

# **The Domains of Health Responsiveness**

## **A Human Rights Analysis**

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## Executive summary

In addition to improving health and ensuring equitable financing of health systems, the way health systems interact with individuals can impact on their well-being. Some researchers have termed this area of work "patient experience"; WHO has termed this work health system "responsiveness" and has proposed that a health system's performance in this area also be evaluated alongside the measurement of health system performance with more traditional indicators like mortality, morbidity and utilization statistics. If a health system is responsive, it is possible that interactions people have within the health system will improve their well-being, irrespective of improvements to their health. The concept of responsiveness has been operationalised in eight domains. These include: (1) respect for the dignity of persons; (2) autonomy to participate in health-related decisions; (3) confidentiality; (4) prompt attention; (5) adequate quality of care; (6) communication; (7) access to social support networks; and (8) choice of health care providers.

This brief report discusses the human rights context for the recognition of these domains in the provision of health services to the public. Human rights and the domains of health system responsiveness share a common goal: furthering the rights of individuals and communities in the context of the health system. As we discuss, we will trace the foundation for each of these domains in human rights principles set forth in declarations, treaties, and other legal instruments. These principles include rights to security, health, life, privacy, free expression and association, non-discrimination, and respect for human dignity.

Human rights principles can enhance, or justify, the relevance of responsiveness domains to the evaluation of public and private health services in three principal ways:

- \* ***Synergy***; human rights theory and principles support the need to pay attention to the responsiveness domains when delivering health services not only to improve health outcomes, but to further respect for human rights that underlie the intrinsic value of the domains themselves.
- \* ***Authority and Accountability***; human rights provide a universally endorsed and thus authoritative legal basis for the domains, demanding accountability among governmental and other actors.
- \* ***Cohesion***; all human rights demonstrate commonalities between various domains and help identify potential gaps.

## Introduction

The World Health Organization has been working on a framework to evaluate the performance of health systems in a comparable way <sup>1</sup>. In its *World Health Report 2000: Health Systems: Improving Performance*, the World Health Organization (WHO) broadly considered the role of health systems and the efforts of millions of health care workers (henceforth referred to as HCWs) to improve the health of populations. The report includes a consideration of how national health systems achieve a goal of responsiveness to individuals' health care expectations. Stated alternatively, how well do these systems respond to the health needs of patients? On September 13 and 14, 2001, WHO's Global Programme on Evidence for Health Policy convened a panel of international experts to further discuss the key components, or domains, of health system responsiveness.

Consistent with earlier formulations drawn from the fields of social science research and principles within medical ethics (autonomy, beneficence, justice), the panel supported the operationalisation of the following eight domains (although noting that service "continuity" was an aspect requiring further operationalisation): (1) respect for the dignity of persons; (2) autonomy to participate in health-related decisions; (3) confidentiality of information; (4) prompt attention; (5) adequate quality of basic amenities; (6) clarity of communication (to patients); (7) access to social support networks (at the time of writing this paper there was discussion of changing the domain label to "family and community involvement and, or, support"); and (8) choice of health care providers.

In this paper, we discuss how these same domains have been recognized in the context of human rights and the provision of health services to the public. Human rights provide a vitally important framework for examining these domains. Like principles of ethics, human rights provide or support appropriate standards for human conduct. Yet, unlike some ethical principles, human rights are internationally recognized and globally accepted. Moreover, governments have agreed to be legally bound to upholding principles of human rights <sup>2</sup>. Human rights are deliberately broad and elastic to allow for limited differences in interpretation based on cultural or religious beliefs. "While the significance of national and regional particularities and various historical, cultural and religious backgrounds must be borne in mind, it is the duty of States, regardless of their political, economic and cultural systems, to promote and protect all human rights and fundamental freedoms"<sup>3</sup>. Consequently, the terminology and concepts underpinning human rights are particularly appropriate in providing a normative framework for measuring the domains of health systems responsiveness.

We first discuss these domains by referring to provisions in international human rights instruments, including the human right to health. We further analyse the ways that the understanding of these domains may be enhanced through an understanding of their underlying human rights principles.

## **The domains of health responsiveness—a human rights analysis**

The international human rights framework is robust and authoritative. Arising out of the atrocities of World War II<sup>4</sup>, human rights stand for the proposition that rights cannot be given nor taken away by government, but exist innately for all human beings. Human rights are comprised of civil, cultural, economic, political, and social rights. They are part of customary international law as evidenced by the world embracing the principles of the Universal Declaration of Human Rights (UDHR). Human rights are also part of binding and enforceable international law, as evidenced by the broad treaty obligations of the two major international covenants: the International Covenant on Economic, Social, and Cultural Rights (ICESCR), and the International Covenant on Civil and Political Rights (ICCPR). These documents contain a wide range of health-related rights including "the right to health" and have been widely ratified by governments globally. Additional human rights conventions and guidelines govern the rights of women<sup>5</sup>, children<sup>6</sup>, religious or ethnic minorities<sup>7</sup>, and persons with physical (e.g., HIV/AIDS<sup>8</sup>) and mental disabilities<sup>9</sup>.

What do responsiveness and human rights have in common? They both recognise a framework within which the improvement of health is the main goal of health systems. As the WHO has previously stated, "without health, other rights have little meaning"<sup>10</sup>. The WHO framework for evaluating the performance of health systems lists the goal of "health" as the primary goal of health systems. Promoting the health of populations is also a prime goal of human rights. Indeed health *is* a human right. The right to health may be defined as the duty of society to ensure the conditions necessary for the health of individuals and populations. The late Jonathan Mann espoused how protecting human rights is synergistic with improving public health<sup>11</sup>. Promoting the health of people enables them to exercise their fundamental rights; safeguarding the human rights of people empowers them to lead safe and healthy lives; and thus protecting human rights and public health are mutually re-enforcing. Similarly for responsiveness, by ensuring that people are treated in ways that correspond to their needs, they are empowered to lead healthier lives. Promoting and protecting human rights within the health system can therefore re-enforce the goal of achieving better health, in addition to being a goal in its own right. This is consistent with the notion of a "human rights-based approach to health" which pays equal attention to process (how people's rights are respected within the health system) as well as outcome (the goal of improving health).

This synergistic relationship means that the well-being of people everywhere can be attained only through systematic efforts to protect and promote other relevant human rights within the health system as well as their right to health. The right to health is recognized in numerous international instruments. Article 25.1 of the UDHR affirms: "Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services." ICESCR, Article 12.1 comprehensively refers to the right to health as "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." Specific health-related duties to certain populations (e.g., racial groups, women, children) are further recognized in international treaties and declarations.

The Committee on Economic, Social, and Cultural Rights (CESCR) has noted in its General Comment No. 14 (interpreting ICESCR, Article 12) that the right to health is closely related to and dependent upon the realization of other human rights. These include “rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement.”

When, however, government acts to restrict any human right (that is derogable or not absolute) in order to promote and protect public health, its action must adhere to criteria established by the Siracusa Principles in 1985. Under these principles, interference with, for example, freedom of movement, (1) must be provided for and carried out in accordance with the law; (2) further a legitimate objective of general interest; (3) avoid impairing the democratic functioning of the society; and (4) not be imposed arbitrarily or in a discriminatory manner. Government limitations must also represent the least restrictive means needed to reach the stated goal (UNECOSOC 1985) <sup>12</sup>.

In essence, what health system responsiveness and human rights are concerned with is the process in which the essential societal goal of improving health outcomes is furthered. In the sections below, we discuss how human rights conceptions support, clarify, or reshape each of the domains of health system responsiveness identified by WHO. In many cases, human rights concepts transcend the boundaries of the formal responsiveness domains.

### **Respect for the dignity of persons, including the rights to security & freedom from discrimination**

Respect for the dignity of persons in the delivery of public health and individual health services is a core component of health system responsiveness because it protects each individual from potential abusive practices, bodily infringements, and mental harms. Respect for dignity is also a consistent theme in human rights. The first article of the UDHR proclaims the important role of dignity: “*All human beings are born free and equal in dignity and rights.*” (*Human Rights and Public Health in the AIDS Pandemic* (OUP Oxford 1997) vii). As eloquently articulated by the UN High Commissioner for Human Rights and Executive Director of UNAIDS:

*It is not necessary to recount the numerous charters and declarations ... to understand human rights ... All persons are born free and equal in dignity and rights. Everyone ... is entitled to all the rights and freedoms set forth in the international human rights instruments without discrimination, such as the rights to life, liberty, and security of the person, privacy, health, education, work, social security, and to marry and found a family. Yet, violations of human rights are a reality to be found in every corner of the globe* <sup>13</sup>.

In human rights terms, dignity implies a bundle of rights and freedoms ensuring that all individuals are treated with respect and remain free to pursue their own hopes and dreams. Human rights doctrine also protects human dignity in quite specific ways as the following discussion illustrates.

In human rights law, the doctrine of informed consent is entrenched under the right to security<sup>14</sup> and is pivotal to respecting the dignity of persons. Thus, for example, competent adults are empowered to make inherently personal decisions, such as whether to accept or refuse medical treatment. The doctrine of voluntary consent to medical tests, treatment and research also arises from other norms and agreements. Notably, there are numerous ethical standards for protecting the dignity of human subjects, including the Nuremberg Code, Declaration of Helsinki, and Guidelines of the Council of International Organisations of Medical Sciences (CIOMS).

Perhaps the most important way of ensuring human dignity is to fight invidious discrimination. Discrimination on the basis of race, sex, religion, ethnicity, political views, property, birth, disability, or other status is deeply hurtful to the human condition. The International Bill of Rights strongly promotes the right of non-discrimination in numerous covenants and declarations. ICCPR, Article 26 illustrates:

All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

The right not to be subject to discrimination is especially important in health care and public health. Since health services are so fundamental to human well-being, they must be allocated fairly among all persons and based primarily on need.

### **Autonomy to participate in health-related decisions**

Human rights support the autonomy of individuals to participate fully in health-related decisions. This ties into key human rights principles such as freedom to seek, receive and impart information (ICCPR, Article 19) and the right to free, meaningful and effective participation (Declaration on the Right to Development, 1986, Article 2) in decisions which affect one's development. Consistent with the formulation of ethical principles, moreover, which underlie the relationship of HCWs and health researchers with their patients, freedom of choice is an essential quality in the delivery of health services. As stated above, the right to security of persons requires that for an individual to provide meaningful consent to medical procedures, she must be fully informed of the risks and purposes of the medical intervention. In the absence of complete and objective information, an individual cannot make an autonomous decision about one's medical services.

Furthermore, like principles of ethics, human rights recognise the need for the individual to be fully capable of making health-related decisions. Persons must be competent to make these decisions. That is, the person must be able to understand the basic nature and purpose of treatment to make an informed decision. Persons who lack competency (e.g., persons with significant mental or intellectual disabilities) are entitled to the assistance of others (e.g., parents, caregivers) to help make a decision that is in their best interests. These findings derive directly from human rights

instruments concerning the rights of children and the mentally disabled. Under the Convention on the Rights of the Child, for example, the child's best interests shall be a primary consideration in all actions taken and his or her views should be heard and taken into consideration. (CRC, Articles 3 & 12).

Thus, human rights support an individual's autonomy with regard to participation in health-related decisions and being fully informed, in the context of a person being capable of making decisions based on available information.

### **Privacy and confidentiality**

Respect for persons in the health care context includes the duty to keep a patient's medical information private and confidential. Article 12 of the UDHR specifically recognizes the right to privacy: "No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence." The European Court of Human Rights has also recognized the right to privacy in several cases<sup>15</sup>. The human right to privacy means that patients should have substantial control over how their intimate health information is shared with others. In the health care setting, privacy and confidentiality refer to the patient's right to expect that HCWs or others will not improperly access, use, or disclose identifiable health data without the person's consent.

Health data may include not only a patient's sensitive health status, but also those facts or circumstances that the patient reveals to HCWs as part of seeking medical treatment. Thus, for example, where a patient living with HIV/AIDS reveals that he may have contracted the virus by sharing needles with other injecting drug users, this statement should be held in confidence even though drug use may be illegal. As with the doctrine of informed consent, the right to privacy and confidentiality must be applied sensitively, with respect for different cultural, social, and religious traditions.

### **Prompt attention**

This responsiveness domain refers to having timely service so as to avoid potential anxiety and inconvenience created by any delays in receiving attention or care. It remains a separate issue from receiving prompt medical attention in a life-threatening situation. Most of the human rights literature refers to the need of patients to receive prompt medical attention, especially in cases of emergency where access to medical care is critical. The preservation of life is a fundamental human right (UDHR, Article 3; ICCPR, Article 6). Whenever an individual's life is jeopardized by her medical status, a human right to life supports the obligation of the state to assure that medical attention is accessible and provided. The European Court of Human Rights<sup>16</sup> and domestic courts such as the Supreme Court of India<sup>17</sup> have affirmed that the right to life encompasses a right to adequate health care in an emergency. Closely linked to the right to life is the right to health, which incorporates access to basic health services as an important pillar. The importance of ensuring access to health service in complying with obligations under the right to health supports the notion of "prompt attention"<sup>18</sup> which is used in the responsiveness domains. In particular, the issue of accessibility has been articulated in General Comment 14 adopted by the UN Committee on Economic, Social and Cultural Rights. Accessibility in this literature has four

overlapping dimensions: non-discrimination, physical accessibility, economic accessibility and information accessibility. Two of these dimensions relate to the domain of prompt attention, namely, non-discrimination and physical accessibility. Non-discrimination with regards to health facilities means that 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. With regard to physical accessibility, accessibility means that goods and services must be within safe physical reach for 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 with HIV/AIDS. Accessibility also implies that medical services and underlying determinants of health, such as safe and potable water and adequate sanitation facilities, are within safe physical reach, including rural areas. Accessibility further includes adequate access to buildings for persons with disabilities. This last issue links with the domain of basic amenities.

### **Adequate quality of basic amenities**

This domain links to the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions including healthy and edible food (ICESCR, Article 11). In addition, the General Comment on the Right to Health which articulated the normative content of ICESCR, Article 12, underscored that health facilities, goods and services must be of quality which includes, *inter alia*, safe and potable water, and adequate sanitation.

### **Communication**

Health care analysts have traditionally perceived the quality of health care as the combination of technical and inter-personal measures. A HCW may be technically proficient, but may be viewed by individuals as delivering low quality care because of his or her lack of inter-personal skills, most notably, the ability to effectively communicate with patients. In support of the provision of quality health care, then, the right to health equally sustains the need of HCWs to communicate with patients in ways that benefit the individual. A patient that lacks adequate medical information from her provider cannot make autonomous decisions about her health services or options. Failing to effectively communicate may infringe the realization of an individual's enjoyment of human rights, particularly the right to seek, receive and impart information.

HCWs must be prepared to provide health information to patients in language and format that furthers a patient's understanding. Thus, a communication to a patient through written correspondence in the patient's secondary language may be ineffective. Such communication does not allow for interactive discussion or the opportunity to confirm the patient's receipt or comprehension of the information.

In order to achieve a goal of clear communication to patients, clear communication between health workers is therefore necessary. This helps to address the identified gap of "continuity of care", as the transfer of information between health care workers would impact on the patient's experience of continuity.

Governmental or private sector limits on the communication of health information may infringe on individual freedom to exchange information. UDHR, Article 19 states: “Everyone has the right to freedom of opinion and expression; this right includes freedom to . . . seek, receive, and impart information and ideas through any media and regardless of frontiers.” Freedom of expression may be violated by a government law that prohibits the dissemination of health data to patients or others at risk of adverse health consequences.

### **Access to social support networks, family and community support**

Access to social support networks (also referred to as family and community support) can be a key condition for the amelioration of negative health traits among individuals. Individuals with illnesses or disabilities often need assistance in accommodating their conditions at work, home, or public places. Familial or other support helps individuals reach their health goals. Human rights, including respect for the dignity of persons, the right to health, the freedom to associate, and the right to familial assistance (ICESCR, Article 10) generally uphold this need for access. Unwarranted limitations on the ability of a person to seek their family, friends, or others within a social network for support concerning the person’s health status may infringe these rights.

### **Choice of medical providers**

The realization of human rights, including the right to health, neither requires nor precludes any particular form of government or economic system. The human right to political participation (the right to vote and to take part in the conduct of public affairs) ensures that societies can freely choose the type of system which the peoples residing in it find most conducive to the fulfillment of their rights and needs. The result is that health systems vary in terms of priorities and approaches used and values underpinning both of these. Offering individuals a choice of medical providers is a valued feature of health systems in industrialized countries like the United States (where provider choices, at times, are viewed as excessive). A choice among providers is considered to help improve patient access to care, as well as the quality of care. In terms of international human rights law, however, there are no specific provisions indicating whether a health system should or should not offer choice in terms of medical providers. Human rights provisions are deliberately broad and elastic to allow countries to meet the needs and wishes of their populations in terms of devising systems which fulfil the basic human rights of all the population paying particular attention to the most vulnerable and marginalized.

### **Enhancing the domains of health responsiveness through human rights**

Each of the health responsiveness domains discussed above in our analysis is arguably supported by one or more principles of human rights. We have attempted to show what human rights principles share with responsiveness domains. Beyond mere support, there are at least three ways that human rights principles enhance these domains.

*Synergy*; Health authorities and human rights advocates have long extolled the connection

between protecting human rights and maintaining human health. As discussed above, human rights and health are synergistic. People need to be healthy to fully enjoy their human rights; respecting human rights encourages healthy behaviours, choices, and options for individual and community health services. The domains of health system responsiveness parallel multiple human rights obligations designed to improve the health status of individuals and populations. As a result, respecting the domains of health system responsiveness can improve individual and community health outcomes. In other words, human rights theory and principles support the need to deliver health services consistent with these domains not only to improve health outcomes, but also to further a respect for human rights that underlie the intrinsic value of the domains themselves. This synergy suggests the need to conceive and build a rights-based approach to the delivery of health care services. Essentially, responsiveness supports a rights-based approach to health systems as related to the interactions between patients and health systems.

***Authority and accountability;*** In addition to the need to recognise these domains in the delivery of health services, the field of human rights provides an international set of norms that sustains their acceptance. Adhering to these domains in the provision of health services is not only consistent with good health practice that promotes individual and community health, but is also mandated by human rights. Reframing these domains in terms of human rights obligations offers an additional, authoritative justification for public and private sectors to respect these domains. Failures to respect these domains may lead to human rights violations that may be reviewed by international tribunals, human rights monitoring bodies, or through public opinion. Violations of human rights carry similar and sometimes additional penalties, as would legal violations. The potential for direct or indirect response assigns a degree of accountability against those who infringe or violate human rights. When fairly enforced, human rights provide a universal standard that holds governmental and other actors accountable.

***Cohesion;*** In many ways, the eight domains of health system responsiveness are distinct yet related. Respecting the dignity of individuals, for example, includes respecting their autonomy to participate in health-related decisions. It also requires that an individual's interests in protecting the privacy and confidentiality of her intimate health data be protected. Human rights analysis affirms the underlying construct of responsiveness, common to all the domains, and bridges any perceived or actual gaps between domains (e.g. the implications of communication for continuity of care). Thus, as discussed above, the human right to health supports the need to provide prompt medical treatment and keeping information private. Failing to deliver on one of these domains for the sake of the other (outside medical or public health emergencies) may be viewed as infringing on the right to health, notwithstanding justifications offered by health care workers or government authorities. In this way, international human rights law provides cohesion to the domains that require HCWs to strive to fulfil these components in the delivery of health services.

## Endnotes

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- <sup>1</sup> Murray CJL, Frenk J. *A framework for assessing the performance of health systems. Bulletin of the World Health Organization* 2000, 717-731
- <sup>2</sup> *Vienna Declaration and Programme of Action*, Article 1.
- <sup>3</sup> *Vienna Declaration and Programme of Action*, (United Nations General Assembly document A/CONF.137/23) adopted at the World Conference on Human Rights, Vienna, 14-25 June 1993, par. 5.
- <sup>4</sup> See, e.g., Henry J. Steiner and Philip Alston. *International Human Rights In Context: Law, Politics, Morals*. Oxford Univ. Press, NY; 1996: 59-117.
- <sup>5</sup> See, e.g., *The Convention on the Elimination of All Forms of Discrimination Against Women* (1979).
- <sup>6</sup> See, e.g., *The Convention on the Rights of the Child* (1989).
- <sup>7</sup> See, e.g., *International Convention on the Elimination of All Forms of Racial Discrimination* (1969).
- <sup>8</sup> See, e.g., United Nations. *HIV/AIDS and Human Rights International Guidelines* (September 1996).
- <sup>9</sup> See, e.g., *The United Nations Declaration on the Rights of Persons with Mental Illness* (1991).
- <sup>10</sup> Steven D. Jamar. The International Human Right to Health. *Southern University Law Review* 22 (Fall 1994): 1-68, citing UN Doc. A/CONF. 32/8.
- <sup>11</sup> Jonathan Mann, Lawrence O. Gostin, Sofia Gruskin, et al. Health and Human Rights, *J. Health and Human Rights* 1994;1:6-22.
- <sup>12</sup> United Nations Economic and Social Council (ECOSOC) (1985). The Siracusa Principles on the limitations and derogation provisions in the international covenant on civil and political rights. UN Doc. E/CN.4/1985/4, Annex.
- <sup>13</sup> Peter Piot & Jose Ayala-Lasso. Foreword to Lawrence O Gostin & Zita Lazzarini *Human Rights and Public Health in the AIDS Pandemic* (OUP Oxford 1997) vii.
- <sup>14</sup> Lawrence O. Gostin & Zita Lazzarini. *Human Rights and Public Health in the AIDS Pandemic* (OUP Oxford 1997) 14-15.
- <sup>15</sup> See, e.g., *Dudgeon v United Kingdom* (No 2) (1982) Series A No 45 (1982) 4 EHRR149.

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<sup>16</sup> *Paul and Audrey Edwards v United Kingdom*, Application no 46477/99 (14 March 2002).

<sup>17</sup> *Paschim Banga Khet Mazdoor Samity v. State of West Bengal*, Supreme Court of India, AIR 1996 Supreme Court 2426.

<sup>18</sup> Committee on Economic, Social, and Cultural Rights (CESCR), *General Comment No. 14. The right to the highest attainable standard of health* (May 2000); Geneva.