The right to the highest attainable standard of health[1]

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Abstract

This chapter introduces the right to the highest attainable standard of health, which is enshrined in several legally binding international treaties, as well as numerous national constitutions. It outlines the complementary relationship between public health and the right to the highest attainable standard of health, and provides a framework for analysing this human right. This analytical framework is then applied, by way of illustration, to neglected diseases, mental disability, sexual and reproductive health, and water and sanitation. The conclusion identifies the key features of a health system from the perspective of the right to the highest attainable standard of health.

Human rights

What are human rights?

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 all human rights are universal, indivisible, interdependent, and interrelated (UN 1993).

Although inspired by moral values, such as dignity and equality, human rights are more than moral entitlements: They are legally guaranteed through national and international legal obligations on duty bearers. They are enshrined, for example, in various international treaties and declarations.

International human rights treaties (often called covenants or conventions), such as the International Covenant on Economic, Social and Cultural Rights (ICESCR), are legally binding on the States that ratify them ('States parties'). In contrast, human rights declarations, such as the Universal Declaration of Human Rights, are non-binding, although many of them do include norms and principles that reflect obligations that are binding under 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. By ratifying international human rights treaties, States assume binding legal obligations to give effect to the human rights enumerated within them.

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

Historic neglect of economic, social, and cultural rights, such as the rights to health and shelter, is gradually being overcome, thanks in part to civil society organizations across the world that have campaigned for their equal representation and advocated for specific mechanisms for their enforcement.

Who has human rights duties?

Although only States are parties to international and regional human rights treaties, and are thus fully accountable for compliance with their provisions, all members of society have responsibilities regarding the realization of human rights, including the right to the highest attainable standard of health (UN 1948, preamble; UNCESCR 2000, para. 42). This includes health workers,[2] families, communities, inter- and non-governmental organizations, civil society groups, as well as the private business sector: These so-called 'non-State actors' all have responsibilities regarding the realization of the right to health. States, as parties to international treaties, have a duty to provide an environment in which all of these individuals and groups can discharge their human rights responsibilities.

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[1] The 'right to health' or the 'right to the highest attainable standard of health' are used as shorthand for 'the right of everyone to the enjoyment of the highest attainable standard of physical and mental health', the full title envisaged in Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR).

[2] A generic term encompassing doctors, nurses, midwives, public health professionals, managers/administrators, traditional health workers, as well as those working in particular contexts or specializations, such as prison health or obstetrics and gynaecology. According to the WHO definition, health workers are 'all people engaged in actions whose primary intent is to enhance health' (WHO 2006a).

Approaches to human rights

One approach to the vindication of human rights is via the courts, tribunals, and other judicial and quasi-judicial processes (the 'judicial' approach). Another approach, however, brings human rights to bear upon policy-making processes so that policies and programmes that promote and protect human rights are put in place (the 'policy' approach). Although the two approaches are intimately related and mutually reinforcing, the distinction between them is important because the 'policy' approach opens up challenging new interdisciplinary possibilities for the operationalization of human rights.

Lawyers have played an indispensable role in developing the norms and standards that today constitute international human rights law. Naturally, when it comes to the 'judicial' and 'policy' approaches, some lawyers are professionally drawn to the former. Indeed, in the context of the right to health, despite some suggestions to the contrary, this approach has a vital role to play and many courts have demonstrated that they have a crucial contribution to make.[3] It is important that this judicial contribution deepens and becomes more widespread.

In addition to this approach, however, it is vital that the right to health is brought to bear upon all relevant local, national and international policy-making processes This 'policy' approach depends upon techniques and tools—indicators, benchmarks, impact assessments, and so on—that demand close cooperation across a range of disciplines. Given its historic role and traditional expertise, public health has an indispensable contribution to make to the 'policy' approach. The Section 'New tools and techniques' below briefly introduces some of these techniques and tools in the specific context of the right to the highest attainable standard of health.

What is the right to health?

Sources of the right to health[4]

The origins of the international right to the highest attainable standard of health can be traced back over 50 years. Adopted in 1946, the World Health Organization's Constitution States: 'The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition'. Two years later, article 25(1) of the Universal Declaration of Human Rights laid the foundations for the international legal framework for the right to health. Since then, the right to health has been codified in numerous legally binding international and regional human rights treaties, and enshrined in many national laws, some of which are signalled in the following paragraphs. This gives rise to one of the most important and distinctive characteristics of human rights, including the right to the highest attainable standard of health. Human rights place legally binding obligations on States.

International human rights law

Concrete legal duties are conferred upon States when they ratify international treaties; they must ensure that all individuals within their jurisdiction can enjoy the rights envisaged within them. The cornerstone protection of the right to health in international law is found in Article 12 of ICESCR. Over 155 States have legally bound themselves, through ratification of this treaty, to its implementation.

Additional right to health protections are contained in international treaties that address issues specific to marginalized groups, such as the International Convention for the Elimination of All Forms of Racial Discrimination (ICERD);[5] the International Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW);[6] and the Convention on the Rights of the Child (CRC).[7]

Authoritative and interpretive guiding principles of several of these treaty provisions on the right to health—called General Comments or General Recommendations—shed further light on the parameters and content of the right to health generally, and in relation to the application of the right to specific groups. In 2000, for example, the United Nations (UN) treaty-body responsible for monitoring ICESCR adopted General Comment 14 on the right to the highest attainable standard of health.

Moreover, some UN treaty-bodies have decided cases that shed light on the scope of health-related rights. Recently, for example, the Human Rights Committee considered the case of a 17-year old Peruvian who was denied a therapeutic abortion. When K.L was 14 weeks pregnant, doctors at a public hospital in Lima diagnosed the foetus with an abnormality that would endanger K.L's health if pregnancy continued. However, K.L. was denied a therapeutic abortion by the hospital's director. In *K.L. v Peru*, the Human Rights Committee decided that by denying the young woman's request to undergo an abortion in accordance with Peruvian law, the Government was in breach of its right-to-life obligations under the International Covenant on Civil and Political Rights (UNHRCttee 2003).

Further standards relating to specific groups are set out in non-binding legal instruments, such as the Declaration on the Elimination of Violence against Women. Additional international human rights instruments contain protections relevant to the right to health in various situations, environments and processes, including armed conflict, development, the workplace, and detention (UNCHR 2003a, Annex I).

Significantly, resolutions of the UN Commission on Human Rights, including those on disabilities and access to medication (UNCHR 2002a, b), have articulated the right to the highest attainable standard of health; while other important resolutions contain provisions that bear closely upon the right (UNCHR 2003a, Annex II).

Far-reaching commitments relating to the right to health have been made in the outcome documents of numerous UN world conferences, such as the International Conference on Population and Development (UN 1994), the Fourth World Conference on Women (UN 1995), and the Millennium Declaration (UNGA 2000). These conferences have helped to place international problems, including health issues such as HIV/AIDS, at the top of the global agenda and their outcome documents influence international and national

[3] For an overview of jurisprudence on the right to health, see UNHRC (2007, paras 55–89).

[4] The 'right to health' or the 'right to the highest attainable standard of health' is employed as shorthand for the full title which is 'the right of everyone to the enjoyment of the highest attainable standard of physical and mental health'.

[5] ICERD provides protection for racial and ethnic groups in relation to 'the right to public health (and) medical care' (Article 5 (e) (iv)).

[6] CEDAW provides several provisions for the protection of women's right to health (Articles 11 (1) f, 12 and 14 (2) b).

[7] CRC contains extensive and elaborate provisions on the child's right to health, including one which is fully dedicated to the right to the health of the child (Article 24), and others containing protections for especially vulnerable groups of children (articles 3 (3), 17, 23, 25, 32, and 28).

policy-making. Several refer to the right to health and health-related rights.

Regional human rights law

The right to health is recognized in human rights treaties drafted and monitored by the different regional human rights systems. These have effect only in their respective regions and include: The African Charter on Human and Peoples' Rights (Article 16); the African Charter on the Rights and Welfare of the Child (Article 14); the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, known as the 'Protocol of San Salvador' (Article 10); and the European Social Charter (Article 11). Other regional instruments provide, through health-related rights, indirect protection of the right to health.[8]

At regional level there are also judicial and other mechanisms that adjudicate cases involving the right to health. A notable case in 2002 was the finding by the African Commission on Human and Peoples' Rights of a violation of the right to health by the Federal Republic of Nigeria, on account of violations against the Ogoni people in relation to the activities of oil companies in the Niger Delta (ACHPR 2001).

Significantly, regional mechanisms have also found breaches of other health-related rights, including the violation of the right to a home and family and private life, arising from environmental harm to human health in *López Ostra v. Spain* (ECtHR 1994), as well as the negative consequences on children's health stemming from the occurrence of child labour in *ICJ v. Portugal* (ECSR 1998).

Another important development has come from the Inter-American Commission on Human Rights, which expressed its willingness to 'take into account' provisions of the regional treaty (the Protocol of San Salvador) related to the right to health when analysing the merits of a case, even though it lacked competence to determine violations under them (IACHR 2000).

National law

A study has shown that 67.5 per cent of the constitutions of all nations have provisions regarding health and healthcare (Kinney & Clark 2004). In addition, a large number of constitutions set out States' duties in relation to health, such as the duty to develop health services, from which it is possible to infer health entitlements.

In some jurisdictions these constitutional provisions have generated significant jurisprudence, such as the decision of the Constitutional Court of South Africa in *Minister for Health v. Treatment Action Campaign.* In this case, the Court held that the Constitution required the Government 'to devise and implement a comprehensive and coordinated programme to realize progressively the right of pregnant women and their newborn children to have access to health services to combat mother-to-child transmission of HIV' (CCSA 2002, para. 135 (2) (a)). This case—and numerous other laws and decisions at the international, regional, and national levels—confirms that the courts have an important role to play in the protection of the right to the highest attainable standard of health.

[8] These include the American Declaration on the Rights and Duties of Man, the American Convention on Human Rights, the Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women, and the European Convention for the Protection of Human Rights and Fundamental Freedoms and its protocols.

Right to health in the context of other human rights

As already indicated, the right to health is closely related to and dependent upon the realization of other fundamental human rights contained within international law. These include the rights to life, food, housing, work, and education, as well as rights based on the freedom not to be tortured or discriminated against. Similarly, the rights to privacy, equality, access to information, and freedom of association, as well as other rights and freedoms, relate to and address integral components of the right to health.

The right to health—like other economic, social, and cultural rights—does not escape controversy and ideological objections. Some States are still reluctant to see it as a right of similar weight to others, such as the right to a fair trial. However, under international law, the right to the highest attainable standard of health is an integral part of the international code of human rights and must be given equal treatment and attention. Importantly, the interdependence and equal footing of all human rights was reaffirmed in the Vienna Declaration (UN 1993, para. 5). Furthermore, jurisprudence and international standards are gradually clarifying the mutually reinforcing relationship between the right to health and other health-related rights, such as the right to life (UNCESCR 2000, para. 3).

The complementary relationship between public health and the right to health

With a few exceptions, the relationship between health and human rights was not subject to close examination until the 1990s. Of course, the Constitution of WHO (WHO 1946) affirms the right to health and so does the Declaration of Alma-Ata (WHO 1978a). Also, some of those who were struggling against HIV/AIDS in the 1980s recognized the crucial importance of human rights. But, for the most part, these important developments were not accompanied by a detailed examination of the substantive relationship between health and human rights. That had to wait until the early 1990s. A great debt is owed to the late Jonathan Mann and his colleagues at the Harvard School of Public Health and the Francois-Xavier Bagnoud Center for Health and Human Rights for their pioneering work on the relationship between health and human rights, especially in the context of HIV/AIDS.

In the 1990s, however, Dr. Mann and others suffered from a serious limitation that does not apply today. At that time, although there was a widespread and detailed understanding of many human rights, there was no comparable understanding of the right to the highest attainable standard of health, even though this human right is the cornerstone of the relationship between health and human rights.

Today, however, the situation is significantly different. In 2000, an authoritative understanding of the right to health emerged when the UN Committee on Economic, Social and Cultural Rights, working in close collaboration with WHO and many others, adopted General Comment 14 (UNCESCR 2000). Also, some international bodies like WHO, UNFPA, UNICEF, and UNAIDS, as well as civil society organizations, have begun to give more careful attention to health-related rights, including the right to the highest attainable standard of health. These and other developments have deepened understanding of the right to health, enabling linkages to be made between public health and human rights, a process that continues to accelerate through good practice, the academic literature and widening jurisprudence.

Although in some quarters there is a presumption that the right to health relates to medical care, such a narrow definition is in fact inconsistent with international human rights law, which encompasses both medicine and public health, as confirmed by Article 12 of ICESCR and Article 24 of CRC. As well as access to medical care, the right to health encompasses the social, cultural, economic, political, and other conditions that make people need medical care in the first place (WHO 1948, preamble; Beaglehole 2002), as well as other determinants of health such as access to water, sanitation, nutrition, housing, and education. This wider perspective underscores the very extensive common ground between public health and the right to the highest attainable standard of health.

The right to the highest attainable standard of health depends upon public health measures, such as immunization programmes, the provision of adequate sanitation systems and clean drinking water, health promotion (e.g. regarding domestic violence, healthy eating, and taking exercise), road safety campaigns, nutrition programmes, the promotion of indoor stoves that reduce respiratory diseases, and so on. Also, however, the classic, long-established public health objectives can benefit from the newer, dynamic discipline of human rights. In other words, just as public health programmes are essential to the realization of the right to health, so too can human rights help to reinforce existing, good, health programmes and identify new, equitable, health policies. This chapter focuses on the relevance of the right to the highest attainable standard of health to public health. However, the indispensable contribution of public health to the right to the highest attainable standard of health also deserves careful study.

Both public health and human rights advocates wish to establish effective, integrated, responsive health systems that are accessible to all. Both stress the importance not only of access to healthcare, but also to water, sanitation, health information, and education. Both understand that good health is not the sole responsibility of the Ministry of Health, but belongs to a wide range of public and private actors. Both prioritize the struggle against discrimination and disadvantage, and both stress cultural respect. At root, those working in health and human rights are both animated by a similar concern: The well-being of individuals and populations.

Health workers—defined in the World Health Report of 2006 (WHO 2006a) as 'all people engaged in actions whose primary intent is to enhance health'—can use health-related rights to help them devise more equitable policies and programmes; to place important health issues higher up national and international agendas; to secure better coordination across health-related sectors, as well as between services within the health sector; to raise more funds from the treasury; to leverage more funds from developed countries to developing countries; in some countries, to improve the terms and conditions of those working in the health sector; and so on. The right to the highest attainable standard of health is not just a rhetorical device, but also a tool that can save lives and reduce suffering, especially among the most disadvantaged.

The following sections provide examples that illustrate the resonance between public health and the right to the highest attainable standard of health.

Although these two disciplines are, in many ways, complementary, in practice public health has been used by some States as a ground for limiting the exercise of some human rights. Indeed, under international law, States are allowed to impose some limitations on human rights, in some circumstances, for the protection of public health, an issue briefly revisited in the following section.

The contours and content of the right to health

The right to health is not a right to be healthy. It is a right to facilities, goods, services, and conditions that are conducive to the realization of the highest attainable standard of physical and mental health. Understanding of the content of the right has evolved considerably over the last 50 years, with jurisprudence, international standards, and practical implementation of the right all contributing to this process.

As we have seen, an inclusive approach to implementing the right to the highest attainable standard of health calls for its reach to extend not only to timely and appropriate medical care, but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, healthy occupational and environmental conditions, and access to health-related education and information (UNCESCR 2000, para. 8).

The right to health can also be broken down into more specific entitlements, such as the rights to: Maternal, child, and reproductive health; healthy workplace and natural environments; the prevention, treatment and control of diseases, including access to essential medicines; and access to safe and potable water.

In times of emergency, States have a joint and individual responsibility to cooperate in providing disaster relief and humanitarian assistance, including medical aid and potable water as well as assistance to refugees and internally displaced persons (UNCESCR 2000, para. 40).

Certain limitations on the right to health do exist, as issues of public health are sometimes used by States as grounds for limiting the exercise of other fundamental rights. For such limitations to be implemented legitimately, they must be in accordance with the law and international human rights standards. In particular, they should be strictly necessary for the promotion of the general welfare in a democratic society, proportional, subject to review, and of limited duration (UNCESCR 2000, paras. 28–9; UN ECOSOC 1985, Annex).

The right to health analytical framework

In recent years, the Committee on Economic, Social and Cultural Rights, WHO, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, civil society organizations, academics, and many others, have developed a way of 'unpacking' or analysing the right to health with a view to making it easier to understand and apply to health-related policies, programmes, and projects in practice. The analytical framework that has been developed is made up of 10 key elements and has general application to all aspects of the right to health, including the underlying determinants of health: This has been demonstrated by the Special Rapporteur in his use of the framework throughout his work.

- *National and international human rights laws, norms and standards*

The relevant laws, norms, and standards relevant to the particular issue, programme, or policy must be identified. These will include both general provisions and standards relating to the right to health, in addition to international instruments that relate to specific groups and contexts (see the Section 'What is the right to health?' above) (UNCHR 2003a, Annex 1).

◆ *Resource constraints and progressive realization*

International human rights law recognizes that the realization of the right to health is subject to resource availability. Thus, what is required of a developed State today is of a higher standard than what is required of a developing State. However, a State is obliged—whatever its resource constraints and level of economic development—to realize progressively the right to the highest attainable standard of health (UN 1966b, Art. 2(1)). In essence, this means that a State is required to be doing better in 2 years time than it is doing today. In order to measure progress (or the lack of it) over time, indicators and benchmarks must be identified (see the Section 'New tools and techniques).

◆ *Obligations of immediate effect*

Despite resource constraints and progressive realization, the right to health also gives rise to some obligations of immediate effect, such as the duty to avoid discrimination (UNCESCR 2000, para. 43). These are obligations without which the right would be deprived of its raison d'être and as such they are not subject to progressive realization, even in the presence of resource constraints. (UNCESCR 1990, para.10). The precise scope of these immediate obligations has not yet been clearly defined; for the health and human rights communities, this remains important work-in-progress.

◆ *Freedoms and entitlements*

The right to health includes both freedoms (for example, the freedom from discrimination or non-consensual medical treatment and experimentation) and entitlements (for example, the provision of a system of health protection that includes minimum essential levels of water and sanitation). For the most part, freedoms do not have budgetary implications, while entitlements do.

◆ *Available, accessible, acceptable and good quality*

All health services, goods, and facilities should comply with each of these four requirements. An essential medicine, for example, should be *available* within the country. Additionally, the medicine should be *accessible*. Accessibility has four dimensions: Accessible without discrimination, physically accessible, economically accessible (i.e. affordable), and accessible health-related information. As well as being available and accessible, health services should be provided in a culturally *acceptable* manner. This requires, for example, effective coordination and referral with traditional health systems. Lastly, all health services, goods, and services should be of *good quality*; a medicine, for example, must not be beyond its expiry date. These four requirements are further explored and applied in Section 'Right to health issues through the analytical framework'.

Note the similarity between these requirements and the four 'As' of public healthcare envisaged since the 1978 Alma Ata Declaration: Geographical accessibility; financial accessibility; cultural accessibility; and functional accessibility (WHO 1978b).

◆ *Respect, protect, fulfil*

This subsidiary framework relates to the tripartite obligations of States to respect, protect, and fulfil the right to the highest attainable standard of health, as explained and used by CESCR, the Committee on the Elimination of Discrimination Against Women (CEDAW) and the Sub-Commission on the Promotion and Protection of Human Rights. A version of this subsidiary framework is also enshrined in the Constitution of South Africa.

For example, the obligation to *respect* places a duty on States to refrain from interfering directly or indirectly with the enjoyment of the right to health. The obligation to *protect* means that States must prevent third parties from interfering with the enjoyment of the right to health. The obligation to *fulfil* requires States to adopt necessary measures, including legislative, administrative and budgetary measures, to ensure the full realization of human rights, including the right to the highest attainable standard of health.

◆ *Non-discrimination, equality and vulnerability*

Because of their crucial importance, the analytical framework demands that special attention be given to issues of non-discrimination, equality, and vulnerability in relation to all elements of the right to the highest attainable standard of health.

◆ *Active and informed participation*

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 to freedom of expression and association.[9] The right to health requires that there be an opportunity for individuals and groups to participate actively and in an informed manner in health policy-making processes that affect them (UNCESCR 2000, para. 54).

◆ *International assistance and cooperation*

In line with obligations envisaged in the UN Charter and some human rights treaties,[10] developing countries have a responsibility to seek international assistance and cooperation, while developed States have some responsibilities towards the realization of the right to health in developing countries.

◆ *Monitoring and accountability*

The right to health introduces globally legitimized norms or standards from which obligations or responsibilities arise. These obligations have to be monitored and those responsible held to account. Without monitoring and accountability, the norms and obligations are likely to become empty promises. Accountability mechanisms provide rights-holders (e.g. individuals and groups) with an opportunity to understand how duty-bearers have discharged their obligations, and it also provides duty-bearers (e.g. ministers and officials) with an opportunity to explain their conduct. In this way, accountability mechanisms help to identify when—and what—policy adjustments are necessary. Accountability tends to encourage the most effective use of limited resources, as well as a shared responsibility among all parties. Transparent, effective, and accessible accountability mechanisms are among the most crucial characteristics of the right to the highest attainable standard of health.

These 10 key elements of the right-to-health analytical framework underscore what the right to health contributes to public health. For example, the pre-occupation with non-discrimination, equality, and vulnerability requires a State to take effective measures to address the health inequities that characterize some populations. The focus on active and informed participation requires a State to adopt, so far

[9] For example, *International Covenant on Civil and Political Rights* (ICCPR), articles 19, 22, 25; *International Covenant on Economic, Social and Cultural Rights* (ICESCR), article 13; *Convention on the Elimination of All Forms of Discrimination Against Women* (CEDAW): articles 7, 8.

[10] UN Charter; ICESCR (Article 2); CRC (Article 4).

as possible, a 'bottom-up' participatory approach in health-related sectors. The requirement of monitoring and accountability can help to ensure that health policies, programmes, and practices are meaningful to those living in poverty.

Crucially, the key elements of the right-to-health analytical framework are not merely to be followed because they accord with sound management, ethics, social justice, or humanitarianism. States are required to conform to the key features *as a matter of binding law*. Moreover, they are to be held to account for the discharge of their right-to-health responsibilities arising from these legal obligations.

Right to health issues through the analytical framework

In this section, elements of the analytical framework signalled in Section 'The contours and content of the right to health' are applied to a selection of health issues. While space does not permit all of the elements to be applied to all of the selected issues, each element is applied to at least one of them.

The selected health issues are: Neglected diseases; mental disability; sexual and reproductive health, including maternal mortality; and water and sanitation. The right to health is among the most extensive and complex in the international lexicon of human rights. As already signalled, it extends much further than these four issues which are simply provided as an illustration of how the right-to-health analytical framework applies to this selection of important health issues.

Neglected diseases[11]

Although there is no standard global definition of 'neglected diseases', nor are they homogenous, they tend to share some common features. For example, they typically affect neglected populations, those least able to demand services. They are a symptom of poverty and disadvantage. Fear and stigma are attached to some neglected diseases, leading to delays in seeking treatment and to discrimination against those afflicted.

Neglected diseases include lymphatic filariasis, schistosomiasis, onchoocerciasis (river blindness), trachoma, buruli ulcer, soil-transmitted helminths, leishmaniasis, leprosy, and human African trypanosomiasis (sleeping sickness). According to WHO, 'the health impact of . . . neglected diseases is measured by severe and permanent disabilities and deformities in almost 1 billion people' (WHO 2002).

Where curative interventions for neglected diseases exist, they have generally failed to reach populations early enough to prevent impairment. Furthermore, the development of new tools to diagnose and treat them has been underfunded, largely because there has been little or no market incentive (WHO 2004a, p. 22).

◆ *Non-discrimination, equality and vulnerability*

Discrimination and social stigma can be both causes and consequences of certain neglected diseases. As non-discrimination and equal treatment are cornerstone principles in international human rights law, a rights-based approach to neglected diseases pays particular attention to policies, programmes, and projects that impair the equal enjoyment of the human rights of people suffering from these diseases.

Stigmatization and discrimination heighten people's vulnerability to ill health. Often, stigmatization is based on myths, misconceptions, and fears, including those related to certain diseases or health conditions. In turn, fear of stigmatization can lead people living with neglected diseases to avoid diagnosis, delay seeking treatment and hide the diseases from family, employers, and the community at large.

Discrimination involves acts or omissions which may be directed towards stigmatized individuals 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 healthcare and education.

The socioeconomic consequences of stigmatization and discrimination associated with neglected diseases can have devastating consequences for individuals and groups that are already marginalized, leading to further vulnerability to neglected diseases. For example, stigma related to tuberculosis can be greater for women: It may lead to ostracism, rejection, and abandonment by family and friends, as well as loss of social and economic support and other problems (WHO 2001, p. 12). Social and behavioural research on stigma and neglected diseases suggests that women also may experience more social disadvantages than men, in particular from physically disfiguring conditions like lymphatic filariasis (Coreil *et al.* 2003, p. 42).

The guarantee of non-discrimination and equal treatment enshrined under national and international human rights law requires the government to adopt wide-ranging measures, including through the implementation of health-related laws and policies, which confront discrimination in the public and private sector.

◆ *Active and informed participation*

A human rights approach not only attaches importance to reducing the incidence and burden of neglected diseases, but also to the democratic and inclusive processes by which these objectives are achieved. Such processes require the active, informed, and meaningful participation of communities affected by neglected diseases.

Affected communities have sometimes participated in 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. Communities have also been involved in treatment strategies, for example, through community health workers who have been selected and trained to administer vaccinations and treatment (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. While it is not suggested that affected communities should participate in all the technical deliberations that underlie policy formulation, their participation can help to avoid some of the top-down, technocratic tendencies often associated with old-style development plans and policy implementation.

Although effective participation is not straightforward, and takes time to generate, it is nonetheless an important means by which to empower and build capacity in affected communities, enhance accountability, and improve the effectiveness of interventions.

[11] See WHO and TDR (2007).

Therefore, as demonstrated in the following examples, participation has a positive impact on the enjoyment of the right to health.

In Peru in the 1980s, patients' associations, spontaneously set up in response to the government's failure to provide drugs and financial compensation for people who had suffered from leishmaniasis, were eventually successful in securing support from the regional and national health authorities. They became forums for discussions of wide-ranging social and political issues. This movement, which became more structured and organized over time, provided local institutions with detailed knowledge and made links with local populations so that it became possible to determine the best control and intervention strategies, and implement them successfully (Guthman *et al.* 1997).

In Uganda, Village Health Teams are able to help dispel the neglect that characterizes certain diseases and populations, ensuring that local needs are clearly identified, understood, and addressed. Moreover, the Teams can provide the crucial grassroots delivery mechanisms for community interventions in relation to neglected diseases, and health protection generally.

Vehicles for community participation such as these require adequate resources, training, and support. They must be listened to and used strategically as delivery mechanisms in relation to neglected diseases, with smooth and effective coordination, cooperation, and collaboration between them and the local political structure and health centres. For this reason, government, development actors, and others should sustain and foster vital community-based initiatives to ensure that full and effective participation can support the realization of the right to health.

- *Monitoring and accountability*

In practice, few accountability mechanisms give sufficient attention to neglected diseases, and often prove inaccessible to impoverished members of neglected communities. Within a national jurisdiction, parliamentarians might hold the Minister of Health to account in relation to the discharge of his or her responsibilities, yet the ability of these and other general mechanisms (such as judicial processes) to provide adequate accountability in relation to neglected diseases and the right to health is doubtful.

The right to the highest attainable standard of health demands accessible, transparent, and effective monitoring and accountability mechanisms that are meaningful to neglected communities. These could include independent national human rights institutions that monitor the incidence of neglected diseases and the initiatives taken to address them. Adopting an evidence-based approach, the institution could scrutinize who is doing what and whether or not they are doing all that can reasonably be expected of them to realize the right to health of those concerned. Whenever possible, the institution should identify realistic and practical recommendations for all those involved.

International human rights machinery can also draw attention to the issue of neglected diseases and neglected populations. For example, when a relevant State presents its periodic reports to CESCR, both the Government's reports and the human rights body's examination of them, should give careful attention to the issue of neglected diseases and neglected populations, in accordance with the national and international right to health standards to which the Government is bound.

- *International assistance and cooperation*

This feature of the right to health requires that donors and the international community pay particular attention to the health problems of the most vulnerable and disadvantaged individuals and communities in developing countries. For example, donors and the international community have a duty to help developing countries enhance their capacity so they can determine their own national and local health research and development priorities, such as neglected diseases.

Mental disabilities[12]

Too often, disability issues do not attract the attention they demand and deserve. This is especially true in the context of mental disabilities. The right to the highest attainable standard of health demands that due attention is given to both physical and mental disabilities.

A significant development in the field of disability was achieved with the adoption of a new international human rights treaty in 2006, the Convention on the Rights of Persons with Disabilities. Alongside this important new treaty, which will enter into force once ratified by 20 States, there are many important provisions contained in non-binding principles that have profound connections to the right to health, even if some elements are inadequate and need revisiting.[13] Where appropriate, these specialized instruments should be used as interpretive guides in relation to the right to health as it is enshrined in international law.

International human rights treaties and specialized international instruments relating to mental disabilities are mutually reinforcing, even if, as the UN Secretary General recently put it, 'a more detailed analysis of the implementation of State human rights obligations in the context of mental health institutions would be desirable' (UNGA 2003, para. 43). Inadequate attention has been given to the implementation of these obligations to date. In this context it is heartening that the new UN Convention received the highest number of signatories of any such Convention on its opening day.[14]

- *Freedoms and entitlements*

Freedoms

Freedoms of particular relevance to the experience of individuals with mental disabilities include the right to control one's health and body. Forced sterilizations, rape, and other forms of sexual violence, to which women with mental disabilities are particularly vulnerable, are inherently inconsistent with their sexual and reproductive health rights and freedoms, are psychologically and physically traumatic, and thus jeopardize mental health even further.

Several international human rights instruments allow for exceptional circumstances in which persons with mental disabilities can be involuntarily admitted to a hospital or another designated

[12] Noting the wide range of terminology available, the generic term 'mental disability' has been adopted for efficiency as an umbrella term, though it is recognized that it encompasses many profoundly different conditions. These include all major and minor mental illness and psychiatric disorders, as well as intellectual disabilities. 'Disability' refers to a range of impairments, activity limitations, and participation restrictions, whether permanent or transitory.

[13] See, for example, the *UN Principles for the protection of persons with mental illness and the improvement of mental health care*, ('UN Mental Illness Principles') (1991) (UNGA 1991).

[14] 82 countries signed the Convention on the day it opened to signature, 30 March 2007.