 14. The right to health extends not only to timely and appropriate *health care*, but also to the *underlying determinants of health* (i.e. access to education, clean water, housing, etc.).

The right to health calls for immediate and targeted steps to be taken to progressively ensure that health services, goods and facilities are *available, accessible, acceptable and of good quality*.

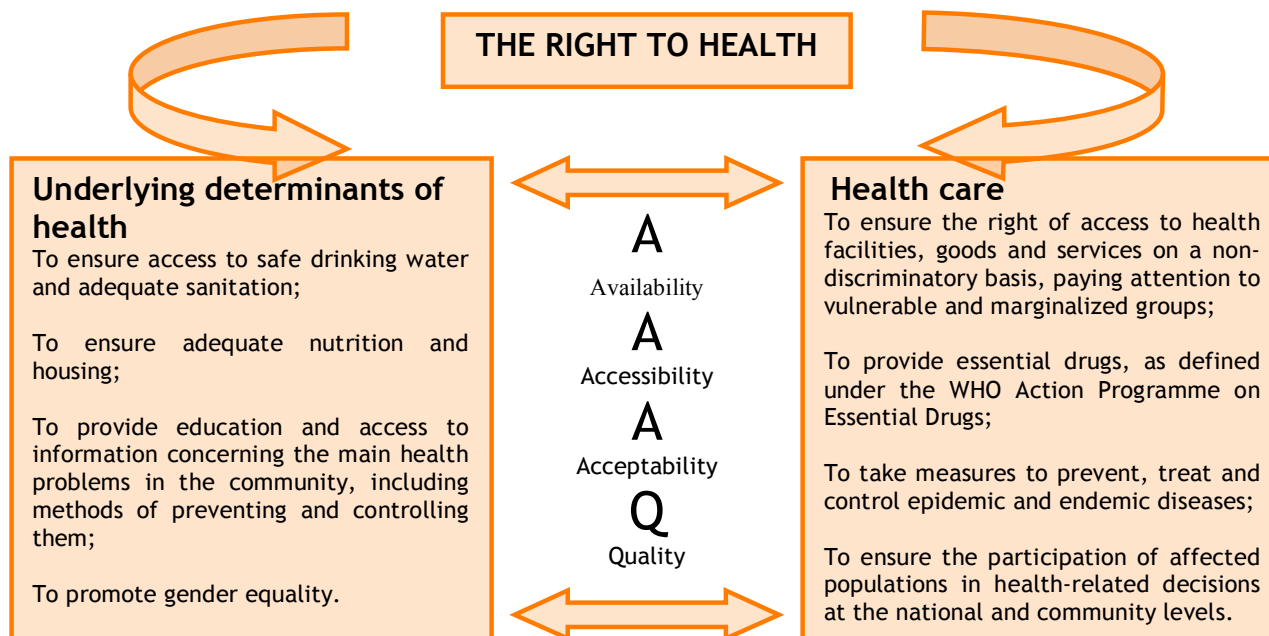
A human rights-based approach requires that the interventions and processes in response to neglected tropical diseases are guided by human rights principles, such as *participation, non-discrimination and accountability*.

In 2008 the **Human Rights Council (HRC)** passed a resolution addressing discrimination in relation to leprosy (Resolution 8/13). The resolution calls upon Governments to eliminate any type of discrimination.

The **World Health Assembly (WHA)** has passed resolutions directly bearing on several neglected tropical diseases. For example, WHA57.9 calls for completion of eradication of guinea-worm disease by 2009 while WHA60 aims to strengthen control of leishmaniasis. The WHA has also adopted a global strategy and plan of action on public health, innovation and intellectual property, which promotes new thinking in innovation and access to medicines (WHA61.21). This will encourage needs-driven research and development to target diseases that disproportionately affect people in the developing countries.

From the perspective of the right to health, interventions should be population-based; respond to specific local needs; and form part of, or at least not undermine, the regular health system.

The figure below illustrates core obligations of Governments as they relate to neglected tropical diseases.



**Availability, Accessibility, Acceptability and Quality**

**Availability:** functioning public health and health care facilities, goods, services and programmes in sufficient quantity

**Accessibility:** non-discrimination, physical accessibility, economic accessibility (affordability), information accessibility

**Acceptability:** respectful of medical ethics and culturally appropriate, sensitive to age and gender

**Quality:** scientifically and medically appropriate

## Participation

People are entitled to participate in decisions that directly affect them, such as the design, implementation and monitoring of health interventions. Participation should be active, free and meaningful, and include affected women, men, boys and girls. Specific attention must be focused on people living in poverty and other vulnerable groups.

Communities affected by neglected tropical diseases are sometimes involved in prevention, treatment and control programmes, such as vector control programmes or administration of treatment. However, a human rights-based approach requires that affected communities participate not only in implementing programmes, but also in priority-setting at local, national, and international levels.

### Participation - an example from Peru

In Peru, seasonal workers from the Cuzco region were increasingly affected by leishmaniasis while working in the mining industry in the forest region of Madre de Dios. In 1975 leishmaniasis was declared an endemic occupational disease in Peru. While treatment and financial compensation were to be provided to the people working in the forest, this did not take place.

Many of those who had contracted leishmaniasis began forming patients' associations. One of their main objectives was to obtain treatment. Over time, the associations also demanded that the government provide better support for those who had contracted leishmaniasis, improved living conditions, and that minimum standards for working conditions be imposed on the mining companies.

The associations received support from a variety of governmental and non-governmental organizations, including the Ministry of Health, and became more structured and organized. The close links with the local population provided knowledge that made it possible to determine and implement better control and intervention strategies.

*Guthman et al (1997), cited in P. Hunt, Neglected diseases: a human rights analysis, Social, Economic and Behavioural Research, Special Topics No 6, WHO/TDR*

## Non-Discrimination

States have an obligation to ensure equality and non-discrimination in laws, policies and the distribution and delivery of resources, health services and underlying determinants of health. This requires identification and targeting of vulnerable groups. Authorities need to take steps to ensure that prevalence data, mass drug administration and facility-based treatments are available for all at-risk populations.

Children and women are disproportionately affected by some neglected tropical diseases and may face additional barriers to seeking and receiving treatment. Women also tend to suffer more severely from social stigma. Dissemination of information is necessary for awareness-raising, and for impeding stigmatization, which is both a cause and consequence of neglected tropical diseases.

### Non-discrimination - an example from Sri Lanka

For a long time, leprosy was considered shameful and people hid their symptoms for fear of ostracism despite free and effective multidrug therapy. In 1990, the Sri Lankan Ministry of Health, assisted by international support, launched a powerful and broad-based advertising campaign to change the public image of leprosy. By portraying leprosy as just another treatable disease, the campaign hoped to encourage people with suspicious lesions to come forward for early diagnosis and cure free of charge. The campaign strongly reduced the stigma attached to leprosy. The image of leprosy has moved from one of fear and loathing to one of hope and cure. As a result, leprosy has been eliminated in Sri Lanka since 1996.

*WHO, Neglected Tropical Diseases, Hidden successes, Emerging Opportunities, 2006*

## Accountability

Rights and obligations demand accountability. Governments and other decision makers need to be transparent about process and actions and justify their choices. Also, redress mechanisms should be in place. Accountability comes in many forms. These are some of the possible mechanisms:

- Judicial mechanisms, e.g. incorporating human rights obligations in domestic law, court cases;
- Quasi-judicial mechanisms, e.g. national, human rights commissions or ombudspersons;
- Administrative and policy mechanisms, e.g. development and review of health policies and plans, human rights impact assessments;
- Political mechanisms, e.g. parliamentary processes, monitoring and advocacy by NGOs;
- Ratification and reporting on human rights treaties incorporating the right to health.

### Accountability - an example from Uganda

In response to a recommendation by the UN Special Rapporteur on the right to health, the Uganda Human Rights Commission (UHRC) created a new unit in 2006 dedicated exclusively to the right to health. The unit initially focused on neglected tropical diseases. A key function is to monitor policies, programmes and projects. Activities include sensitizing health workers and policy makers to a rights-based approach to health planning and service delivery. This will be followed by sensitizing communities to their health related rights. The unit will also investigate any complaints related to the right to health.

## Global plan 2008-2015

The global plan to combat neglected tropical diseases, 2008-2015, is based on the following principles:

- The right to health;
- Existing health systems as a setting for interventions;
- A coordinated response by the health system with other sectors;
- Integration and equity;
- Intensified control as an integral part of pro-poor policies.

## WHO country level support

WHO is supporting country efforts to:

- Include neglected tropical diseases control in basic public health packages;
- Allot earmarked budget for de-worming programmes in schools;
- Adhere to a multi-disease approach;
- Eliminate the stigma and discriminatory attitudes attached to the diseases through national campaigns.

World Health Organization  
Health & Human Rights  
team  
Department of Ethics,  
Equity, Trade and Human  
Rights  
E-mail:  
humanrights@who.int  
Website:  
www.who.int/hhr

World Health Organization  
Department of Control of  
Neglected Tropical  
Diseases  
E-mail: ntddocs@who.int  
Website:  
www.who.int/neglected\_  
diseases

Special Programme for  
Research and Training in  
Tropical Diseases (TDR)  
E-mail: tdr@who.int  
Website: www.who.int/tdr

## Neglected tropical diseases (non-exhaustive list)

**Buruli ulcer** is a severe skin disease caused by a bacterium. When left untreated, the disease leads to extensive destruction of the skin and, in some cases, bone, eyes and other tissues. Buruli ulcer has been reported in over 30 countries; mainly in Africa.

**Chagas disease (American trypanosomiasis)** is a parasitic disease resulting from the bite of a protozoan parasite or transfusion of infected blood. Patients with severe chronic disease become progressively ill and ultimately die. Chagas disease afflicts people in Latin America with 12-14 million infections and 100 million people at risk.

**Dengue** is a mosquito-borne viral infection and an estimated 50 million cases occur worldwide every year. Dengue haemorrhagic fever is a complication characterized by high fever, haemorrhagic phenomena and circulatory failures. It is a leading cause of hospitalization and death among children in Asia.

**Dracunculiasis (guinea-worm disease)** is an excruciatingly painful and disabling parasitic disease. It causes an intensely painful swelling, a blister, and then an ulcer accompanied by fever, nausea, and vomiting. Rural communities in Africa, with access only to unprotected water sources for drinking, are invariably affected.

**Human African trypanosomiasis (sleeping sickness)** is spread by the bite of the tsetse fly. Untreated, the disease invariably progresses to body wasting, somnolence, coma and death. The disease affects some 70 000 people in Africa.

**Leishmaniasis** is a parasitic infection transmitted by the bite of the sandfly. The disease has four forms ranging in severity from self-healing cutaneous ulcers to severe life-threatening infection. An estimated 12 million people are infected and around 1.5 to 2 million new infections occur each year.

**Leprosy** has a notorious history as a cause of deformity, disability, loathing and fear. However, the disease is not highly infectious and is curable. If untreated, it can cause permanent damage to the skin, nerves, limbs and eyes. Today 116 out of 122 endemic countries have eliminated leprosy as a public health problem.

**Lymphatic filariasis** is caused by thread-like parasitic worms and is transmitted by mosquitoes. The worst symptoms generally appear in adults: damage to the lymphatic system, kidneys, arms, legs or genitals. Over 120 million people are currently infected.

**Onchocerciasis (river blindness)** is a parasitic disease caused by the filarial worm that is transmitted to humans through the bites of black flies. It causes visual impairment, including permanent blindness. Other devastating effects are intolerable itching and disfigurement of the skin. Some 37 million are estimated to be infected and over 99% of those affected live in Africa.

**Schistosomiasis (bilharzia)** is a parasitic disease that leads to chronic ill health. An estimated 70 million people with urinary schistosomiasis in Africa alone suffer from blood in the urine, indicating damage of the bladder and urinary tract.

**Soil-transmitted helminthiasis (intestinal worms)** is caused by ingestion of eggs from contaminated soil or by active penetration of the skin by larvae in the soil. Worm infections aggravate malnutrition and amplify rates of anaemia. More than 1 billion people - one sixth of the world's population - are at risk of infection.

**Trachoma** is an eye infection, which spreads from person to person and often begins during infancy or childhood and can become chronic. If left untreated, the infection eventually causes the eyelid to turn inwards. This ultimately leads to irreversible blindness, typically between 30 and 40 years of age. Trachoma affects about 84 million people of whom about 8 million are visually impaired.

**Yaws** is a contagious infection, which is usually transmitted through direct skin contact and mainly affects children under 15 years of age. Without treatment, multiple lesions appear all over the body. Yaws is a significant public health problem in some countries in South-East Asia, Africa and the Western Pacific region.