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Neglected diseases: A human rights analysis

Paul Hunt

United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

with the assistance of:

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Social, Economic and Behavioural (SEB) Research

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ABBREVIATIONS AND ACRONYMS

ACHR	American Convention on Human Rights
ACHPR	African Charter on Human and Peoples' Rights
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CRC	Convention on the Rights of the Child
DNDi	Drugs for Neglected Diseases Initiative
ECHR	European Convention for the Protection of Human Rights and Fundamental Freedoms
HIV/AIDS	Human immunodeficiency virus/acquired immunodeficiency syndrome
ICCPR	International Covenant on Civil and Political Rights
ICERD	International Convention on the Elimination of All Forms of Racial Discrimination
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICRMW	International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families
IGO	Intergovernmental organization
MDGs	Millennium Development Goals
MSF	Médecins sans Frontières
NGO	Nongovernmental organization
OHCHR	United Nations Office of the High Commissioner for Human Rights
R&D	Research and development
TDR	UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases
TRIPS	Trade-related Aspects of Intellectual Property Rights
UDHR	Universal Declaration of Human Rights
UN	United Nations
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
WHO	World Health Organization
WIPO	World Intellectual Property Organization
WTO	World Trade Organization

EXECUTIVE SUMMARY

For the purpose of this report, neglected diseases are those diseases understood to be primarily affecting people living in poverty in developing countries, in particular in rural areas.

There are clear links between neglected diseases and human rights. Neglected diseases are more likely to occur where human rights, such as the rights to health, education and housing are not guaranteed. Neglected diseases also often result in violations of human rights and fundamental freedoms, including equality and non-discrimination.

Addressing the human rights issues that cause or are a consequence of neglected diseases has an important role to play in helping to prevent and treat these diseases, as well as in ensuring the dignity and well-being of those afflicted. However, the human rights implications of neglected diseases, and the contribution that human rights can make to addressing neglected diseases, have not been given the attention they deserve.

This report aims to equip practitioners with an understanding of human rights, how human rights abuses cause and result from neglected diseases, and how a human rights approach can contribute to the fight against neglected diseases.

About the project partners

This report is the result of collaboration between the Special Programme for Research and Training in Tropical Diseases (TDR), the Health and Human Rights Team of the WHO Department of Ethics, Trade, Human Rights and Health Law, the Office of the United Nations High Commissioner for Human Rights and the United Nations Special Rapporteur on the right of everyone to the highest attainable standard of health.

UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR)

TDR was created in 1975 and is an independent global programme of scientific collaboration, co-sponsored by the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the World Bank, and the World Health Organization (WHO) in order to support research on the public health problems related to neglected infectious diseases that disproportionally affect poor and marginalized populations (www.who.int/tdr). The mandate of TDR is twofold:

- To improve existing and develop new approaches for preventing, diagnosing, treating, and controlling neglected infectious diseases which are applicable, acceptable and affordable by developing endemic countries, which can be readily integrated into the health services of these countries, and which focus on the health problems of the poor; and
- To strengthen the capacity of developing endemic countries to undertake the research required for developing and implementing these new and improved disease control approaches.

Health & Human Rights Team, Department of Ethics, Trade, Human Rights and Health Law (ETH/SDE)

The Health & Human Rights Team is located within the Department of Ethics, Trade, Human Rights and Health Law (ETH/SDE). It plays the role of catalyst, coordinator, and facilitator to WHO technical work areas, ensuring consistent and coherent approaches to health and human rights across the organization (www.who.int/hhr).

The objectives are:

- To advance the Right to Health in international law and international development processes through advocacy, input to UN mechanisms and development of indicators;
- To strengthen WHO's capacity to adopt a human rights-based approach in its work through policy development, research and training; and
- To support governments to adopt a human rights-based approach in health development through development of tools, training and projects.

Office of the United Nations High Commissioner for Human Rights (OHCHR)

The Office of the United Nations High Commissioner for Human Rights is the principal organization dealing with the protection and promotion of human rights across the United Nations system. Among its activities related to the right to health, the OHCHR:

- Provides the Secretariat support to the Committee on Economic, Social and Cultural Rights and other Committees that monitor State parties' compliance to treaties relevant to the right to health, including draft general comments on health issues;
- Supports the mandate of the UN Special Rapporteur on the right to the highest attainable standard of health;
- Provides support to other mandates and initiatives of the Human Rights Council related to the right to health; and
- Promotes the right to health as part of its work to promote economic,social and cultural rights through research, development of tools and training materials, technical cooperation programmes, and through its field offices around the world.

Special Rapporteur on the right to the highest attainable standard of health

In 2002, the Commission on Human Rights decided to appoint, for a period of three years, a Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health[1] (Resolution 2002/31). As an independent expert, the Special Rapporteur is requested to: gather, request, receive and exchange information from all relevant sources on the realization of the right to health; develop a regular dialogue and discuss possible areas of cooperation with all relevant actors; report on the status, throughout the world, of the realization of the right to health and on developments relating to this right; and make recommendations on appropriate measures to promote and protect the realization of the right to health. In August 2002, Paul Hunt (New Zealand) was appointed as Special Rapporteur. He has chosen to organize his work around two main, inter-related themes: poverty and the right to health; and stigma and discrimination and the right to health.

The problem of neglected diseases is connected both to poverty and discrimination. The Special Rapporteur has addressed the problem of neglected diseases in several reports to the Commission on Human Rights, on an official country mission to Uganda, on an official mission to the World Trade Organization (WTO), and in expert meetings (United Nations Special Rapporteur, 2003a, 2003b, 2004a, 2004b, 2005a, 2005b, 2006a). In 2004, the Commission on Human Rights invited the Special Rapporteur, within his existing mandate, to continue his analysis of the human rights dimensions of the issues of neglected diseases and diseases particularly affecting developing countries, and also the national and international dimensions of those issues (Resolution 2004/27). In 2005, the Commission on Human Rights extended the Special Rapporteur's mandate for a further three years (Resolution 2005/24).

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[1] The full title of the Special Rapporteur is the "Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health". Throughout this publication, we have also used the terms "right to health" and "right to the highest attainable standard of health", as a short-hand for this title.

1. INTRODUCTION

Neglected diseases are both a cause and consequence of human rights violations. The failure to respect certain human rights, such as the rights to water, adequate housing, education and participation, increases the vulnerability of individuals and communities to neglected diseases. People afflicted by neglected diseases are vulnerable to violations of their human rights, including the rights to health, life, non-discrimination, privacy, work, education, and to enjoy the benefits of scientific progress. These human rights causes and consequences of neglected diseases have important implications for the global fight against neglected diseases.

In recent years, there has been a growing interest in neglected diseases as a public health issue. However, there has been less attention given to the connections between neglected diseases and human rights. This report aims to introduce and explore some of these connections. Having established the linkages, the next challenge will be for all parties collaboratively to identify the practical implications of applying human rights to the design, implementation, monitoring and evaluation of policies, programmes and projects for neglected diseases. While this challenge will have to be the subject of another study, a step in this direction was taken by a recent report on Uganda, neglected diseases and human rights (United Nations Special Rapporteur, 2006a).

The objective of this chapter is to explain what is meant, for the purposes of this report, by the phase 'neglected diseases' and to signal their relationship with neglected populations. The chapter also provides a brief introduction to human rights, as well as some of the broad connections between health and human rights.[2] The subsequent discussion builds on these foundations to explore in detail the relationship between neglected diseases and human rights.

1.1 Neglected diseases and neglected populations

The term 'neglected diseases' refers to diseases that continue to burden the poorest of the poor. A WHO publication defines neglected diseases as those that "affect almost exclusively poor and powerless people living in rural parts of low-income countries." (Kindhauser, 2003). They sometimes attract other labels, such as tropical diseases or poverty-related diseases. For the purposes of this report, the term 'neglected diseases' is preferred.

Neglected diseases include leishmaniasis (kala-azar), onchocerciasis (river blindness), Chagas disease, leprosy, tuberculosis, schistosomiasis (bilharzias), lymphatic filariasis, African trypanosomiasis (sleeping sickness), and dengue.[3] Some neglected diseases are life-threatening, while others result in high morbidity and severe disabilities. The Annex contains a brief summary of the global burden of several neglected diseases. According to WHO, "the health impact of these neglected diseases is measured by severe and permanent disabilities and deformities in almost 1 billion people" (Kindhauser, 2003). Globally, 75% of all disability-adjusted life years due to communicable diseases occur in children aged less than 14 years (WHO, 2004: p. 8). In addition to the physical and psychological suffering they cause, neglected diseases inflict an enormous economic burden on affected communities owing to lost productivity and high costs associated with long-term care, which in turn contributes to the entrenched cycle of poverty and ill-health for neglected populations.

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[2] There is an increasingly rich literature on the relationship between health and human rights. This report provides an introduction to key elements of this relationship.

[3] Diseases such as HIV/AIDS, tuberculosis and malaria continue to pose massive health—and human rights—challenges. While much more needs to be done, in recent years these diseases have attracted increasing international attention and resources. This report, however, focuses primarily (but not exclusively) on neglected diseases that have received less attention and funding. Nonetheless, in some respects, HIV/AIDS, tuberculosis and malaria remain 'neglected diseases'.

Neglected diseases are by no means homogenous. However, many neglected diseases share the following common characteristics:

- They typically affect neglected populations—the poorest in the community, usually the most marginalized and those least able to demand services. These often include women, children ethnic minorities, displaced people, as well as those living in remote areas with restricted access to services. Neglected diseases are often a symptom of poverty and disadvantage;
- The introduction of basic public health measures, such as access to education, clean water and sanitation, would significantly reduce the burden of a number of diseases. Improved housing and nutrition would also help in some cases;
- Where curative interventions exist, they have generally failed to reach populations early enough to prevent impairment;
- Fear and stigma attach to some diseases, and lead to delay in seeking treatment as well as discrimination against those affected;
- Although the eradication and elimination of certain diseases can be achieved at low cost per patient, the total cost at the national level can be significant in view of the number of people affected by the diseases;
- The development of new tools—new diagnostics, drugs and vaccines—has been under-funded or neglected, largely because there has been little or no market incentive (WHO, 2004: p. 22).

Effective prevention or treatment strategies have been developed for some neglected diseases, including leprosy, soil-transmitted helminths, lymphatic filariasis and onchocerciasis. The tendency for the diseases to be localized assists targeted programme delivery. Several interventions bring rapid physical relief that helps stimulate acceptance and further demand. However, many at-risk populations do not have access to health care and other public health measures that are vital for prevention, treatment and control of neglected diseases.

There is also a growing epidemic of deadly diseases for which modern effective treatment does not currently exist, or is not safe, such as buruli ulcer, Chagas disease, leishmaniasis and African trypanosomiasis.

1.2 Human rights norms and standards

Human rights are freedoms and entitlements concerned with the protection of the inherent dignity and equality of every human being. They include civil, political, economic, social and cultural rights. The international community has accepted the position that human rights are universal, indivisible, interdependent and interrelated (Vienna Declaration and Programme of Action, 1993).

Human rights are inspired by moral values, such as dignity, equality and access to justice. However, they are more than moral entitlements: they are legally guaranteed. In other words, human rights are entitlements underpinned by universally recognized moral values and reinforced by national and international legal obligations on duty bearers.

Human rights are enshrined in various international treaties and declarations. International human rights treaties (often called covenants or conventions) are legally binding on states that ratify them ("states parties"). In contrast, human rights declarations are non-binding, although many of them include norms and principles that reflect binding customary international law.

Human rights have traditionally been concerned with the relationship between the state, on one hand, and individuals and groups, on the other hand. States that have ratified international human rights treaties assume obligations, which are binding under international law, to give effect to the enumerated human rights.

Additionally, all states have enacted national laws that protect some human rights. Moreover, some states have enshrined human rights—civil, political, economic, social and cultural—in their constitutions.

1.3 Health and human rights

Health and human rights are connected in a number of ways (Mann et al., 1994):

- Health can be adversely affected by human rights abuses and violations, such as torture, slavery, forced labour, violence, and harmful traditional practices;
- The design and/or implementation of public health policies and programmes can result either in the promotion or violation of human rights;
- Vulnerability to, and the impact of, ill health can be reduced by taking steps to respect, protect and fulfil human rights.

Human rights having a particularly close relationship with health include the rights to health, non-discrimination, privacy, water, education, information, food, and the right to enjoy the benefit of scientific progress and its applications.

In recognition of the links between health and human rights, human rights have been increasingly integrated into health policies and programmes, in particular in the fields of HIV/AIDS (see Box 1), sexual and reproductive health (United Nations Special Rapporteur, 2004b) and mental health (United Nations Special Rapporteur, 2005c). Experiences of integrating human rights in these fields provide useful lessons and examples of good practice that can be instructive when integrating human rights into policies and programmes for neglected diseases.

Some states have used public health as a ground for limiting the exercise of human rights. States are entitled to limit the exercise of certain human rights, or to derogate from some of their human rights obligations in particular circumstances, for example, in time of public emergency and for the protection of national security or public health (International Covenant on Civil and Political Rights (ICCPR); European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR); American Convention on Human Rights (ACHR)). Economic, social and cultural rights can be limited solely for the purpose of promoting the general welfare in a democratic society. Limitations are subject to stringent requirements, such as proportionality (ICESCR: article 4; Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights, 1985; CESCR, General Comment No. 14, 2000).

The primary focus of this report is the relationship between human rights and neglected diseases. While it does not attempt to set out a human rights programme, the report identifies some of the key human rights considerations that need to be taken into account when formulating a human rights approach to neglected diseases. The report also signals how the failure to give effect to human rights makes individuals and communities more vulnerable to neglected diseases; and how the realization of human rights is hampered by the prevalence of these diseases.

Of course, even where human rights have not been explicitly integrated into public health programmes, such programmes have often contributed to the realization of human rights. Without explicitly mentioning human rights, numerous public health programmes have enhanced access to primary health care (or sanitation, clean water, and so on), as well as participation in the design and implementation of health policies, thereby helping to realize the rights to health, water and participation. While the primary focus of this report remains the contribution of human rights to public health programming in the context of neglected diseases, it also provides examples of the crucial contribution that public health programmes can make towards the realization of human rights.

Box 1. Human rights as a driving force in the fight against HIV/AIDS

The Declaration of Commitment on HIV/AIDS, adopted by the United Nations General Assembly in 2001, recognizes: "the full realization of human rights and fundamental freedoms for all is an essential element in a global response to the HIV/AIDS pandemic, including in the areas of prevention, care, support and treatment, and that it reduces vulnerability to HIV/AIDS and prevents stigma and related discrimination against people living with or at risk of HIV/AIDS" (Para. 16).

The promotion and protection of human rights is central to the fight against HIV/AIDS. Individuals denied their human rights and fundamental freedoms, such as the rights to education and freedom of expression, are more vulnerable to infection. People who are known or suspected to be living with HIV/AIDS often suffer discrimination and stigma; this impedes access to healthcare, education and employment, in violation of their human rights. The fight against HIV/AIDS is often most difficult where human rights are not ensured. For example, groups that may suffer discrimination and stigma, such as sex workers or intravenous drug users, are often driven underground which makes it harder to reach them with prevention efforts.

Since responses to the pandemic began in the 1980s, a wide variety of laws, policies and programmes concerning HIV/AIDS have integrated human rights. In 1998, the Office of the High Commissioner for Human Rights (OHCHR) and the Joint United Programme on HIV/AIDS (UNAIDS) published "International Guidelines on HIV/AIDS and Human Rights" to help guide States' responses to HIV/AIDS. The Guidelines outline how states should integrate human rights into their responses to HIV/AIDS, and provide practical examples (United Nations Office of the High Commissioner of Human Rights/Joint United Nations Programme on HIV/AIDS, 1998, 2002).

The following are three varied examples of how human rights have been integrated into responses to the pandemic by a range of different actors.

Cambodian Law on the Prevention and Control of HIV/AIDS

In 2002, the National Assembly of Cambodia enacted the Law on the Prevention and Control of HIV/AIDS. The law integrates human rights, including through its guarantee that persons living with HIV/AIDS are fully entitled to all the human rights enshrined in the Cambodian constitution.

Network of Zambian People Living with AIDS

In 2000, the Network of Zambian People Living with AIDS established a human rights referral centre in order to raise awareness of HIV/AIDS and human rights among people living with HIV/AIDS, and to educate the public about the human rights of people living with HIV/AIDS. The Network centre also refers cases of HIV/AIDS-related human rights abuses to appropriate partners who offer free legal redress and/or social services (François-Xavier Bagnoud Center for Health and Human Rights, International Council of AIDS Service Organizations, 2005).

Canadian HIV/AIDS Legal Network

The Canadian HIV/AIDS Legal Network ran a three-year (2002–2005) programme to promote a rights-based approach to HIV/AIDS in Canada. The project aimed to raise awareness about the links between health and human rights in the context of the HIV/AIDS pandemic; promote the use of the "International Guidelines on HIV/AIDS and Human Rights"; and assess the status of Canada's laws and policies in the light of the Guidelines and Canada's human rights obligations. The project was to culminate in the publication of a report on the results of the assessment of Canada's performance and recommendations about actions to be taken.[4]

[4] See Canadian HIV/AIDS Legal Network, http://www.aidslaw.ca.

1.4 Right to the highest attainable standard of health

The preamble of the WHO Constitution, adopted in 1946, proclaims that the "enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being" (Constitution of the World Health Organization, adopted 22 July 1946 and entered into force 7 April 1948). Since then, the right to health has been recognized in a wide range of international and regional human rights instruments (Universal Declaration of Human Rights, 10 December 1948: article 25(1); ICESCR: article 12 (see Box 2); International Convention on the Elimination of All Forms of Racial Discrimination (ICERD), of 21 December 1965, entered into force 4 January 1969: article 5(e)(iv); Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), of 18 December 1979, entered into force 3 September 1981: articles 11(l)(f), 12 and 14(2)(b); Convention on the Rights of the Child (CRC), of 20 November 1989, entered into force 2 September 1990: article 24; International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families (ICPMW), adopted and opened for signature and ratification by the UN General Assembly Resolution 45/158 of 18 December 1990, entered into force 1st July 2003: articles 28, 43(e) and 45; European Social Charter, adopted by the Council of Europe on 18 October 1961 and entered into force 26 February 1965, and European Social Charter (Revised), adopted by the Council of Europe on 3 May 1996 and entered into force 1 July 1999: articles 11 and 13; African Charter on Human and Peoples' Rights, adopted 27 June 1981 and entered into force 21 October 1986, article 16; Additional Protocol to American Convention on Human Rights in the Area of Economic, Social and Cultural Rights "Protocol of San Salvador", adopted 17 November 1988 and entered into force 16 November 1999: article 10), as well as in the outcome documents of international conferences organized under the auspices of the UN, and in domestic law (United Nations Special Rapporteur, 2003a). The central recognitions of the right to health in international human rights law are found in the following international human rights treaties:

- ICESCR (article 12) (see Box 2);
- ICERD (article 5.e.iv);
- CEDAW (article 12);
- CRC (article 24).

At the domestic level, over sixty national constitutions enshrine the right to health or the right to health care (United Nations Special Rapporteur, 2003a: para. 20; also see Kinney & Clark, 2004).

In recent years, there has been increasing attention to the right to health, including by the independent committees which monitor international human rights treaties ("treaty bodies"). In 2000, General Comment No. 14 on the right to health was adopted by Committee on Economic, Social and Cultural Rights (CESCR). This General Comment, together with other important documents relating to health adopted by the Committee on the Elimination of Discrimination Against Women, and the Committee on the Rights of the Child, have helped clarify the nature and scope of the right to health (CEDAW, General Recommendation No. 24, 1999; CRC, General Comment No. 2003; CRC, General Comment No. 4, 2003).[5]

There is also an increasingly rich literature on the right to the highest attainable standard of health (Toebes, 1999; Asher, 2004; Gruskin et al., 2005). In his work, the UN Special Rapporteur on the right to the highest attainable standard of health has drawn upon these important documents and this growing literature, as well as other sources, to clarify the contours and content of the right to health.[6] Thus, today it is possible to confirm the following key features of the right to health:

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[5] These interpretative texts are not legally binding upon States. However, they are widely regarded to be authoritative and to have significant legal weight. In practice, General Comments have been used to positive effect by applicants submitting cases on economic, social and cultural rights issues to some regional human rights commissions and domestic courts, while courts and commissions have drawn inspiration from the analysis contained in General Comments.

[6] As of 1 February 2006, the Special Rapporteur has written fourteen reports on the right to health. The reports can be found at http://www2.essex.ac.uk/human_rights_centre/rth/rapporteur.shtm.

Box 2. International, regional and domestic protections of the right to health

International Covenant on Economic, Social and Cultural Rights, article 12:

"1. 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.

2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

(a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;

(b) The improvement of all aspects of environmental and industrial hygiene;

(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;

(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness."

African Charter on Human and Peoples' Rights, article 16

"1. Every individual shall have the right to enjoy the best attainable state of physical and mental health. 2. States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick."

Constitution of Brazil (1988), article 196

"Health is the right of all persons and the duty of the State and is guaranteed by means of social and economic policies aimed at reducing the risk of illness and other hazards and at universal and equal access to all actions and services for promotion, protection and recovery of health."

- The right to health is "a right to the enjoyment of a variety of facilities, goods and services and conditions necessary for the realization of the highest attainable standard of health" (CESCR, General Comment No. 14, 2000: para. 9);
- The right to health contains both general freedoms and entitlements, including: freedom to control one's health and body; freedom from non-consensual medical treatment and experimentation; and an entitlement to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health (CESCR, General Comment No. 14, 2000: para. 8);
- The right to health is an inclusive right, extending not only to timely and appropriate health care, but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health (CESCR, General Comment No. 14, 2000: para. 11);
- The right to health can be broken down into more specific entitlements, such as the rights to: health facilities, goods and services; prevention, treatment and control of diseases; maternal, child and reproductive health; and healthy natural and workplace environments (CESCR, General Comment No. 14, 2000: paras 13–17);
- Non-discrimination and equal treatment are among the most critical components of the right to heath. International human rights law proscribes any discrimination in access to health care and the underlying determinants of health on the internationally prohibited grounds, such as sex, ethnicity and health status (see chapters 2.2 and 3; also CESCR, General Comment No. 14, 2000: paras 18–19);

- The right to health includes the active and informed participation of individuals and communities in decision-making that bears upon their health. In other words, the right not only attaches importance to health outcomes, but also to the processes by which they are achieved (see chapter 2.3);
- The right to health extends to international assistance and cooperation. While the parameters of international assistance and cooperation are not yet clearly drawn, developed states have some responsibilities towards the realization of the right to health in developing countries (see chapter 1.5);
- Accountability is a vital element of the right to health. Like all human rights, the right to health grants entitlements to some (i.e. individuals and communities) and places legal obligations on others (i.e. primarily states). By emphasizing obligations, it requires that all duty-holders be held to account for their conduct (see chapter 2.4).

By way of summary, the right to health demands *an effective and integrated health system, encompassing health care and the underlying determinants of health, which is responsive to local health priorities and accessible to all.*

1.5 Human rights obligations on states

Under international human rights law, states have the primary responsibility for ensuring the realization of human rights. Through ratifying international human rights treaties, states accept obligations, which are binding under international law, to give effect to the enumerated rights. Domestic law also often contains obligations to give effect to human rights. States therefore have national and international legal obligations to take action to remedy human rights abuses that cause or result from neglected diseases.

International human rights treaties impose various types of obligations on states parties. The nature of these obligations is set out in the provisions of each treaty (see Box 3), and has been clarified by the jurisprudence of international treaty monitoring bodies, and regional and national case law.

Box 3. Nature of obligations on states parties under the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights

International Covenant on Civil and Political Rights, article 2(1):

"Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status."

International Covenant on Economic, Social and Cultural Rights, article 2(1):

"Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and cooperation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures."

1.5.1 Obligations to respect, protect, fulfil

Under international human rights law, states are considered to have three layers of obligations towards human rights: obligations of *respect*, *protect* and *fulfilment* (CESCR, General Comment No. 14, 2000: para. 33).

- The obligation to *respect* places a duty on states to refrain from interfering directly or indirectly with the enjoyment of human rights;
- The obligation to *protect* means that states must prevent third parties from interfering with the enjoyment of human rights and provide adequate redress;
- The obligation to *fulfil* requires states to adopt necessary measures, including legislative, administrative and budgetary measures, to ensure the full realization of human rights.

1.5.2 Immediate and progressive obligations

ICCPR, the main international human rights treaty guaranteeing civil and political rights, places immediate obligations on states to realize these human rights. In contrast, ICESCR provides that states parties undertake to take steps, to the maximum of their available resources, with a view to achieving *progressively* the full realization of the rights recognized in the Covenant, such as the rights to work, shelter, food, health and education (ICESCR, 1966: article 2(1)). The principle of progressive realization acknowledges that the realization of all economic, social and cultural rights is impossible to achieve instantaneously, and allows for realization over a period of time. However, these rights still give rise to some obligations of immediate effect. Immediate obligations include:

- Taking deliberate, concrete and targeted steps towards the realization of economic, social and cultural rights (CESCR, General Comment No. 3: para. 2). These steps may consist of legislative, administrative, financial, educational and social measures or the provision of remedies through the judicial system;
- Guaranteeing without delay non-discrimination and equal treatment (CESCR, General Comment No. 3: para. 1);
- Ensuring that the minimum essential levels of each right is realized forthwith. This immediate obligation is known as a core obligation (see Box 4) (CESCR, General Comment No. 3: para. 10).[7]

Even in time of severe resource constraints, vulnerable persons must be protected by the adoption of relatively low-cost programmes (CESCR, General Comment No. 3: para. 12).

Box 4. Core obligations relating to neglected diseases

General Comment 14 provides a list of core obligations arising from the right to health (CESCR, General Comment No. 14, paras. 43–44). A number of these immediate obligations are of special importance for the fight against neglected diseases, such as the obligations:

- To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable and marginalized groups;
- To ensure access to basic shelter, housing and sanitation, and an adequate supply of safe and potable water;
- To provide essential drugs, as from the time to time defined under the WHO Action Programme on Essential Drugs;
- To provide immunization against the major infectious diseases occurring in the community;
- To take measures to prevent, treat and control epidemic and endemic diseases; and
- To provide education and access to information concerning the main health problems in the community, including methods of preventing and controlling them.

[7] These 'core obligations' are not yet well-defined. For an interesting book on core obligations, see Chapman & Russell, 2002.

1.5.3 International assistance and co-operation

The Charter of the UN, UDHR, ICESCR and CRC all recognize that states have a responsibility to engage in international cooperation towards economic, social and cultural rights (Charter of the UN, 1945: articles 55 and 56; UDHR: articles 22 and 28; ICESCR: articles 2(1), 11(1), 15(4), 22 and 23; CRC: article 4, 17(b), 24(4), 28(3)). For example, ICESCR (article 2(1)) requires states parties to take steps, individually and through international assistance and cooperation, especially economic and technical, to ensure the enjoyment of the rights contained therein. CESCR has interpreted this to mean that:

- States parties that are in position to assist others have particular duties to do so (CESCR, General Comment No. 3: para. 14);
- States parties have the duty to respect, protect and facilitate the enjoyment of economic, social and cultural rights in other countries (CESCR, General Comment No. 12: para. 36; General Comment No. 14: para. 39; General Comment No. 15: paras. 31, 33, 34);
- Economic, social and cultural rights should be given due attention in international agreements (CESR, General Comment No. 12: para. 36; General Comment No. 13: para. 56; General Comment No. 14: para. 39; General Comment No. 15: para. 35);
- States parties are required to take into account economic, social and cultural rights in their actions as members of international organizations (CESCR, General Comment No. 13: para. 56; General Comment No. 14: para. 39; General Comment No. 15: para. 36);
- States parties have a joint and individual responsibility to provide disaster relief and humanitarian assistance in times of emergency, including assistance to refugees and internally displaced persons (CESCR, General Comment No. 12: para. 38; General Comment No. 14: para. 40; General Comment No. 15: para. 34);
- States parties should refrain at all times from imposing embargoes or similar measures where these may have a negative impact on the right to health (CESCR, General Comment No. 12: para. 37; General Comment No. 14: para. 41; General Comment No. 15: para.32);
- It is particularly incumbent on states that are in a position to assist to provide international assistance and cooperation, particularly economic and technical, which enables developing countries to fulfil their core obligations (CESCR, General Comment No. 14: para. 45).

In his work, the UN Special Rapporteur continues to explore the scope of the human rights responsibility of international assistance and cooperation in health (e.g. United Nations Special Rapporteur, 2005e).

1.5.4 Human rights violations

A state may violate human rights by its actions or omissions. However, the non-realization of human rights does not necessarily mean that a state is in breach of its international human rights obligations. Owing to the principle of progressive realization, states cannot always be considered responsible for non-fulfilment of human rights if they have taken all reasonable measures towards the realization of these rights as expeditiously as possible within the resources available to them. It is important to distinguish between inability and unwillingness to guarantee human rights. A state that is unwilling to use the maximum of its available resources or take steps towards the realization of economic, social and cultural rights, may be in violation of its human rights obligations (CESCR, General Comment No.14: para. 47).

1.6 Human rights and private sector responsibility

International human rights law recognizes the impact of private sector activities on human rights. Private sector responsibility is engaged in two ways.

1.6.1 Legal obligations of states to protect against harm by the private sector

Under international human rights law, states bear the primary responsibility to guarantee human rights. This responsibility includes an obligation to protect the human rights of individuals and groups against harm by third parties (see Box 5) (Maastricht Guidelines: para. 18; for examples of the human rights obligation to protect in regional case law, see Clapham & Garcia Rubio, 2002). In other words, States should take actions to ensure that activities of private actors do not obstruct the realization of human rights.

In the context of the health sector, states should, for example, adopt legislation or other measures ensuring equal access to health care provided by third parties (CESCR, General Comment No. 14: para. 35). In the field of essential medicines, states have a responsibility to ensure that patent protections of pharmaceutical products do not make these medicines inaccessible, on account of high prices charged by pharmaceutical companies (see chapter 5).

Box 5. The duty of states to protect against harm by third parties

Case: Social and Economic Rights Action Committee and the Center for Economic and Social Rights v. Nigeria, Decision of the African Commission on Human and Peoples' Rights (2001)

Facts: The State-owned Nigerian National Petroleum Company and the Shell Petroleum Development Corporation were part of a consortium of oil companies exploiting oil reserves in Ogoniland, Nigeria. Toxic waste was deposited into the local environment and waterways causing environmental degradation and serious health consequences for the Ogoni people. The Nigerian Government had allegedly failed to require the consortium to conduct impact assessments, consult with local populations and comply with standard safety procedures. The Government had failed to monitor the consortium's operations and placed legal and military powers at the disposal of the oil companies.

Decision: The African Commission held the former military Government of Nigeria responsible for violations of a wide range of human rights, including the right to health. It appealed to the Government to ensure protection of the environment, health and livelihood of the people of Ogoniland and requested it to ensure a range of safeguards.

1.6.2 Human rights responsibilities of private sector actors

Human rights law does not traditionally impose direct binding obligations on private sector actors, such as private pharmaceutical companies.

However, in recent years, there has been growing acceptance that private companies, including pharmaceutical companies, do have some human rights responsibilities. For example, the UN Sub-Commission on the Promotion and Protection of Human Rights has adopted norms on transnational corporations and other business enterprises with regard to human rights (Norms on the responsibilities of transnational corporations and other business enterprises with regard to human rights: para. 1).[8] This non-binding document states that while states have primary obligations towards human rights, "within their respective spheres of activity and influence, transnational corporations and other business enterprises have the obligation to promote, secure the fulfilment of, respect, ensure respect of and protect human rights recognized in international as well as national law" (also see CESCR, General Comment No. 14: para. 42; and Dukes, 2002).

[8] In 2004, the Commission on Human Rights adopted decision 2004/116 in which it emphasized that the norms are not legally binding. In 2005, the Commission on Human Rights adopted resolution 2005/69 in which it decided to appoint a Special Representative to the Secretary General on human rights and transnational and other business enterprises.

In some situations, civil society has sought legal redress for policies of pharmaceutical companies, such as the imposition of high prices for essential medicines. Human rights have sometimes been a factor in the judgements of these cases (see Box 6; also see chapter 5).

For their part, some companies have also signed up to international codes of conduct, or adopted company-specific codes of conduct enshrining human rights norms (see Box 7).

Box 6. Selected cases challenging patent protection

AIDS Access Foundation, Mrs Wanida C and Mr Hurn R v. Bristol-Meyers Squibb Company and the Department of Intellectual Property, The Thai Central Intellectual Property and International Trade Court (2002)

Facts: Two patients living with HIV and a Thai foundation brought a petition against Bristol-Myers Squibb and the Thai Department of Intellectual Property alleging that they had conspired to "intentionally delete the dose restriction" to the Didanosine (antiretroviral drug) patent, with a view to extending the patent. The effect of this was that generic production of the drug was blocked. However, Didanosine cost US$ 136 per month (the average wage of an office worker in Thailand is US$ 120 per month), making it inaccessible to many.

Decision: The Thai Central Intellectual Property and International Trade Court ruled that the removal of the restriction was unlawful, insofar as it was intended to extend the patent protection. The Court held that those in need of the medicine protected by patent are interested parties to the granting of the patent and can challenge them as injured parties. The Court further stated that "medicine is one of the fundamental factors necessary for human beings, as distinct from other products or other inventions that consumers may or may not choose for consumption" and that "lack of access to medicines due to high price prejudices the human rights of patients to proper medical treatment". (Aids Access Foundation, Mrs Wanida C and Mr Hurn R v. Bristol-Meyers Squibb Company and the Department of Intellectual Property, 2002; Ford et al., 2004).

Case against GlaxoSmithKline and Boehringer Ingelheim before the South African Competition Commission (South African Competition Commission, 2003a, 2003b).[9]

Facts: In 2002, eleven plaintiffs lodged a complaint before the South African Competition Commission against GlaxoSmithKline and Boehringer Ingelheim for charging excessive prices on their following patented antiretroviral drugs: zidovudine (AZT), lamivudine, AZT and lamivudine in combination, and nevirapine. The plaintiffs were people living with HIV/AIDS, health-care workers and civil society organizations. The Commission is an independent body, which is mandated to ensure that companies compete fairly in the market and that where companies dominate a particular market, they do not abuse their position.

Decision: In October 2003, the South African Competition Commission found both pharmaceutical firms in contravention of the Competition Act of 1998 for excessive pricing of their antiretroviral drugs and abusing their patents. The Commission decided to refer this matter to the Competition Tribunal for adjudication.

Settlement: In December 2003, the plaintiffs entered into settlement agreements with both pharmaceuticals firms. According to the terms of agreements, GlaxoSmithKline committed to grant licences to four generic companies to produce and/or import, sell and distribute AZT and lamivudine. Boehringer Ingelheim agreed to grant licences to three generic companies to produce and/or import, sell and distribute nevirapine. These agreements also allowed licences to export the three antiretroviral drugs that are manufactured in South Africa to all 47 Sub-Saharan African countries.

[9] More information available at http://www.tac.org.za.

Box 7. The private sector, codes of conduct and human rights

In recent years, some private sector organizations have explicitly integrated human rights considerations into their operations. Some have committed to international codes of conduct promoting human rights, such as the UN Global Compact,[10] while others have developed their own codes of conduct.

UN Global Compact

The UN Global Compact, launched in 2000, is a voluntary initiative that requires companies to commit themselves to ten principles relating to human rights, protection of the environment and labour rights. According to the two human rights principles, businesses should support and respect the protection of internationally proclaimed human rights and make sure that they are not complicit in human rights abuses. The Compact seeks to advance responsible corporate citizenship.

Novartis Code of Conduct

Novartis adopted its first global Code of Conduct in 1999 and amended it in 2001 in order to comply with the UN Global Compact.[11] This Code of Conduct describes the standards its employees must meet, including the support of and respect for the protection of internationally proclaimed human rights.

[10] See http://www.unglobalcompact.org.

[11] See http://www.novartis.com/corporate_citizenship/en/02_2003_code_of_conduct.shtml.

2. THE GENERAL FEATURES OF A RIGHTS-BASED APPROACH TO HEALTH

The previous chapter provided an introduction to health and human rights, but what is the value-added of adopting a rights-based approach to pressing health issues? What are the general features of a rights-based approach to health problems, such as neglected diseases?

Part of the answer to these questions is contextual: it depends on the circumstances of the local and national societies in question. Just as health and human rights problems are varied and contextual, so are their solutions. The value-added of human rights in one setting might be different in another.

Nonetheless, as already observed, an increasing range of organizations—governmental, intergovernmental and nongovernmental—are beginning to adopt rights-based approaches to health issues. From this experience it is possible to identify some of the general benefits that may arise.

In broad terms, these benefits include:

- A set of widely accepted standards provided by international human rights instruments, as interpreted by treaty bodies and other human rights mechanisms;
- An inclusive framework for analysis and action that takes account of social, economic, cultural, political and civil dimensions of human development;
- Enhanced empowerment and informed participation;
- Enhanced accountability, by identifying specific duty bearers and requiring mechanisms to hold them to account;
- An authoritative basis for advocacy and social justice, deriving from the global legitimacy of international human rights and the framework of entitlements and duties deriving from it.[12]

This chapter briefly explores some of the general features of a rights-based approach to health, in particular: forging express linkages to human rights norms, participation, non-discrimination and equality, monitoring and accountability, and empowerment. It refers to neglected diseases by way of illustration.

2.1 Linkages to human rights

A rights-based approach must explicitly be based on specific human rights and make explicit linkages to the normative framework of international, regional and national human rights norms, principles and standards (WHO, 2002: p. 17).

A rights-based approach to the prevention, treatment and control of neglected diseases engages a wide range of human rights including the rights to health; life; information; an adequate standard of living; non-discrimination; education; and to the benefits of scientific progress and its applications. This chapter, as well as the following chapters, identifies the human rights that are of particular relevance in the context of neglected diseases, and that must explicitly guide a rights-based approach to neglected diseases.

As policies are formulated and operationalized in relation to neglected diseases, the relevant national and international human rights norms should be identified, the links established, and the rights fully taken into account.

[12] See United Nations Office of the High Commissioner for Human Rights website pages on rights-based approaches to development: http://www.unhchr.ch/development/approaches.html.

2.2 Equality and non-discrimination, and their relationship to equity

Equality and non-discrimination are among the most fundamental principles of international human rights law. The principle of non-discrimination includes a prohibition on discrimination in law or practice. International and regional human rights treaties proscribe discrimination on grounds of, among others, race, colour, nationality, language, religion, property, sex, political opinions, national or social origin. This list is illustrative and, in recent years, the prohibition of discrimination has been interpreted to include sexual orientation, age, disability and health status (CESCR, General Comment No. 5: para. 5; General Comment No. 6: paras. 11–12; General Comment No. 14: para. 18; CRC, General Comment No. 3: para. 9).

Discrimination has been defined as any distinction, exclusion, restriction or preference which is based on a prohibited ground and which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise by all persons, on an equal footing, of all rights and freedoms (Human Rights Committee, General Comment No. 18: para. 7). Not all differences in treatment are discriminatory; equality does not always mean identical treatment (Bayefsky, 1990). International human rights law authorizes differences of treatment that are based on objective and reasonable criteria (Human Rights Committee, General Comment No.18: para. 13).

In addition to the right to be free from discrimination, several human rights treaties enshrine a right to equality (ICCPR: article 26; ACHR: article 24; ACHRP: article 3). The right to equality includes an entitlement to equality before the law, and to equal protection before the law, in other words to protection against arbitrary and discriminatory treatment.

The twin principles of equality and non-discrimination impose a responsibility on states to take positive measures to protect and expand opportunities for vulnerable and marginalized individuals and communities (Human Rights Committee, General Comment No. 18: para. 10; ICERD: article 1(4); CEDAW: article 4). There is no "universal checklist" of who is vulnerable in a given society (United Nations Office of the High Commissioner for Human Rights (OHCHR), 2000: p. 7). The collection and analysis of data disaggregated by sex, race, economic status, religion or other categories of human rights concern is indispensable for assessing discrimination and inequality.[13]

A rights-based approach to neglected diseases must pay particular attention to legislation and policies that, in practice, impair the equal enjoyment of the human rights of people suffering from these diseases. Because of the particular importance of non-discrimination and equality in relation to neglected diseases, chapter three is devoted to these issues.

Equality and non-discrimination are closely linked to the ethical concept of equity. Equity is grounded in distributive justice and the concern to reduce inequalities in health arising from unequal opportunities to be healthy, which are often associated with belonging to a particular social group, for example a particular ethnic minority (Braveman & Gruskin, 2003). The concept of equity is increasingly used as an analytical tool to assess and guide policies in the field of public health (e.g. Global Equity Gauge Alliance, 2003).

The grounding of equality and non-discrimination in international law means that they represent widely endorsed, legitimate reference points for challenging power imbalances and provide a framework of accountability which can help to achieve equity in practice.

[13] This issue of data disaggregation is important and complex. See, for example, UN Special Rapporteur, 2006b.

2.3 Participation

Box 8. Participation of affected communities in shaping policy and holding duty bearers to account in the context of neglected diseases

Patients' associations for the control of leishmaniasis in Peru (Guthman et al., 1997)

The people of Cuzco region, Peru, provide an extraordinary example of community participation in tropical disease control that has had a significant effect on the incidence of mucocutaneous leishmaniasis in the area. From the early 1970s, people in the altiplano highlands in Cuzco migrated to the forest area of Madre de Dios, after gold deposits were discovered there. Madre de Dios is an endemic zone for leishmaniasis, and from the 1980s onwards, cases of mucocutaneous leishmaniasis increased markedly here. Although most people contracted leishmaniasis while working in Madre de Dios, mucocutaneous lesions often did not appear until the seasonal workers had returned to their homes in the mountainous areas of Cuzco.

Leishmaniasis was declared an occupational disease in Peru in 1975, and treatment was to be provided free of charge to people who worked in the forests. In practice, however, drugs and financial compensation were not made available to people who suffered from the disease. In 1983, in the town of Sicuani, people who had contracted the disease formed patients' associations. The Catholic Church supplied them with drugs and publicized their activities on a local radio station. Over the next ten years, eight more patients' associations were established in the region, representing 1648 members.

One of the main objectives of the patients' associations was to obtain appropriate medication for their members. Over time, the associations also demanded that the government provide better support for those who contracted leishmaniasis, that living conditions in Madre de Dios be improved, and that minimum standards for working conditions be imposed on the mining companies. The patients' associations thus became forums for discussions of wide-ranging social and political issues.

The patients' associations received support from a variety of governmental and non-governmental organizations, including the Ministry of Health. "In 1990, these institutions established a committee to coordinate leishmaniasis control in the Cuzco region, which subsequently received support from the regional and national health authorities. The movement, which started as a spontaneous initiative, thus became more structured and organized." All of the institutions involved had close links with the local populations and detailed knowledge of their localities. Armed with this knowledge it was possible to determine the best control and intervention strategies, and implement them successfully.

Community-directed treatment for onchocerciasis (TDR, 2003)

Community-directed treatment, in which the community itself designs and implements treatment of members has been effective for treating onchocerciasis in Africa. Community-directed treatment with ivermectin is currently the principal drug delivery strategy for onchocerciasis control, and has reached many neglected communities who do not have easy access to orthodox health services. Community directed distributors of the drug are also often involved in other health activities, including immunization, water and sanitation-related activities and development projects.

Mariela Cecilia Viceconte v. Ministry of Health and Social Welfare, National Court of Appeals for the Federal Contentious-Administrative Jurisdiction of Argentina (1998)

Facts: Three and a half million inhabitants living in the Pampa region of Argentina were vulnerable to contracting Argentinean hemorrhagic fever. The most effective measure to combat the disease is the "Candid 1" vaccine. Yet the vaccine was not widely available. The plaintiff and the National Ombudsman filed a complaint requesting the Court to order the State to take protective measures against the fever, including producing the Candid 1 vaccine, in order to protect the right to health of people living in affected areas.

Decision: The Federal Court of Appeals ruled that any individual could bring complaints based on the international obligations of the State towards the right to health, since the Argentine Constitution incorporates international treaties into domestic law. The Court held that the State was legally obliged to intervene to provide health care when the health of individuals could not be guaranteed either by themselves or the private sector. The Court ordered the government to manufacture and make available a vaccine (Candid 1) against the hemorrhagic fever for three and half a million affected people.

The human rights approach not only attaches importance to reducing the incidence and burden of neglected diseases, but also to democratic and inclusive processes by which these objectives are achieved. This approach requires active and informed participation by communities affected by neglected diseases. This should include meaningful participation by: individuals who have a neglected disease and their families; women; people living in poverty; and other affected groups that are marginalized within a given community or policy-making process.

Participation is grounded in internationally recognized human rights, such as the rights to participate in the formulation and implementation of government policy, to take part in the conduct of public affairs, and freedom of expression and association (e.g. ICCPR: articles 19, 22, 25; ICESCR: article 13; CEDAW: articles 7, 8; ICERD: article 5(c), 5(d)(ix); CRC: articles 12, 15, 23; ICRMW: articles 26, 40, 41(1)). The right to health includes a specific entitlement of individuals and groups to participate in health policy-making processes that affect them (CESCR, General Comment 14: para. 54).

Affected communities have frequently participated in some aspects of prevention, treatment and control of neglected diseases. For example, they are sometimes involved in vector control programmes, such as bed net impregnation to combat malaria, or housing improvements to combat Chagas disease, which is caused by parasites living in cracks in housing. At times, communities are also involved in treatment strategies—for example, community health workers have been selected and trained to administer vaccinations and treatment (for a review, see Espino et al., 2004).

However, the human rights approach means that affected communities should participate in a range of contexts, not just in implementing programmes. They should be actively involved in setting local, national and international public health agendas; decision-making processes; identifying disease control strategies and other relevant policies; and holding duty bearers to account (see Box 8). While it is not suggested that affected communities should participate in all the technical deliberations that underlie policy formulation, their participation should extend beyond the implementation of policies that are decided by others. Participation can help to avoid some of the top-down, technocratic tendencies often associated with old-style development plans.

Of course, effective participation is not easy to generate and takes time. Nonetheless, it is an important means for communities and countries to democratically identify, develop and implement health priorities. Participation can empower and build capacity in affected communities, enhance accountability, and improve the effectiveness of interventions. Participation therefore has a positive impact on numerous human rights, including the right to health.

2.4 Monitoring and accountability

Human rights empower individuals and communities by granting them entitlements and placing legal obligations on others. Critically, rights and obligations demand accountability: unless supported by a system of accountability they can become no more than window-dressing. Accordingly, a human rights approach emphasizes obligations and requires that all duty-holders be held to account for their conduct. Also, if a human right is violated, the victim is entitled to an effective remedy (ICCPR: article 2(3); ECHR: article 13; ACHR: article 25).

All too often, however, "accountability" is used to mean blame and punishment. But this narrow understanding of the term is too limited. A right to health accountability mechanism establishes which health policies and institutions are working and which are not, and why, with the objective of improving the realization of the right to health for all. In other words, accountability has two dimensions. First, an accountability device identifies good practices, as well as those who should take credit for them. Secondly, an accountability device clarifies who has the responsibility to do what, and whether or not they have done it, and if they have not done it, the device should explore why not and identify appropriate redress.

Sometimes there is confusion between general accountability, such as by way of free and fair parliamentary elections, and human rights accountability. Although vitally important, general accountability mechanisms are not—for the most part—designed to provide human rights accountability. Usually general accountability mechanisms are not well suited to consider the conduct of a specific duty-bearer in relation to specific human rights standards. For this reason, in addition to general mechanisms of accountability, a human rights approach also requires one or more mechanisms that provide accountability in relation to specific right to health standards.

Monitoring is a precondition for accountability, but it is not the same as accountability. While it is commonplace for the impact of health policies to be monitored, it is less common for a health policy to be assessed against a right to health standard and for those responsible for the policy to be held to account for the discharge of their duties arising from the right to health. Such accountability, however, is what the right to health requires, with a view to enhancing enjoyment of the right to health for all, including those living in poverty.

Accountability comes in many forms. Moreover, in relation to a human right as complex as the right to health, a range of general and human rights accountability mechanisms are required. Also, the form and mix of devices will vary from one State to another. At the national level, for example, there are:

- Judicial mechanisms, e.g. involving litigation before tribunals;
- Quasi-judicial mechanisms, e.g. ombudsman and national human rights commissions;
- Administrative mechanisms, e.g. the preparation, publication and scrutiny of human rights impact assessments; and
- Political mechanisms, e.g. parliamentary processes.

At the international level, there is also a range of accountability mechanisms that play an important role in holding states to account. These mechanisms include the "treaty bodies" (Committees of independent experts that monitor states' compliance with their international human rights obligations).[14] States parties to any of the seven international human rights treaties must submit regular reports to the respective Committee on how the rights are being implemented at the national level. In the light of all the information available, which often includes information submitted by NGOs or by IGOs, the Committees adopt "Concluding Observations", which include a summary of positive developments, concerns, and recommendations to the relevant State party. Several treaty bodies are also entitled to receive and consider individual communications alleging human rights violations.[15] These reporting processes and complaint procedures are types of accountability mechanism (United Nations Office of the High Commissioner of Human Rights, Fact Sheet 7, Revision 1).

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[14] The Human Rights Committee monitors the International Covenant on Civil and Political Rights; the Committee on Economic, Social and Cultural Rights monitors the International Covenant on Economic, Social and Cultural Rights; the Committee on the Elimination of Racial Discrimination monitors International Convention on the Elimination of All Forms of Racial Discrimination; the Committee on the Elimination of Discrimination against Women monitors the Convention on the Elimination of All Forms of Discrimination against Women; the Committee against Torture monitors the Convention Against Torture; the Committee on the Rights of the Child monitors the Convention on the Rights of the Child; and the Committee on the Protection of the Rights of All Migrants Workers and Members of their Families monitors the International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families.

[15] The following Committees are mandated to receive and consider individual communications: the Human Rights Committee, the Committee on the Elimination of Racial Discrimination, the Committee on the Elimination of Discrimination against Women, and the Committee against Torture and the Committee on the Protection of the Rights of All Migrants Workers.

At the regional level, several intergovernmental organizations—the Council of Europe, the Organization of American States and the African Union—have set up their own monitoring and accountability mechanisms.

While states are the primary duty bearers under international human rights law, accountability mechanisms should extend to a range of actors including states, businesses, donors, international organizations and nongovernmental organizations.

All accountability devices, whether at the national or international levels, and whether in relation to states or non-state actors, should be effective, transparent and accessible.

How does this bear upon neglected diseases? The monitoring requirement demands that states, and other actors, collect good quality data on neglected diseases. However, because these diseases afflict neglected communities, this does not always happen. The record also suggests that neither general nor human rights accountability mechanisms give sufficient attention to neglected communities. Isolated rural communities, for example, wield scant political power and their interests usually attract little parliamentary attention. Also, judicial mechanisms of accountability are invariably inaccessible to impoverished members of neglected communities.

The right to health requirement of monitoring and accountability requires that innovative mechanisms are devised that are meaningful to neglected communities. For example, many states have established independent national human rights institutions that report to the legislature. Usually, the right to health falls within their mandates and often these national human rights institutions are empowered to conduct public enquiries. Such independent institutions should be encouraged to monitor all policies, programmes and projects relating to neglected diseases. They might track the incidence of neglected diseases and the initiatives taken to address them.

However, national human rights institutions should go beyond monitoring. They should hold actors to account in relation to neglected diseases and the right to health. Adopting an evidence-based approach, they should assess which initiatives are working and which are not—and if not, why not. If a particular actor said it would take a specific measure, the national human rights institution should check to see that the proposed action was taken and how effective it was.

National human rights institutions should be encouraged to consider the acts and omissions of all actors—whether at the local, national, or international levels—bearing upon neglected diseases within their jurisdiction. They might monitor and hold to account national and international actors in the public and private sectors, make practical recommendations, and report publicly to their national legislature.

At the international level, monitoring and accountability also has a role to play in relation to neglected diseases. The international and regional human rights machinery should draw attention to the issue of neglected diseases and neglected populations. For example, when a relevant State presents its periodic reports to CESCR, the African Commission on Human and Peoples' Rights, and so on, the Government's reports and the human rights bodies should give careful attention to the issue of neglected diseases and neglected populations.

2.5 Conclusion: the empowering role of human rights

The indispensable contribution of human rights is that they help to ensure that the interests and needs of the powerless are not neglected but given due weight in national and international policy making processes. When combined, the essential features of human rights—non-discrimination, equality, participation, entitlement, obligation, accountability, and so on—empower the powerless. This signals why human rights are so important in the context of neglected diseases and neglected communities.

Neglected diseases are complex phenomena. In part, they arise from a failure to correct the severely imbalanced research and development agenda. But they also arise because existing drugs, vaccines and

other services are not reaching all those who need them, such as disadvantaged individuals and communities. Both failures reflect the relative powerlessness of those afflicted with, and most vulnerable to, neglected diseases.

When properly taken into account, human rights can help to redress the powerlessness that characterizes the individuals and communities that are primarily associated with neglected diseases. In other words, human rights can help to ensure that neglected diseases attract equitable levels of research and development, and that existing drugs, vaccines and other services reach all those who need them.

3. DISCRIMINATION AND STIGMA

Discrimination and social stigma are both causes and consequences of some neglected diseases. As we have seen, non-discrimination and equal treatment are cornerstone principles in international human rights law. A human rights analysis addresses the different forms of discrimination suffered by those afflicted with neglected diseases.

3.1 Discrimination enhances vulnerability to neglected diseases

Discrimination and stigma heighten people's vulnerability to ill health. In all countries of the world, the burden of disease is disproportionately borne by vulnerable and marginalized groups, who often suffer from other social inequities as well as discrimination (United Nations Special Rapporteur, 2003a: para. 59). Discrimination and stigma can also be an obstacle to prevention and treatment.

The communities and groups that are the most affected by neglected diseases generally are people living in poverty in low-income countries. Poor people are often subject to different forms of overt and implicit discriminatory attitudes by public authorities and private actors.

This form of discrimination against people living in poverty can be reinforced by other forms of discrimination, such as on grounds of sex or race, which further increase vulnerability to neglected diseases. For example, the status of women in many countries, including their lack of ownership of resources, affects their access to prevention and treatment.

International human rights law prohibits any discrimination in access to health-care services and underlying determinants of health on grounds including: race, sex, language, physical or mental disability, and health status (CESCR, General Comment No. 14: para. 18). In accordance with the prohibition of discrimination, states are obliged to discharge the three types of human rights obligations:

- States must abstain from adopting discriminatory laws, policies and practices (obligation to *respect*). For instance, states must abstain from denying or limiting equal access for all persons to preventive, curative and palliative health services. They may not impose discriminatory practices relating to women's health status and needs (CESCR, General Comment No. 14: para. 34; see also CEDAW: article 12). Strategies and programmes designed to eliminate health-related discrimination can be pursued with minimum resource implications, for example the repeal of offensive legislation (CESCR, General Comment No. 14: para. 18);
- States have to adopt and enforce laws for preventing discriminatory policies and practices by non-state actors, including in the context of public-private partnerships (obligation to *protect*);
- States must take positive action to afford effective protection to the most vulnerable, marginalized, excluded and discriminated groups in society (obligation to *fulfil*). For instance, the right to health requires states to ensure that health-care staff is trained to recognize and respond to the specific needs of vulnerable or marginalized groups (CESCR, General Comment No. 14: para. 37).

3.2 Discrimination on the grounds of health status or disability

People suffering from neglected diseases are sometimes subject to discriminatory policies and practices on account of their health status and/or related disabilities. For example, leprosy, lymphatic filariasis and leishmaniasis may cause severe physical disabilities, including deformities and scarring, giving rise to discrimination in the workplace, and access to health care and education. These forms of discrimination are experienced in the public and private sectors (see Box 9). Often women affected by neglected diseases may be particularly vulnerable to stigma and discrimination.

Health status, including HIV/AIDS, is recognized to be a prohibited ground of discrimination in the context of the right to health (CESCR, General Comment No. 14: para. 18; see Resolutions 1995/44: para. 1). International human rights law also proscribes discrimination on the grounds of disability (e.g. CRC: article 2(1); CESCR, General Comment No. 14: para. 18). Under international human rights law, states are obliged to adopt appropriate legislative, budgetary, judicial, promotional and other measures addressing discrimination and to ensure compensation for those who are victims of discriminatory policies or behaviour.

Box 9. Cases related to discrimination on grounds of disability or health status

Leprosy Prevention Law in Japan

Under the Japanese Leprosy Prevention Law (1953), patients with leprosy were forced to enter isolation yards in special medical centres, which were located in small islands or distant mountains. This segregation policy was only repealed in April 1996. Hundreds of former patients filed damage claims with district courts in Kumamoto, Tokyo and Okayama against the Japanese government. In May 2001, the Kumamoto District Court ruled that the government should pay compensation to 127 plaintiffs, who claimed the State violated their human rights by forcing them into isolation. The Court considered the government's policy unconstitutional and in breach of human rights.[16]

Case: Hoffmann v. South African Airways, Constitutional Court of South Africa (2000)

Facts: South African Airways refused the appellant employment as a cabin attendant in view of his HIV-positive status. The appellant alleged that the refusal to employ him constituted unfair discrimination and was an infringement of his constitutional rights to equality, human dignity and fair labour practices. Section 9(3) of the South African Constitution provides "The State may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth." However, Section 9(5) states "Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair."

Decision: The Constitutional Court of South Africa found "the denial of employment to the appellant because he was living with HIV impaired his dignity and constituted unfair discrimination" (para. 40). Apart from the payment of reparation, South African Airways were ordered to offer to employ the appellant as a cabin attendant.

3.3 Stigma and neglected diseases

In many societies, certain neglected diseases—including lymphatic filariasis, leishmaniasis, tuberculosis and leprosy—are a source of fears, stereotypes and prejudices deriving from ancient religious, cultural and traditional beliefs, or more recent misconceptions about the origins, transmission and effects of these diseases.

Social stigma attached to neglected diseases worsens the spread and impact of the diseases. Fear of stigmatization can lead people living with a neglected disease to reject diagnosis, delay seeking treatment and hide the disease from employers, family and community. In short, stigma deters diagnosis, treatment and support (WHO, 2001: p. 7). It is also an underlying cause of discrimination.

[16] See http://news.bbc.co.uk/1/hi/world/europe/1324539.stm.

The socioeconomic consequences of stigma can be more acute for vulnerable people or groups that are already subject to discrimination and marginalization, such as women, minorities, indigenous peoples, migrants, refugees and displaced peoples. For example, stigma attached to tuberculosis can be greater for women: it may lead, inter alia, to ostracism, rejection and abandonment by her partner. It may also be considered an obstacle to marriage or lead to divorce and loss of social and economic support (WHO, 2001: p. 12). Research on stigma and tropical diseases reveals that women may experience more social disadvantages than men from physically disfiguring conditions, such as lymphatic filariasis (Coreil et al., 2003).

Unlike discrimination and equality, stigma is not a legal concept. Nevertheless, it is an important human rights concern. Stigma can lead to the denial of human rights. Moreover, the effective promotion and protection of human rights has the potential to fight and eradicate stigma (see Box 10). For example:

- The realization of the right to access to treatment can constitute an effective way of combating stigma arising from neglected diseases. The realization of the right to access to treatment can constitute an effective way of combating stigma arising from neglected diseases (CESCR, General Comment No. 14: para. 12(b));
- Access to health-related education and information, which is a component of the right to health, can facilitate prevention and control of neglected diseases and help combat stigma and discrimination (CESCR, General Comment No. 14: para. 11). The right to health gives rise to an obligation on states to promote health education and organize information campaigns relating to health (CESCR, General Comment No. 14: para. 36).

Box 10. Discrimination, stigma and access to treatment being addressed in the context of HIV/AIDS and leprosy

In recognition of the impact of stigma, the Declaration of Commitment on HIV/AIDS "Global Crisis-Global Action" (adopted by the UN General Assembly Special Session on AIDS of 25–27 June 2001: para. 58) commits states to developing strategies to combat stigma and social exclusion connected with the epidemic. Many international HIV/AIDS campaigns emphasize that access to treatment has helped combat discrimination and stigma. According to UNAIDS, HIV-related stigma and discrimination largely arise from the perception that that HIV/AIDS is seen as incurable. Increasing access to medications not only helps to realize the right to health and overcome inequities due to poverty, it also changes attitudes (Joint United Nations Programme on HIV/AIDS, 2002: p. 64).

In the case of leprosy, field studies have showed that awareness-raising campaigns and improvement in accessibility to treatment have positively impacted on the stigma attached to this disease (Paz et al., 1990).

3.4 Right to privacy

The full enjoyment of the human right to privacy is highly important in the context of health (CESCR, General Comment No. 14: para. 3). A denial of privacy may discourage persons from seeking treatment, and may lead to abuses of other human rights.

Many human rights instruments enshrine the right to privacy (Universal Declaration of Human Rights: article 12; ICCPR: article 17; CRC: article 16; ICRMW: article 14; ECHR: article 8; ACHR: article 11). In the health-care setting, the right to privacy requires confidentiality in all matters related to the patients' health. This right gives patients substantial control over how their intimate health information can be shared with others (Gostin et al., 2003: p. 7).

The right to privacy ensures, for instance (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2002: p. 63):

- The non-disclosure of personal health information, such as health status, to third parties without the patient's consent (see Box 11) (CRC, General Comment No. 3: para. 24);
- The prohibition of mandatory testing for HIV;
- The confidentiality of counselling services concerning prevention and treatment (CRC, General Comment No.4: paras. 3 and 11).

Health professionals play an important role in relation to the enjoyment of the right to privacy and confidentiality (CRC, General Comment No.3: para. 20). In compliance with their obligation to respect and protect the right to privacy, states must take steps to prevent health professionals working for the State, or in the private sector, from interfering with this right.

Like many other human rights, the protection of the right to privacy is not absolute, and may sometimes be limited in the interests of society in some specific circumstances (see Box 11).

Box 11. Health and the right to privacy

Case: Jansen van Vuuren v. Kruger, Appellate Division of South Africa (1993)

Facts: A medical practitioner disclosed the appellant's HIV status, without his informed consent, to two medical practitioners in the course of a golf game.

Decision: The Appellate Division held that the disclosure was a breach of the patient's right to confidentiality in relation to medical information. The Division declared that the public interest did not justify the disclosure, because the practitioners were not at risk of any infection and, more especially, the patient specifically requested that his medical information should not be disclosed.

Case: Mr X v. Hospital Z, Supreme Court of India (1998)

Facts: Mr X was HIV-positive and arranged to marry Y. The respondent hospital disclosed his HIV status to Y and her family. Mr X filed a petition against the hospital arguing that the disclosure of his health status was a breach of his right to medical confidentiality under the Code of Medical Ethics, and his fundamental rights to privacy and marriage.

Decision: The Supreme Court dismissed the appeal, by considering that the hospital was not bound to keep the appellant's HIV status confidential. The Code of Medical Ethics contains exceptions to the rule of confidentiality in the public interest, such as an immediate or future health risk to others. The Court held that the right to privacy was an essential component of the right to life and liberty enshrined in Article 21 of the Indian Constitution. The right to privacy might be restricted for the prevention of crime or disorder, or the protection of health, morals or personal rights and freedoms. According to the Court, the disclosure of the appellant's HIV status was intended to protect Y from contracting the disease.

4. HEALTH SYSTEMS: THE RIGHT TO HEALTH CARE AND THE UNDERLYING DETERMINANTS OF HEALTH

While the right to the highest attainable standard of health is both complex and extensive, it can be understood as a right to an effective and integrated health system, encompassing health care and the underlying determinants of health, which is responsive to local health priorities and accessible to all.

One of the key elements in this formulation is integration. In the context of neglected diseases, integration has two meanings of particular importance. First, so far as possible, an intervention for one disease should be designed in such a way that it can be used as a vehicle for one or more interventions in relation to one or more other diseases. Second, so far as is possible, interventions should form part of—be integrated into—the regular health system. Interventions need to contribute to the long-term goal of health system strengthening.

Another key element in this formulation is that a health system must be responsive to local health priorities. The participatory dimension of the right to health was emphasized in chapter 2 and will not be repeated here. Properly trained community health workers, village health teams and so on, often have vital knowledge of a community's health priorities, including neglected diseases. They often know which neglected diseases afflict their communities, and their knowledge can usefully complement and supplement that of health officials from the regional or national capitals. Community participation has a vital role to play in relation to policy making, as well as implementation of health programmes and projects against neglected diseases.

A third key element is accessibility to all. As already discussed in chapters 2 and 3, equality and non-discrimination are among the most fundamental principles of international human rights.

Finally, a fourth key element of this formulation of the right to health is that the health system encompasses both health care and the underlying determinants of health. This, too, has particular relevance to neglected diseases. Those afflicted with neglected diseases require good quality health care and effective drugs. Additionally, however, communities are entitled to potable drinking-water and adequate sanitation that can reduce the incidence of many neglected diseases. Both health care and the underlying determinants of health are critical components of an effective and integrated health system that lies at the heart of the right to health.

Because of their importance, this chapter provides a brief introduction to health care and the underlying determinants of health from the perspective of the right to health, in the context of neglected diseases.

4.1 Underlying determinants of the right to health

Addressing poverty and introducing basic public health measures such as access to education, clean water, and sanitation in neglected communities would significantly reduce the burden of many neglected diseases. These are important measures for the realization of the rights to health, education, water, and housing and, provided they are rolled out in a participatory and equitable manner, are integral features of a human rights approach to neglected diseases. States must ensure that these goods and services are available in adequate numbers within a state; accessible on the basis of non-discrimination; economically and geographically accessible; acceptable to different cultures; and of good quality.[17]

[17] For an explanation of this framework of availability, accessibility, acceptability and quality, see chapter 4.2, which applies this framework in the context of health care. However, the framework also relates to the underlying determinants of health, such as safe drinking-water and adequate sanitation.

4.1.1 Poverty

While poverty has been conventionally defined in economic terms, in recent years greater recognition has been given to the multidimensional nature of poverty and its relationship to human rights (see Box 12).

Box 12. Committee on Economic, Social and Cultural Rights, Statement on poverty and the International Covenant on Economic, Social and Cultural Rights

This Statement, adopted by the Committee on Economic, Social and Cultural Rights, on 4 May 2001, states:

"In the light of the International Bill of Rights, poverty may be defined as a human condition characterized by sustained or chronic deprivation of the resources, capabilities, choices, security and power necessary for the enjoyment of an adequate standard of living and other civil, cultural, economic, political and social rights."

"While the common theme underlying poor people's experiences is one of powerlessness, human rights can empower individuals and communities. The challenge is to connect the powerless with the empowering potential of human rights. Although human rights are not a panacea, they can help to equalize the distribution and exercise of power within and between societies."

Poverty, neglected diseases and the enjoyment of human rights are closely entwined. People suffering from neglected diseases are more likely to become impoverished, and the poor are more vulnerable to neglected diseases and associated disabilities. Many neglected diseases share features which mean that they flourish where poverty prevails. People living in poverty have poorer access to the underlying determinants of the right to health, such as adequate housing, water, and health information and education. The marginalization of people living in poverty also means that their voices are less often heard in political processes.

A human rights approach to neglected diseases involves taking steps towards poverty reduction. This will include measures towards reducing vulnerability to neglected diseases, such as through improving housing, sanitation, drinking-water and health information and education. These goods and services are underlying determinants of the right to health. They are also self-standing human rights.

Under international human rights law, states have an obligation to ensure the realization of these fundamental human rights. A state party to ICESCR in which any significant number of individuals is deprived of basic shelter, education, essential foodstuffs, or essential primary health care, is, prima facie, failing to discharge its obligations under the Covenant (CESCR, General Comment No. 3: para. 10). States have an obligation to take steps towards the realization of these human rights, both through domestic efforts and within the framework of international assistance and cooperation.

4.1.2 Right to health information and education

Access to health-related education and information is a determinant of health. Information and education on prevention, treatment and causes of neglected diseases plays an important role in reducing their incidence and burden. For example, information on modes of transmission can help combat misconceptions about the causes of neglected diseases. These misconceptions, including that some neglected diseases have supernatural causes, often mean that people do not take appropriate preventative measures, or only seek treatment at a late stage. Misconceptions can also lead to stigma and discrimination against those affected (see chapter 5).

Access to health-related education and information is a crucial aspect of the right to health (ICESCR: article 12; CEDAW: article 12; CRC: article 24; CESCR, General Comment No. 14: para. 11). It is also closely related to other internationally recognized human rights, such as the right to education (ICESCR: article 14; CRC: article 28), and freedom of expression—which includes the freedom to seek, receive and impart ideas of all kinds (ICCPR: article 19(2)).

Individuals are entitled to a full range of information on health issues affecting themselves and their communities. This includes information on preventive and health promoting behaviour, how to access health services, and how to administer treatment. Information needs to be accessible. Therefore, it must be widely distributed and made available in ways that will reach remote communities, people who speak minority languages, illiterate persons, children and adolescents, and so on. For example, cartoons, street-theatre, radio programmes, leaflets in local languages and health information in schools can all be important means of outreach.

4.1.3 Right to adequate housing

Inadequate housing can increase the risk of some neglected diseases, notably Chagas disease, which is transmitted by a bloodsucking bug that lives in the cracks and crevices of substandard housing in rural areas and urban slums in Latin America.

The right to adequate housing includes an entitlement to, inter alia, habitable housing that provides the inhabitants with adequate space and protection from threats to health, structural hazards, and disease vectors (UDHR: article 25; ICESCR: article 11; CRC: article 27). An adequate shelter must contain certain facilities essential for health, including safe drinking-water, sanitation and washing facilities, refuse disposal and site drainage (CESCR, General Comment No. 4: para. 8).

4.1.4 Right to water

Unsafe water and inadequate sanitation sustain transmission cycles and support the proliferation of vectors in the case of neglected diseases such as malaria, dengue, lymphatic filariasis and schistosomiasis.

The right to water, derived from the rights to health and to an adequate standard of living (ICESCR: articles 11(1) and 12; CEDAW: article 14(2); CRC: article 24(2)), includes an entitlement to sufficient, safe, acceptable, physically accessible and affordable water for domestic and personal uses (CESCR, General Comment No. 15: para. 2). The right gives rise to an obligation on states to take measures to prevent, treat and control diseases linked to water, in particular ensuring access to adequate sanitation (CESCR, General Comment No. 15: para. 37). Safe drinking-water and adequate sanitation are also underlying determinants of the right to health, as well as components of the right to adequate housing (CESCR, General Comment No. 14: para. 4; General Coment No. 15: para. 8(b)).

4.2 Right to health care

While the underlying determinants of health provide important means to prevent and control neglected diseases, persons at risk of, or infected with, neglected diseases also need access to health-care facilities, goods and services.

A well-functioning health-care system is dependent on health facilities, skilled human resources, financial resources and financing systems, management competencies, drug supply and storage facilities, community participation and accountability. Yet, in many developing countries, health-care systems are dysfunctional or in crisis (Freedman et al., 2005). Constraints on providing health care for neglected diseases may often, depending on the setting, include: shortages and poor distribution of qualified staff; weak technical guidance and programme management; inadequate drug or medical supplies; lack of equipment and infrastructure; and poor accessibility of health services (Commission on Macroeconomics and Health, 2001).

The right to health gives rise to an obligation on states to create "conditions which would assure to all medical service and medical attention in the event of sickness." (ICESCR: article 12(2)(d)). States must ensure: provision of equal and timely access to basic preventive, curative, rehabilitative health services and health education; regular screening programmes; appropriate treatment of prevalent diseases, illnesses, injuries and disabilities, preferably at a community level; and provision of essential drugs.

CESCR spells out that the right to health gives rise to an obligation on states to ensure that health facilities, goods and services are "available, accessible, acceptable and of good quality." Table 1 shows the various dimensions of availability, accessibility, acceptability and good quality, how this relates to the struggle against neglected diseases, and the human rights obligations on states in this context. There is much overlap in the prevention and management of neglected diseases, which emphasizes the need for combined programmes integrated into existing health infrastructures, rather than vertical interventions.

4.3 Conclusion

As observed in this chapter, the right to health care includes access to essential medicines. Clearly, essential medicines have a cardinal role to play in relation to neglected diseases. Therefore, the next chapter is devoted to a consideration of this vital aspect of the right to health.

Table 1. Problems inhibiting prevention, treatment or control of neglected diseases and relevant provisions relating to availability, accessibility, acceptability and quality of health-care goods, services and facilities, and the underlying determinants of the right to health[a]

Problem	Relevant provisions
Lack of adequate health-care facilities, goods or services—including drugs and health professionals—available in a country.	*Availability* means that functioning public health and health-care facilities, goods and services, including essential drugs and programmes, have to be available in sufficient quantity within State Parties. The precise scale and nature of the facilities, goods and services will vary depending on numerous factors, including the State party's development level. However, regardless of the development level, the health facilities, goods and services must include: • The underlying determinants of health, such as safe and potable drinking-water and adequate sanitation facilities; • Hospitals, clinics and other health-related buildings; • Trained health professionals receiving domestically competitive salaries; and; • Essential drugs, as defined by the WHO Action Programme on Essential Drugs.
Health care, including services or necessary drugs, not within geographical reach and therefore inaccessible, as is frequently the case for rural populations, or unaffordable, which is a problem for many people living in poverty in developing countries. Some groups, including women, persons living with HIV/AIDS, and indigenous groups, face discrimination in their access to health-care services.	*Accessibility* requires that health facilities, services and goods, including essential drugs, must be accessible on the basis of: *Non-discrimination*: Health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds. *Physical accessibility*: Health facilities, goods and services must be within safe physical reach of all sections of the population especially vulnerable or marginalized groups, such as ethnic minorities and indigenous populations, women, children, adolescents, older persons, persons with disabilities and persons living with HIV/AIDS. *Economic accessibility or affordability*: Health facilities, goods and services must be affordable for all. Payment for health-care services, as well as services related to the underlying determinants of health, has to be based on the principle of equity, ensuring that these services, whether privately or publicly provided, are affordable for all, including socially disadvantaged groups. Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households. *Information accessibility*: Accessibility includes the right to seek, receive and impart information and ideas concerning health issues. However, accessibility of information should not impair the right to have personal health data treated with confidentiality.

Problem	Relevant provisions
Some groups—including women, people with disabilities, and people affected by certain illnesses—face stigmatizing attitudes from health professionals within the health system.	*Acceptability* means all health facilities, goods and services must be respectful of medical ethics and culturally appropriate. In practice, health facilities, goods and services must: • Be respectful of the culture of individuals, minorities, peoples and communities; • Be sensitive to gender and life-cycle requirements; • Be designed to respect confidentiality; and • Improve the health status of those concerned.
The most effective drugs for some neglected diseases, such as for malaria, are expensive and often not supplied to communities needing them. Some neglected diseases require effective vector control.	*Quality* means health facilities, services and goods must be scientifically and medically appropriate and of good quality. That requires, for instance: • Skilled medical personnel; • Scientifically approved and unexpired drugs and hospital equipment; and • Safe and potable water and adequate sanitation.

5. ESSENTIAL DRUGS

Access to essential drugs has become a major issue of international concern, particularly in the context of the HIV/AIDS pandemic (Ruxin, 2005). One third of the world's population lacks access to essential medicines; in the poorest parts of Africa and Asia this can rise to one half (Ruxin, 2005).

Since 1977, WHO has regularly published a Model List of Essential Medicines, and States are invited to adopt their own list at the domestic level (Laing et al., 2003). Many of the existing drugs for the treatment of neglected diseases are already on this list. Access to these drugs is often inhibited for a range of inter-connected reasons, including high prices of drugs; inequitable (or poor) distribution of drugs; a lack of health-care facilities or personnel to prescribe or administer drugs; and poor quality diagnosis. These barriers combine national and international obstacles.

In recent years, the human rights implications of access to essential medicines have been given increasing attention. Numerous domestic court judgements have considered the unavailability or inaccessibility of essential medicines as violations of the rights to health and life (see Box 13). At the international level, the General Assembly and the Commission on Human Rights have recognized that access to medication within the context of pandemics such as HIV/AIDS, malaria and tuberculosis is "one fundamental element for achieving progressively the full realization of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." (Resolution 2003/29)

5.1 Access to essential drugs in the context of health care: the rights to health and life

The provision of essential drugs is a core obligation of the right to health (CESCR, General Comment No. 14: para. 43; for a further discussion of core obligations, see chapter 1). States parties to ICESCR may therefore be considered to have an immediate and compulsory duty to make them accessible as required by those affected by neglected diseases. Since developed states have a particular obligation to help developing countries fulfilling core obligations (see section 1.5), they should ensure that they provide international assistance and cooperation towards ensuring the accessibility of essential medicines. This might include action in a range of spheres, including development assistance, and the enforcement and interpretation of international trade law relating to intellectual property rights.

As we have seen, the right to health gives rise to an obligation on states to ensure that health facilities, goods, and services are available, accessible, acceptable, and of adequate quality. However, often drugs for neglected diseases have not been made available in adequate numbers within a state, they have not been equitably distributed throughout a state, and are not provided free or at a price making then financially accessible to all. The unavailability and inaccessibility of essential medicines may amount to a violation of the right to health, but it may also result in a violation of the right to life.

The right to life traditionally refers to the prohibition of arbitrary deprivation of life, such as by summary or extra judicial executions or forced disappearances, but in recent years, the right to life has been linked to life-saving interventions, including life-saving drugs. Many cases have been taken to courts concerning access to life-saving treatment. The right to life is often invoked in combination with the right to health (see Box 13). Several cases have been effective in remedying human rights violations as well as influencing policy making and administrative decisions (see Centre on Housing Rights and Evictions, 2003: p. 6). These cases have particular significance in relation to neglected diseases with high-mortality rates, where deaths could be prevented through preventative measures or administration of an available treatment

Box 13. Using the right to life to ensure access to treatment

Human Rights Committee, General Comment No. 6, The right to life

The Human Rights Committee is the treaty body responsible for monitoring the International Covenant on Civil and Political Rights. In 1982 the Committee adopted a General Comment on the right to life. The Comment states that reducing infant mortality and increasing life expectancy are important responsibilities on states to guarantee the right to life:

"The expression 'inherent right to life' cannot properly be understood in a restrictive manner, and the protection of this right requires that States adopt positive measures. In this connection, the Committee considers that it would be desirable for States parties to take all possible measures to reduce infant mortality and to increase life expectancy, especially in adopting measures to eliminate malnutrition and epidemics" (Human Rights Committee, General Comment No. 6: para. 5).

Case: *Cruz Bermudez et al. v. Ministry of Health and Social Assistance, Supreme Court of Venezuela* (1999)

Facts: More than 170 plaintiffs living with HIV/AIDS filed a constitutional writ against the Ministry of Health, due to its failure to supply prescribed antiretroviral treatment. They alleged violations of their rights to life, health, liberty and security, equality and benefits of science and technology. The Venezuelan Constitution of 1961 enshrined, inter alia, the rights to life (article 58) and health (article 76).

Decision: Despite serious budgetary constraints on the Ministry of Health, the Supreme Court held that the government violated the right of health of the plaintiffs. According to the Court, the Ministry had available legal mechanisms to seek additional funds for providing adequate medical treatment. The Ministry was ordered to provide free antiretroviral drugs, medications for opportunistic infections and diagnostic testing. The decision primarily focused on the right to health; however, it acknowledged that the rights to health and life are closely linked to the right to access to the benefits from science and technology. In addition, the Court held that the decision applied not only to the specific plaintiffs but also to all people living with HIV/AIDS in Venezuela.

Case: Edgar Carpio Castro Jofre Mendoza y otros v. Ministry of Health, Constitutional Court of Ecuador (2004)

Facts: In 2002, up to 153 Ecuadorian nationals living with HIV/AIDS requested precautionary measures from the Inter-American Commission on Human Rights. They alleged, inter alia, that State health agencies failed to provide basic testing to determine the course of the disease as well as adequate treatment. The Commission granted the plaintiffs precautionary measures and requested the State to provide the beneficiaries with the medical examination and treatment indispensable for their survival. As the Ecuadorian State failed to fully comply with these precautionary measures of the Commission, four Ecuadorians living with HIV/AIDS filed a constitutional writ against the Public Health Ministry and the Director of the HIV/AIDS National Program. They invoked, inter alia, violations of their rights to life and health. The right to life is guaranteed in article 23 of the Ecuadorian Constitution. The right to health is enshrined in the Ecuadorian Constitution (article 42 states: "The State guarantees the right to health, its promotion and protection," and article 43 states, "Public health programmes, services and actions will be free for all"), the American Declaration of the Rights and Duties of Man (article XI) and the Protocol of San Salvador (article 10).

Decision: The Constitutional Court found that the decision of the Ministry of Health to stop the provision of anti-retroviral treatment for people living with HIV/AIDS amounted to a violation of the rights to life and health. The lack of anti-retroviral therapy jeopardized the life of the people living with HIV/AIDS. The Court acknowledged that, despite being an autonomous right, the right to health is a component of the right to life. The Court concluded that the right to health is directly enforceable by the plaintiffs.

5.2 Intellectual property rights

The high cost of drugs for the treatment of some neglected diseases limits their availability and accessibility in many developing countries. The system of patents on drugs and drug-related technological processes allows patent holders to exclude competitors from certain acts, including reproducing and selling the drugs, for a minimum period of 20 years. Since patent protection temporarily excludes generic competition, the patent holder can use the grant of a patent as a tool to increase the price of pharmaceuticals (United Nations Special Rapporteur, 2004b: para. 43). In some situations, generic competition has lowered the prices of the drugs. For example, in 2000, UNDP reported that in India the generic production of flucanazole, a drug for the treatment of HIV, had kept the price at US$ 55 for 150 milligrams compared with US$ 697 in Malaysia, US$ 703 in Indonesia and US$ 817 in the Philippines, where generic versions were not available (UNDP, 2000: p. 84; UN High Commissioner for Human Rights, 2001: para. 44).

There is much that pharmaceutical companies can do to help guarantee human rights in the context of neglected diseases. For example, drug donations can help realize the right to health, provided they are sustainable and support a country's health system; and pricing of drugs to make them more affordable in developing countries also has an important role to play for the enjoyment of the right to health.

5.2.1 The TRIPS Agreement, the Doha Declaration and protection of public health

The Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS), adopted by Members of the WTO in 1994, set international minimum standards for the protection and enforcement of intellectual property rights, including patent protection. The Agreement allows WTO Member States to insert public health concerns into their national intellectual property laws: "Members may, in formulating or amending their laws and regulations, adopt measures necessary to protect public health and nutrition" (article 8). At the WTO Fourth Ministerial Conference, held in Doha in November 2001, WTO Member States stressed the primacy of public health concern over intellectual property rights, recognizing that TRIPS: "Can and should be interpreted and implemented in a manner supportive of WTO Members' right to protect public health and, in particular, to promote access to medicines for all" (Doha Declaration on the TRIPS agreement and public health: para. 4). This right to protect public health provides an important opportunity for the protection of the right to health.

A number of flexibilities are included in the TRIPS agreement, including the right of each state to use parallel imports, and their right to issue a compulsory licence to authorize third parties to work a patent without authorization of the patent holder, in certain circumstances including in cases of national emergency (Doha Declaration, articles 30 and 31; also see WHO, 1999: p. 44).

The Doha Declaration (para. 5(b)) reaffirms that each WTO Member State has the right to use compulsory licences and the freedom to determine the grounds upon which such licences are granted. According to the Declaration (para. 5(c)), public health crises, including those relating to HIV/AIDS, tuberculosis, malaria and other epidemics can represent a national emergency or other circumstances of extreme urgency. Several countries have issued compulsory licences, or engaged in parallel importation, in order to facilitate access to affordable drugs (see Box 14).

Under the TRIPS Agreement (article 31(f)), production under compulsory licences was to be predominantly for the supply of the domestic market. However, in the Doha Declaration (para. 6), WTO Members recognized that countries with insufficient or no manufacturing capacities face difficulties in making effective use of compulsory licensing. On 30 August 2003, the WTO General Council waived the obligation of predominant domestic supply (Decision of the WTO General Council: para. 2; WTO, 2003). This decision permits countries producing generic copies of patented drugs under compulsory licensing to export the generic drugs to countries with no or poor drug manufacturing capacity. This landmark decision could enhance access to affordable medicines for the people living in low-income countries, including people living with neglected diseases (United Nations Special Rapporteur, 2004b: para. 43).

Box 14. Compulsory licences and parallel imports[18]

Zimbabwe: Declaration of Period of Emergency (HIV/AIDS): General Notice 240 of 2002, relating to the Patents Acts (Chapter 26:03)

"2. In view of the rapid spread of HIV/AIDS among the population of Zimbabwe, the Minister hereby declares an emergency for a period of six months, with effect from the date of promulgation of this notice, for the purpose of enabling the State or a person authorized by the Minister under section 34 of the Act:

- to make or use any patented drug, including any antiretroviral drug, used in the treatment of persons suffering from HIV/AIDS or HIV/AIDS-related conditions;
- to import any generic drug used in the treatment of persons suffering from HIV/AIDS or HIV/AIDS-related conditions."

Mozambique: Industrial Property Code, approved by Decree no.18/99, Article 70

"1. The invention may be exploited under authorization given by the responsible Ministry, without the consent of the proprietor of the patent, including use of patent by the Government or by third parties, in the following instances:

- When a potential user has endeavoured to obtain the consent of the proprietor of the patent under reasonable commercial conditions and negotiations have been unsuccessful for a reasonable time, and where the proprietor does not agree to transfer the use of the patent;
- Use of the patent in a case of emergency or in any other circumstances of extreme urgency, either of an economic or a social nature, or for the development of other sectors that are vital to the national economy, when the circumstances so require [...]

5. The proprietor of the patent shall be given adequate remuneration, which shall be adjusted according to each particular case, taking into account the economic value of the authorization."

Ministry of Commerce and Industry of the Republic of Mozambique, Compulsory Licence No. 01/MIC/04, 5 April 2004.

On 5 April 2004, the Ministry of Commerce and Industry of the Republic of Mozambique decided to grant a compulsory licence to the company Pharco Moçambique Lda for manufacturing a triple compound of lamivudine, stavudine and nevirapine (antiretroviral therapy). This compulsory licence was motivated by the extreme urgency created by the HIV/AIDS pandemic in Mozambique, which constitutes "a serious handicap in the national struggle against hunger, illness, underdevelopment and misery".

5.2.2 TRIPS, regional and bilateral trade agreements and the right to health

The Commission on Human Rights has recognized that the TRIPS "Agreement can and should be interpreted and implemented in a manner supportive of members' right to protect public health and, in particular, to promote access to medicines for all." The Commission on Human Rights "reaffirmed the right of members to use, to the full, the provisions in the TRIPS Agreement, which provide flexibility for this purpose" (Resolution 2002/32: para. 7).

[18] More examples are presented at: http://www.cptech.org/ip/health/cl.

When negotiating and implementing international, regional or bilateral trade agreements, states have a duty to comply with their national and international legally binding human rights obligations, including obligations deriving from the right to health to make essential medicines available and accessible. The Committee on Economic, Social and Cultural Rights has underlined that "any intellectual property regime that makes it more difficult for a State party to comply with its core obligations in relation to health, food, education, especially, or any other right set out in the Covenant, is inconsistent with the legally binding obligations of the State party" (Statement adopted by CESCR, 14 December 2001: para. 12). The Committee has also emphasized that "intellectual property is a social product and has a social function. States parties thus have a duty to prevent unreasonably high costs for access to essential medicines [...] from undermining the rights of large segments of the population to health" (CESCR, General Comment No. 17: para. 35).

In 2006, the Fifty-Ninth World Health Assembly adopted resolution WHA59.24 which urged Member States "to make global health and medicines a priority sector"... and "to encourage trade agreements to take into account the flexibilities contained in the Agreement on Trade-Related Aspects of Intellectual Property Rights and recognized by the Doha Ministerial Declaration on the TRIPS Agreement and Public Health." According to the United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, developed and developing states should ensure, when negotiating bilateral or regional trade agreements, that they include safeguards recognizing the right and duty of countries to adopt measures to protect human life and health and the right to health (United Nations Special Rapporteur, 2005d).

In the context of patent protection, developed states must also take into account their duty of international assistance and cooperation for the realization of the right to health in developing states. The Committee on Economic, Social and Cultural Rights has stressed that "it is incumbent upon developed States, and other actors in a position to assist, to develop international intellectual property regimes that enable developing states to fulfil at least their core obligations to individuals and groups within their jurisdictions" (Statement adopted by CESCR, 14 December 2001: para.13). Likewise, the Commission on Human Rights has called upon all states: "To ensure that their actions as members of international organizations take due account of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and that the application of international agreements is supportive of public health policies which promote broad access to safe, effective, and affordable preventive, curative and palliative pharmaceuticals and medical technologies." (Resolution 2002/32: para. 6(b)).

Box 15. Canadian Act to export generic drugs to developing countries[19]

In 2003, the Government of Canada introduced a bill into Parliament to amend the Patent Act and the Food and Drugs Act in order to make it easier for Canadian generic manufacturer to produce, and developing countries to import, generic low-cost drugs.

The Bill C9, also known as "The Jean Chrétien Pledge to Africa Act", was passed on 14 May 2004. This new legislation allows for the issuance of compulsory licences to Canadian generic manufacturer authorizing them to produce patented drugs for export to certain developing and least-developed countries. The bill contains a list of pharmaceutical products for which a compulsory licence may be issued. This list principally derives from the WHO's Model List of Essential Medicines and includes the antiretroviral drugs that are currently approved for sale in Canada.

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[19] See news releases on Industry Canada's departmental website at http://www.ic.gc.ca: Office of the US Trade Representative, *US and Canada agree to assist poor countries' access to medicine* [press release], 16 July 2004; MSF, *The amendment to the Canadian Patent Act must ensure access to medicines for the developing world*, Briefing Paper, 14 January 2004; Canadian HIV/AIDS Legal Network, *Global access to treatment: Canada´s Bill C-9 and the compulsory licensing of pharmaceuticals for export to countries in need*, July 2004; Canadian HIV/AIDS Legal Network, *Human rights advocacy group welcomes Canadian law coming into force, urges generic drug companies and government to follow through with lower cost medicines* [press release], 13 May 2005.

5.3 Research and development and human rights

A small number of countries, such as Canada, have amended their legislation in light of the Doha Declaration and 30th August 2003 decision, with a view to facilitating export of generics in a manner which can be considered consistent with the duty of international assistance and cooperation for the right to health (see Box 15).

The obligation to fulfil the right to health includes promoting medical research (CESCR, General Comment No. 14: para. 36). Low-income states often lack the economic or technological capacity to subsidize research and development (R&D) into major health issues facing their populations. In a resolution on the right to health, the General Assembly recognized:

> "the need for further international cooperation and research to promote the development of new drugs, vaccines and diagnostics tools for diseases causing a heavy burden in developing countries, and stresses the need to support these countries in their efforts in this regard, taking into account that the failure of market forces to address such diseases has a direct negative impact on the progressive realization in these countries of the right of everyone to the highest attainable standard of physical and mental health" (Resolution 58/173).

The right to health is closely linked to the "right of everyone to enjoy the benefits of scientific progress and its applications" (UDHR: article 27(1); ICESCR: article 15(1)(b)). States in a position to assist should promote the use of new scientific knowledge and techniques for R&D into neglected diseases, as well as facilitate the transfer of the benefits to endemic countries. CESCR has stated, for example, that:

> "States parties should prevent the use of scientific and technical progress for purposes contrary to human rights and dignity, including the rights to life, health and privacy, e.g. by excluding inventions from patentability whenever their commercialization would jeopardize the full realization of these rights" (Human Rights Committee, General Comment No. 18: para. 35).

The right to enjoy the benefits of scientific progress gives rise to national and international obligations. Article 15(4) of ICESCR underlines the importance of the encouragement and development of international contacts and cooperation in the scientific and cultural fields.

R&D is essential for improving and making available new treatment for neglected diseases. Currently, only 10% of global funding for research goes towards diseases which affect 90% of the world's population, a phenomenon often referred to as the 10/90 gap or the 10/90 disequilibrium. According to MSF, of the 1393 total new drugs approved between 1975 and 1999, only 1% (16 drugs) was specifically indicated for tropical diseases and tuberculosis (Trouiller et al., 2002).

This imbalance in R&D is the consequence of a failure of both public policy and of the market. Over the last decades, the private sector has increasingly taken the lead in the fields of R&D. The priorities of research-based pharmaceuticals companies are primarily determined by potential return on investment. Consequently, market-driven R&D does not meet the needs of the poor in low-income countries with low purchasing power. Neglected diseases are not considered to be 'profitable diseases'.

States may resort to a variety of economic, financial and commercial incentives in order to influence R&D into specific health issues and to compensate market failures. For example, states can provide direct funding for the promotion of public research, or provide incentives to the private sector through tax credits, patents, subventions and grants. The Drugs for Neglected Diseases Initiative is a recent and important new scheme to ensure R&D in the context of neglected diseases (see Box 16).

Box 16. The Drugs for Neglected Diseases Initiative

A variety of international and national programmes and initiatives aim to encourage and enhance scientific cooperation for R&D into neglected diseases (Ruxin et al., 2005). The Drugs for Neglected Diseases Initiative, launched in 2003, seeks to address the need for research and development of new field-adapted, effective, and affordable drugs for persons suffering from neglected diseases. Through collaboration with research institutes, foundations and governments in developing countries, this not-for-profit collaboration intends to apply cutting-edge science and technology for the development of drugs that are suitable and affordable for the poorer patients.[20] Funding is sought from national and international agencies, foundations and private donors.

5.3.1 Research and development: A wider agenda

When considering R&D in the context of neglected diseases, the focus tends to be upon drugs, vaccines and diagnostics—the usual pre-occupations of classic medical R&D—and certainly these need urgent attention.

However, the application of a human rights lens to neglected diseases highlights the crucial importance of a health policy research agenda that includes, but goes beyond, classic R&D.

As we have seen, the right to the highest attainable standard of health encompasses the right to both health care and the underlying determinants of health, such as access to safe drinking-water. Additionally, however, the underlying determinants of health include other societal preconditions for the enjoyment of the right to health, such as the absence of gender discrimination. Moreover, the right to health has other dimensions, too. For example, it demands that those affected by health policy-making, including disadvantaged individuals and communities, are provided with opportunities to influence those policy-making processes. Significantly, from the human rights perspective, participation should not be confined to the implementation of health policies and projects: it should also extend to participation in the processes that shape those policies and projects.

Thus, from the human rights point of view, it is essential that a health research agenda encompass social, economic, political and policy issues that lie beyond classic R&D. A contemporary health research programme will have to consider, for example, issues of equitable access to health care and how to dismantle societal, discriminatory obstacles to health technologies and essential medicines.

In short, the health and human rights research agendas overlap. A human rights analysis complements and reinforces health research, including in relation to neglected diseases. Indeed, if a research and development programme for neglected diseases confines itself to drugs, vaccines and diagnostics, it will fail to address some of the vital human rights dimensions of the issue.

[20] The main partners are Médécins Sans Frontières, TDR, Pasteur Institute, Indian Council for Medical Research and the Brazilian government pharmaceutical organization Fiocruz. For more information, see: http://www.dndi.org.

6. CONCLUSION

When applied to policy-making, human rights bring a set of fundamental principles, such as dignity, autonomy, non-discrimination and equality. Human rights place the well-being of individuals and communities at the heart of the policy-making process. They bring a keen preoccupation with the vulnerable and disadvantaged, including those living in poverty. It is this preoccupation that leads to the identification of neglected diseases as a major human rights problem demanding serious attention.

As for the right to the highest attainable standard of health, it emphasises primary health and demands integrated health systems—health care, safe water, adequate sanitation—that are responsive to local priorities and accessible to all. It places moral and legal obligations on states and requires that they be held to account for their conduct in relation to health. The right to health insists that developed states have a responsibility to help developing states realize the right to health, in this way responding to the shocking inequality in global health that characterizes the contemporary world. However, for those committed to the right to health, the challenge is to clarify what, in more practical terms, the right to health brings to a particular health problem.

This report takes a step towards the practical operationalization of the right to health in relation to neglected diseases. It establishes the numerous linkages between national and international human rights norms, and neglected diseases and communities. For example, the report signals that an integrated health system, proper attention to the underlying determinants of health, affordable drugs, and equitable research and development, are not only needed in the struggle against neglected diseases, they are also vital elements of the right to health.

With these broad linkages established, the next step is for a detailed consideration of their implications. To be most effective, this consideration probably needs to take place in the context of specific countries or communities.

Depending on the context, the examination of neglected diseases through the prism of human rights may underline the importance of developing village health teams, or appointing (and retaining) more health professionals in remote areas, or tackling stigma and discrimination, or more research and development, or better monitoring and accountability of health policies, and so on. A detailed consideration of a specific country or community through the human rights lens will also help to identify the responsibilities of all actors, public and private, at the national and international levels.

It is hoped that the recent report on Uganda, neglected diseases and the right to health is a significant step in this direction (United Nations Special Rapporteur, 2006a). It is also hoped that the present report will encourage others to take the next steps towards the interdisciplinary, practical operationalization of the rights-based approach to neglected diseases.

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ANNEX

Table 2. Global burden of selected neglected diseases

Disease	Burden	Global total	WHO Region[b]					
			Africa	Americas	Eastern Mediterranean	Europe	South-East Asia	Western Pacific
Buruli ulcer	Incidence[a]	3 154	2 515	24	568	Not endemic	No recent information	47
	Prevalence	—	—	—	—	—	—	—
	YLL	—	—	—	—	—	—	—
	YLD	—	—	—	—	—	—	—
	DALYs	—	—	—	—	—	—	—
Dengue	Incidence	71 000	4 000	—	7 000	—	51 000	9 000
	Prevalence	—	—	—	—	—	—	—
	YLL	646 944	6 018	89 562	84 479	—	355 764	111 121
	YLD	6 180	360	—	599	—	4 456	765
	DALYs	653 125	6 378	89 562	85 078	—	360 221	111 886
Leishmaniasis	Incidence	2 000 000	—	—	—	—	—	—
	Prevalence	12 000 000	—	—	—	—	—	—
	YLL	1 848 930	277 091	27 428	201 699	370	1 321 840	20 503
	YLD	507 679	125 070	32 071	76 286	5 366	264 388	4 497
	DALYs	2 356 609	402 161	59 498	277 986	5 737	1 586 228	24 999
Leprosy	Incidence	174 000	21 000	17 000	17 000	—	112 000	7 000
	Prevalence	897 000	109 000	89 000	84 000	1 000	580 000	35 000
	YLL	64 140	3 011	6 880	4 768	274	47 176	2 032
	YLD	112 443	12 947	11 466	11 182	36	72 238	4 574
	DALYs	176 583	15 957	18 347	15 949	310	119 414	6 606
Lymphatic	Incidence	—	—	—	—	—	—	—
Filariasis	Prevalence	120 000 000	40 800 000	36 000 000	36 000 000	—	58 800 000	19 200 000
	YLL	3 035	27	52	550	745	1 576	86
	YLD	5 641 087	1 933 394	9 612	488 505	1 431	2 800 658	407 487
	DALYs	5 644 122	1 933 421	9 663	489 055	2 176	2 802 234	407 573

Table 2. Global burden of selected neglected diseases (continued)

Disease	Burden	Global total	WHO Region[b]					
			Africa	Americas	Eastern Mediterranean	Europe	South-East Asia	Western Pacific
Rabies	Incidence	—	—	—	—	—	—	—
	Prevalence	—	—	—	—	—	—	—
	Persons treated for exposure	—	413 450	299 190	—	40 452	891 289	—
	YLL	—	—	—	—	—	—	—
	YLD	—	—	—	—	—	—	—
	DALYs	—	—	—	—	—	—	—
	DALYs	—	—	—	—	—	—	—
Schistosomiasis	Incidence	—	—	—	—	—	—	—
	Prevalence	193 000 000	165 000 000	7 000 000	19 000 000	600	420	2 000 000
	YLL	235 072	115 249	14 253	67 395	408	—	37 767
	YLD	1 524 486	1 305 333	69 169	134 240	—	2 484	13 260
	DALYs	1 759 558	1 420 583	83 422	201 636	408	2 484	51 026
Soil-transmitted	Incidence	—	—	—	—	—	—	—
Helminths	Prevalence (estimate)	2 000 000 000	—	—	—	—	—	—
	YLL	342 745	88 853	26 357	18 847	733	164 084	43 871
	YLD	4 363 181	585 332	597 409	248 278	7 462	1 386 179	1 538 520
	DALYs	4 705 926	674 185	623 766	267 126	8 195	1 550 263	1 582 392

From World Health Organization. Intensified control of neglected diseases: report of an international workshop, Berlin, 10–12 December, 2003. Geneva, World Health Organization, 2004 (WHO/CDS/CPE/CEE/2004.45). The authors have modified some presentational aspects of the original document.

—, No data; DALY, Disability-adjusted life years; YLD, Years of life lived with disability due to the disease; YLL, Years of life lost due to premature mortality.

[a] Annual new cases

[b] The WHO Regions include the following countries. Please see page 53.

Table 2. Global burden of selected neglected diseases (continued)

Disease	Burden	Global total	WHO Region[b]					
			Africa	Americas	Eastern Mediterranean	Europe	South-East Asia	Western Pacific
Trachoma	Incidence	—	—	—	—	—	—	—
	Prevalence of active trachoma	81 000 000	21 700 000	1 060 000	9 300 000	—	20 700 000	28 500 000
	Prevalence of trachomatous trichiasis	7 600 000	2 220 000	27 000	1 700 000	—	330 000	3 260 000
	Prevalence of blindness due to trachoma	1 900 000	—	—	—	—	—	—
	YLL	1 774	—	44	281	8	1 395	47
	YLD	3 995 702	1 526 084	—	602 379	—	246 597	1 620 642
	DALYs	3 997 477	1 526 084	44	602 660	8	247 992	1 620 689
Trypanosomiasis	Incidence	—	—	—	—	—	—	—
	Prevalence	—	—	—	—	—	—	—
	YLL	1 504 194	1 469 579	50	34 282	40	225	18
	YLD	93 410	87 810	—	5 599	—	—	0
	DALYs	1 597 603	1 557 390	50	39 881	40	225	18

From World Health Organization. Intensified control of neglected diseases: report of an international workshop, Berlin, 10–12 December, 2003. Geneva, World Health Organization, 2004 (WHO/CDS/CPE/CEE/2004.45). The authors have modified some presentational aspects of the original document.

—, No data; DALY, Disability-adjusted life years; YLD, Years of life lived with disability due to the disease; YLL, Years of life lost due to premature mortality.

[a] Annual new cases

[b] The WHO Regions include the following countries. Please see page 53.

The WHO Regions include the following countries:

Africa: Algeria, Angola, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Cape Verde, Central African Republic, Chad, Comoros, Congo, Côte d'Ivoire, Democratic Republic of the Congo, Equatorial Guinea, Eritrea, Ethiopia, Gabon, Gambia, Ghana, Guinea, Guinea-Bissau, Kenya, Lesotho, Liberia, Madagascar, Malawi, Mali, Mauritania, Mauritius, Mozambique, Namibia, Niger, Nigeria, Rwanda, Sao Tome and Principe, Senegal, Seychelles, Sierra Leone, South Africa, Swaziland, Togo, Uganda, United Republic of Tanzania, Zambia,

Americas: Antigua and Barbuda, Argentina, Bahamas, Barbados, Belize, Bolivia, Brazil, Canada, Chile, Columbia, Costa Rica, Cuba, Dominica, Dominican Republic, Ecuador, El Salvador, Grenada, Guatemala, Guyana, Haiti, Honduras, Jamaica, Mexico, Nicaragua, Panama, Paraguay, Peru, Saint Kitts and Nevis, Saint Lucia, Saint Vincent and the Grenadines, Suriname, Trinidad and Tobago, United States of America, Uruguay, Venezuela (Bolivarian Republic of).

Eastern Mediterranean Region: Afghanistan, Bahrain, Cyprus, Djibouti, Egypt, Islamic Republic of Iran, Iraq, Jordan, Kuwait, Lebanon, Libyan Arab Jamahiriya, Morocco, Oman, Pakistan, Qatar, Saudi Arabia, Somalia, Sudan, Syrian Arab Republic, Tunisia, United Arab Emirates, Yemen.

European Region: Albania, Andorra, Armenia, Austria, Azerbaijan, Belarus, Belgium, Bosnia and Herzegovina, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Luxembourg, Malta, Monaco, Netherlands, Norway, Poland, Portugal, Republic of Moldova, Romania, Russian Federation, San Marino, Slovakia, Slovenia, Spain, Sweden, Tajikistan, The former Republic of Macedonia, Turkey, Turkmenistan, Ukraine, United Kingdom, Uzbekistan, Yugoslavia.

South-East Asia Region: Bangladesh, Bhutan, Democratic Republic of Korea, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand.

Western Pacific Region: Australia, Brunei Darussalam, Cambodia, China, Cook Islands, Fiji, Japan, Kiribati, Lao People's Democratic Republic, Malaysia, Marshall Islands, Micronesia (Federated States of), Mongolia, Nauru, New Zealand, Niue, Palau, Papua New Guinea, Philippines, Republic of Korea, Samoa, Singapore, Solomon Islands, Tonga, Tuvalu. , Vanuatu, Viet Nam.

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