

CHAPTER 8: THE RIGHT TO HEALTH

UN Convention on the Rights of Persons with Disabilities

Article 25, Health:

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a. Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b. Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c. Provide these health services as close as possible to people's own communities, including in rural areas;
- d. Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, *inter alia*, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- e. Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- f. Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

OBJECTIVES

The exercises and background information contained in this chapter will enable participants to work towards the following objectives:

- Understand what is meant by the right to the “highest attainable standard of health”
- Define the relationship between health and disability
- Define the distinction between health care and habilitation/rehabilitation services
- Understand and explain to others the importance of equal access to health care resources for persons with disabilities

- Understand the interrelationship between the right to health and other human rights
- Identify ways in which the right of people with disabilities to the highest attainable standard of health have been promoted, denied or misunderstood
- Understand the provisions on health in the UN **Convention on the Rights of Persons with Disabilities** (CRPD).

GETTING STARTED: THINKING ABOUT HEALTH AS A HUMAN RIGHT

What does the right to health include? Is it a right to be healthy? Is it a right to health care services? Is it something else? We know that with every human right comes a corresponding responsibility for governments and society to ensure that this right is respected, protected and fulfilled. But no one can guarantee that the right to be free from all disease! Many factors related to people's health are beyond the control of governments, such as personal choices of unhealthy behaviours or a genetic predisposition to disease.

However, societies and governments do have great control over many underlying determinants of health, including physical conditions in the environment that affect people's health, such as public sanitation, the availability of clean water, and environmental pollution levels. In addition, societies have laws, policies, and programs aimed at promoting and protecting human health. Every country has a health system to provide medical care and public health programs designed to provide information about health risks, disease prevention, and healthy living. Governments are responsible for the quality and equity of national health systems. Furthermore, health for all people is also directly affected by other human rights, such as access to education, employment, and an adequate standard of living. Poor or uneducated people are far more likely to suffer ill health than those with economic security and decent living conditions. These examples demonstrate how the right to health is **indivisible, interdependent and interconnected** with other human rights.

Poverty, lack of education, poor living conditions, and other human rights issues that impact human health disproportionately affect persons with disabilities. For instance, in many countries, clean water may be publicly available but not accessible to persons with disabilities. Likewise, health care is often not accessible or available to persons with disabilities on an equal basis with others because of factors like inaccessible buildings, lack of communications accommodations in the health care setting, and even denial of treatment based on a disability.

While governments and societies cannot be expected to take responsibility for ensuring that people do not experience any illness or disease, they are responsible for addressing factors in the social, economic, legal, and physical environment that impact health. Therefore, health as a human rights issue is framed in terms of the "*highest attainable standard of health*." In other words, people have a right to the conditions and resources that promote and facilitate a healthy life.

DEFINING HEALTH

In addition to understanding what is meant by the *right* to health, it is also important to understand what is meant by "health." The **World Health Organization** (WHO) defines health in these terms:



Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.¹

The WHO also affirms the definition and importance of the right to health with the following statement:

The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, political belief, economic or social condition . . .

Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.²

When *Human Rights. YES!* refers to the “human right to health,” it is referring to the “human right to the highest attainable standard of health.”

EXERCISE 8.1: Understanding the Right to Health

Objective: To understand rights and responsibilities associated with the right to the “highest attainable standard of health”

Time: 30 minutes

Materials: Paper and pen/pencil or chalkboard and chalk

1. Introduce/Brainstorm:

Emphasize that achieving human health involves both rights and responsibilities. Divide participants into small groups and ask each group to choose one health topic from the list below. Explain that each group should:

- a. List what people’s rights are regarding this health issue.
- b. Decide what the government’s responsibilities are regarding this health issue.
- c. Decide what individuals must do for themselves.

Demonstrate how to structure and record the discussion using a chart as shown below.

2. Report:

Ask a spokesperson from each group to present their findings.

3. Discuss:

- What measures must a government take to meet its responsibility to implement this human right? Is your government succeeding in implementing this right?
- What must individuals do to meet their responsibility to implement this human right? Do you think most people understand their responsibilities?
- What special measures should governments take to ensure that persons with disabilities enjoy this human right?

1 Preamble, World Health Organization Constitution.
<http://www.who.int/governance/eb/constitution/en/index.html>

2 Preamble, World Health Organization Constitution.
<http://www.who.int/governance/eb/constitution/en/index.html>

Health topics for discussion:

- Obesity
- Respiratory Health
- HIV/AIDS
- Sanitary Conditions and Hygiene
- Immunization
- Others issues in your community

Example: Safe Drinking Water

Description of the right: People have a right to drinking water that is free from pollution and chemicals that will make them sick. Every person must have equal access to clean water.

Health Issue: Safe drinking water	
Human right: People have a right to drinking water that is free from pollution and chemicals that will make them sick. Every person must have equal access to clean water.	
Government Responsibilities	Individual Responsibilities
<ul style="list-style-type: none">• Making sure that public sources of water are safe• Making sure that clean water is available to all people equally• Providing information about the importance of avoiding unsafe water and how to counteract its effects• Supplying clean water in emergency situations	<ul style="list-style-type: none">• Refraining from activities that may contaminate drinking water• Taking recommended actions when water might be unsafe (e.g., boiling water before using, going to another source to obtain safe water)• Reporting illnesses they believe may be the result of unclean water from a public source• Reporting sources of water pollution

Disability and Health

While it is commonly accepted that there are many issues, such as the literacy or poverty level that can adversely affect human health, disability has traditionally been viewed as inherently *being* a health issue. In reality, persons with disabilities experience disease and illness in the same way that other people do. They can be in perfect health or poor health, just like anyone else. Some persons with disabilities may be more vulnerable to communicable illnesses such as influenza, and it is certainly true that some disabilities have the potential to create health problems, known as “secondary conditions.” Common examples of secondary conditions include, for example, pressure sores and respiratory distress in people with mobility impairments. It is also true that some health problems can cause permanent disabilities and/or create temporary disabling conditions. In other words, a disability can be both a cause and an effect of a health problem, or a disability can be present in a completely healthy person.³

Unfortunately, people with disabilities experience poorer overall health than the general

³ “The Right to Health: Fundamental Concepts and The American Disability Experience.” 2005. *National Council on Disability*. <http://www.ncd.gov/newsroom/publications/2005/righttohealth.htm>



population, a fact that contributes to the mistaken belief that disability is itself a health problem. The causes of poor health among persons with disabilities include a wide range of factors, most of which are the result of lack of access to the conditions and resources required for any person to be able lead a healthy life. For example, as a result of discrimination in the areas of employment and education, disabled people experience poverty at a higher level than others. Health services and important information about health are often inaccessible to persons with disabilities. Factors such as these have a far greater impact on the health of persons with disabilities than the medical effect of their disabilities.

When disability is classified as a health problem, people think of a disability as being the same thing as an illness or disease. Therefore, the medical community is regarded as responsible for “curing” or “treating” with disability rather than governments and society addressing disability as part of the social or human rights agenda. This “medical model of disability” focuses on prevention, cure, and symptom management of the disability by the health profession. Unfortunately, this approach does nothing to help eliminate the fundamental problems of discrimination, lack of access, and other social and political issues that in reality are the major cause of poor health among persons with disabilities.

Health and Habilitation/Rehabilitation

Related to the confusion of disability as a health issue and reinforced by the medical model of disability is the notion that **habilitation** and **rehabilitation** are also medical subjects and therefore part of the health context. However, the **UN Standard Rules** define habilitation and rehabilitation as “a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence.”⁴ Therefore, habilitation and rehabilitation includes a range of measures – physical, vocational, educational, training-related and others – necessary to empower people with disabilities to maximize independence and the ability to participate in society, not simply to achieve physical or mental health. For this reason, the right to health and the right to habilitation/rehabilitation are addressed separately, both in the Convention on the Rights of Persons with Disabilities and *Human Rights. YES!*. The exception, of course, is that health-related rehabilitation is recognized as part of the right to health. This would include, for example, physical therapy to strengthen muscles that are affected by an injury, illness, or disability.

EXERCISE 8.2: Identifying Barriers to Health for Persons with Disabilities

Objective: To identify the social, legal, and practical challenges persons with disabilities face in claiming the right to health

Time: 45 minutes

Materials: Copies of Article 25 of the CRPD

1. Brainstorm:

Ask participants to give examples barriers that prevent people with disabilities from claiming the right to health. List these.

⁴ See <http://www.ohchr.org/english/law/opportunities.htm>

The Medical Model vs. the Social Model and the Human Rights Model

The disability community has worked hard to redefine disability in the social model and the human rights model, which recognize disability as a the limitations experienced by people with impairments due to the nature of the physical and social environment – NOT as an illness, disease or other medical problem.

The Medical Model of Disability:

Perhaps the most significant and widespread myth affecting human rights and disability is the idea that disability is a medical problem that needs to be solved or an illness that needs to be “cured.” This notion implies that a person with a disability is somehow “broken” or “sick” and requires fixing or healing. By defining disability as the problem and medical intervention as the solution, individuals, societies, and governments avoid the responsibility of addressing the human rights obstacles that exist in the social and physical environment. Instead, they place the burden on the health profession to address the “problem” in the person with the disability.

The Social Model of Disability:

This model focuses on eliminating the barriers created by the social and physical environment that inhibit ability of people with disabilities to exercise their human rights. This includes, for instance, promoting positive attitudes and perceptions, modifying the built environment, providing information in accessible formats, interacting with individuals with disabilities in appropriate ways, and making sure that laws and policies support the exercise of full participation and non-discrimination.

The Human Rights Model of Disability:

Identifies persons with disabilities as rights holders and subjects of human rights law on an equal basis with all people.

Recognizes and respects a person’s disability as an element of natural human diversity, on the same basis as race or gender, and addresses the disability-specific prejudices, attitudes and other barriers to the enjoyment of human rights.

Places the responsibility on society and governments for ensuring that the political, legal, social and physical environments support the human rights and full inclusion and participation of people with disabilities.

For more on this subject see “Attitudes and Perceptions Regarding Disability,” Part I, “Understanding the Human Rights of Persons with Disabilities,” p. 17.

2. Discuss:

Divide participants into three groups and assign each group one general type of disability:

- a) physical disabilities (including sensory disabilities)
- b) intellectual disabilities (cognitive)
- c) psycho-social disabilities

Ask each group to list the barriers experienced by this particular group and try to explain why these barriers exist. Ask if people with certain types of disabilities experience higher levels of discrimination and why this is the case.



3. Report/Discuss:

Have each group read the list of barriers it identified. List these and discuss:

- Do people with certain types of disabilities experience higher levels of discrimination? Why?
- How are the barriers identified addressed in Article 25?
- What actions does the CRPD require States to take to remove these barriers?
- How can persons with disabilities assist governments in implementing these changes?
- How would these changes contribute to the improved health of people with disabilities?

WHAT DOES HUMAN RIGHTS LAW SAY ABOUT THE RIGHT TO HEALTH?

The human right to health was first recognized, although indirectly, in Article 25.1 of **Universal Declaration of Human Rights** (UDHR):

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.⁵

The UDHR focuses on the human rights associated with an adequate standard of living, but clearly states that the ultimate objective of those rights is to achieve the “health and well-being” of the individual. Thus, the right to health is **indivisible**, **interrelated** and **interdependent** with other human rights, such as housing, social security and, of course, medical care itself.

In 1966, the concept of the human right to health was more directly and precisely defined in Article 12 of the **International Covenant on Economic, Social and Cultural Rights** (ICESCR):

The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.⁶

This language remains the fundamental expression of the right to health in the context of human rights. However, given the complexity of the subject, the **Committee on Economic, Social and Cultural Rights**, which monitors implementation of the ICESCR, issued **General Comment 14** to articulate more fully the freedoms, entitlements and substantive obligations associated with the right to the highest attainable standard of health guaranteed by the ICESCR:

The right to health is not to be understood as a right to be healthy. The right to health contains both freedoms and entitlements. The freedoms include the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation. By contrast, the entitlements include the right to a system of health protection that provides equality of opportunity for people to enjoy the highest attainable level of health.⁷

⁵ See <http://www.un.org/Overview/rights.html>

⁶ See http://www.unhchr.ch/html/menu3/b/a_ceschr.htm

⁷ See <http://www.unn.edu/humanrts/gencomm/escgencomm14.htm>

General Comment 14 proceeds to discuss a range of “interrelated elements” essential to the right to health:

- Availability
- Accessibility: consisting of four overlapping dimensions: non-discrimination, physical accessibility, economic accessibility, and information accessibility
- Acceptability
- Quality

General Comment 5 of the ICESCR was developed by the **Committee on Economic, Social and Cultural Rights** to address disability in the context of the Covenant, including the subject of health.⁸ Together, ICESCR General Comments 5 and 14 make it clear that persons with disabilities have the right not only to accessible health care services, but also to equality and non-discrimination in relation to all aspects of the right to health. This includes equal access to available health care services and to equality with respect to the resources, conditions, and underlying determinants required for the highest attainable standard of health.

Rule 2 of the 1993 UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules), entitled “Medical Care,” addresses early intervention for prevention of disability. More importantly, it includes a number of crucial principles related to access and delivery of medical services:

- provision of the same level of medical care within the same system as other persons;
- training and equipping of medical personnel in delivery of care to persons with disabilities and that they have;
- access to relevant treatment methods and technology, and medicines needed to preserve or improve level of functioning.⁹

Article 25 of the CRPD reinforces these previous standards of general equality, non-discrimination, and access issues, and expands upon States’ obligations in specific areas, in particular:

- the right to sexual and reproductive health services;
- access to population-based public health programs;
- services provided as close as possible to people’s communities;
- provision of disability-specific health services, including prevention of further disabilities;
- autonomy and independence in health care decisions, on the basis of free and informed consent;
- non-discrimination in access to health insurance and life insurance;
- prohibiting the denial of care, including food and fluids, on the basis of disability.

ACCESSIBILITY OF HEALTH CARE

CRPD Article 25 does not specifically address accessibility of health care services because the obligation to ensure that all aspects of health care are accessible is thoroughly covered by CRPD Article 9, “Accessibility.” (For more on accessibility see Part 2, Chapter 2, “Accessibility,” p. 36). Article 9 of the CRPD is an *article of general application*, meaning that it is understood to apply to the entire convention. Article 9 addresses the general topic of access, requiring that **States Parties** –

⁸ See <http://www.umn.edu/humanrts/gencomm/escgencomm5.htm>

⁹ See <http://www.ohchr.org/english/law/opportunities.htm>



... take appropriate measures to ensure persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public.

This clearly includes health care services, and, in fact, “medical facilities” are specifically mentioned.

As noted above, General Comment 14 of the Committee on Economic, Social and Cultural Rights defines four “interrelated elements” essential to the right to health, two of which are physical accessibility and information accessibility:

Physical accessibility: health facilities, 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 in rural areas. Accessibility further includes adequate access to buildings for persons with disabilities.

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.

EXERCISE 8.3: Designing Accessible Health Services

Objective: To identify the resources and solutions needed to remove practical barriers to health care services

Time: 45 minutes

Materials: Handout of scenarios

1. Introduce:

Observe that even when health care services are available to the general population, people with disabilities often face barriers in accessing them. Divide the participants into three groups and give each one of the scenarios in which a person with a disability seeks medical care.

Give these instructions:

- a. Read the scenarios and discuss:
 - What are the potential accessibility barriers the patient might encounter in the health care setting? What is likely to happen next when each character enters the medical system (e.g., emergency room, doctor’s office, examining room)?
 - What factors might prevent each person from receiving the best possible care?
 - What solutions are needed to accommodate the disability? What resources do these solutions require?
 - What kind of training would health professionals require to make sure they can provide the best care (e.g., accessibility training, education on the rights of persons with disabilities)?
- b. Based on your discussion, plan two brief role plays showing the best and worst outcomes.

Accessibility: A Universal Problem

Inaccessibility of health services is a problem for developed and developing countries alike in terms of both physical accessibility and other practical matters such as accessible communications and health providers who are trained in disability issues. Even where disability legislation provides for accessible services, persons with disabilities often find that they must fight for this right. Disability Rights Advocates, a US-based advocacy group, conducted a survey of persons with disabilities in California, as part of its *Health Access Project*. The results below represent some of the findings:

- **17% of all people** with mobility disabilities reported difficulty getting in the main entrance of their doctor's office.
- **33% of all people** with mobility disabilities experienced barriers accessing examination rooms.
- **69% of wheelchair users** reported difficulty using exam tables.
- **45% of wheelchair users** reported difficulty using x-ray equipment, such as mammography equipment.
- **26% of individuals** who are deaf reported difficulty in getting interpreters for medical appointments.
- **95% of individuals** who are blind or partially sighted reported NOT receiving medical history forms in alternative formats.
- **59% of individuals** with learning disabilities and 64% of individuals with cognitive disabilities reported that their providers communicate with someone else in the room rather than directly communicating with the patient.
- **79% of individuals** with cognitive disabilities report receiving too little time to communicate their symptoms to the provider and ask questions of the provider that are necessary to ensure effective communication.¹⁰

2. Discuss/Plan:

Give participants plenty of time to plan their role-plays.

3. Present:

Ask each group to present its role plays. Ask for comments after each:

- Are there other possible worst-case outcomes?
- Are there additions to the best-case outcomes to suggest?

4. Discuss:

- Are these role plays realistic?
- What can be done to ensure that people with disabilities receive the best possible care

10 "Health Access Project." *Disability Rights Advocates*. http://www.dralegal.org/projects/health_access/index.php



- when they enter the medical system?
- What kind of training would doctors and health care professionals need to make sure they can provide the best care to people with disabilities?

Note to Facilitator: Adapt these scenarios to the needs and context of your participants (e.g., use other settings, other disabilities, other illnesses, including those related to sexuality and reproduction, other barriers).

Scenario 1:

José is a wheelchair user who is paralyzed from the waist down. He was travelling down a sidewalk with a very uneven surface and his wheelchair tipped over. He has a broken leg and a cut on his forehead.

Scenario 2:

Alika is deaf and has come to the doctor alone with a stomach ache and a fever. She is literate and can communicate in writing.

Scenario 3:

Karen has an intellectual disability. She is 28 and lives with her family. She has an independent social life, a boyfriend and a job in a grocery store. Karen's mother has accompanied her to the doctor. Karen has had several serious respiratory infections over the past year since she began smoking.

Optional Exercise: Design an accessible examination room. Either draw what the room would look like or simply list the features it should have to be accessible to persons with all types of disabilities.

EQUALITY AND NON-DISCRIMINATION IN HEALTH CARE

Article 25 of the CRPD recognizes that “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability” and requires that States Parties –

... provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.

This affirms non-discrimination, another of the four “interrelated elements” essential to the right to health, which General Comment 14 of the Committee on Economic, Social and Cultural Rights defines as:

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.

Nevertheless, people with disabilities continually experience discrimination in health systems.

Disability-based Rationing of Health Care

The CRPD prohibits “denial of health care or health services or food and fluids on the basis of disability.” Stigma, the assumption that the lives of persons with disabilities are unhappy, unfulfilled, or not worth living, financial considerations related to providing long-term care, and other non-medical factors can lead to discriminatory and very dangerous decisions that cost persons with disabilities their health or even their lives.

However, health care is a scarce resource. In nearly all countries, the demand for medicines, hospital beds, doctors or other medical services outweighs the available resources to provide them. Everyone cannot receive every treatment, test or service they may desire or even require. Governments and societies must make difficult decisions regarding how to allocate health resources fairly among *all* members of the community. Although there are no easy answers, the principles of human rights dictate that discrimination in health care solely on the basis of disability is a violation of human rights.

EXERCISE 8.4: Case Studies in Medical Decision-making

1. Discuss:

Explain that this exercise examines the ways in which disability may influence medical decisions. Divide participants into three groups and give each a case study. Explain that they must make a decision about what to do in each case.

Case Study 1: Two children of similar age require heart transplants. One is a child with Down Syndrome and the other is a child with no disability. Neither child has any other known medical condition beside the heart-related illness. The likelihood of success of the transplant is equal for both children. The life expectancy of a person with Down Syndrome is generally estimated to be twenty years less than a person without Down Syndrome (if neither is affected by poverty, neglect or other factors that reduce life-expectancy).

Based on this information, which child should receive the heart transplant?

Case Study 2: Two women who are HIV positive apply to receive expensive retroviral drugs from a public health clinic with limited resources. One woman has a chronic psychosocial disability; the other has no disability. The clinic can only support one new client.

Based on this information, which woman should receive the drugs?

Case Study 3: Two members of the same community step on landmines and lose a leg below the knee. One is a seven-year-old schoolboy and the other a farmer aged forty. Both wish to have an artificial leg, but there are resources for only one to receive a prosthesis. The adult will probably be able to wear his artificial limb for many years, but the boy will outgrow his several times before he reaches adulthood. The boy's rehabilitation will therefore be much more expensive than the man's.

Based on this information, who should receive the artificial leg?



2. Report/Discuss:

Ask a spokesperson from each group to describe their case and the decision they reached. After each report, ask for questions and comments from the other groups and ask questions like there:

- How did you make your decision? What factors influenced your decision?
- Is this disability discrimination?
- How should decisions like these be made in real life?

3. Discuss:

- What are the human rights principles that apply in these situations?
- Who *should* be responsible for making these decisions? Doctors? The government? Ethics committees?
- In fact, how are decisions like these usually made?
- How can people with disabilities be protected from discrimination based on disability?

Health promotion and disease prevention

Many public health programs are information and education-based initiatives, such as those aimed at promoting healthy lifestyles and avoiding preventable illness. These programs may include information on:

- the benefits of exercise, proper nutrition and weight management;
- natural and man-made environmental dangers, such as water pollution, soil contamination and workplace hazards;
- health risks associated with smoking, drug use, unprotected sexual activity and other high-risk behaviors;
- preventive measures to avoid infectious diseases, such as childhood and adult vaccinations, family planning, measures to protect against HIV/AIDS and other sexually transmitted diseases, hand-washing and avoiding contact with persons infected with influenza, and the use of mosquito nets to prevent malaria.

Persons with disabilities benefit from healthy choices and suffer from illnesses and accidents just like everyone else. However, the incidence of infectious diseases and other preventable conditions among persons with disabilities is often higher than for the rest of the population because public health programs fail to provide information in inaccessible formats and do not make an effort to target persons with disabilities. Participation by persons with disabilities and their representative organizations in the design and implementation of public health efforts is essential to ensuring that persons with disabilities are able to benefit from these crucial programs.

The CRPD specifically recognizes the importance of gender-sensitive health services and the need for equal access to sexual and reproductive health and population-based health programs. Even though the CRPD makes it clear that all public health programs must include persons with disabilities on an equal basis with others, these particular subjects are highlighted because they are areas in which persons with disabilities are often assumed to be a-sexual, forgotten, de-prioritized, or simply discriminated against in health care systems and national and international health agendas.

Persons with Disabilities and HIV/AIDS Prevention

Persons with disabilities are often not considered to be at risk for contracting HIV/AIDS. A study by Yale University and the World Bank states:

It is commonly assumed that individuals with physical, sensory (deafness, blindness), or intellectual disabilities are not at high risk of HIV infection. They are incorrectly believed to be sexually inactive, unlikely to use drugs or alcohol, and at less risk of violence or rape than their non-disabled peers.¹¹

However, there is clear evidence that persons with disabilities may be at an even higher risk in many instances and that this risk is increased by the fact that they are excluded from public education initiatives aimed at HIV/AIDS prevention.

The discrimination against disabled people manifests itself in numerous ways. AIDS education seminars are often held in buildings that are not wheelchair accessible. Deaf people, many of whom are literate in neither English nor Swahili, are turned away from AIDS testing centers because nobody knows how to communicate with them. Education campaigns, often on radio or television, do nothing to reach those who cannot see or hear the message.¹²

Community-based services

The CRPD requires that States Parties provide health services specifically required as a result of a person's disabilities and stresses that persons with disabilities have the right to receive health care "as close as possible to their own communities, including in rural areas." (The right to live in the community is addressed in detail in Part 2, Chapter 11, "Living Independently and with Dignity in the Community," p. 148.) In many societies, even when legal and social discrimination would not force a person to live in a segregated institution, persons with psychosocial disabilities may find that they can only access mental health services in psychiatric institutions.

The Standard Rules affirm that persons with disabilities have the right to "provision of the same level of medical care within the same system as other persons." Therefore, in communities in which all persons must travel a far distance from their community to receive health care, persons with disabilities must expect to encounter the same disadvantage. However, if a person's disability prevents him/her from traveling this distance because, for instance, public transportation is not accessible, then this represents an unfair disadvantage and a violation of the right to equal access to health services. In this case, an accommodation must be made to provide the necessary care in the person's home or another locally accessible venue, or special measures to provide appropriate transportation must be taken.

11 Nora Groce, N., "A Population at Risk: HIV/AIDS and Disability: Capturing Hidden Voices." *Findings of the Yale/World Bank Global Survey of HIV/AIDS and Disability*. Washington, DC: The World Bank, 2004. <http://sitesources.worldbank.org/disability/resources/health-and-wellness/HIVAIDS.pdf>

12 "For Africa's Deaf and Blind, AIDS is an Unknown Language." *New York Times*, 28 March 2004.



AUTONOMY AND PARTICIPATION IN MEDICAL DECISION-MAKING

Informed Consent and Legal Capacity

CRPD Article 12, “Equal Recognition Before the Law,” addresses legal capacity and participation in decision-making, emphasizing the continuum of supported decision-making. Article 25 reinforces the principles in Article 12 related to the freedom to make decisions about one’s health care, specifying that States Parties must require health professionals to –

... provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.

Failure to respect the independence, autonomy and dignity of persons with disabilities with respect to medical decision-making has led to some of the most egregious human rights abuses experienced by persons with disabilities, including forced sterilization, cruel methods used to “cure” specific behaviors in persons with psycho-social disabilities, psycho-surgery such as lobotomies, therapeutic and non-therapeutic biomedical research, and experimentation. The right to be free from torture and other forms of violence is addressed in detail in Part 2, Chapter 6, “Freedom from Torture and Other Forms of Abuse,” p. 83.

Even when medical interventions do not amount to torture or other inhuman treatment, if they are made without the informed consent and active participation of the patient, they are a violation of human rights and medical ethics. Persons with disabilities have the right to make their own decisions regarding health care on an equal basis with all others, and doctors have the solemn professional responsibility to respect the wishes of the patient.

Persons with disabilities, like all people, are entitled to all treatment and life-sustaining measures available, and they are also entitled to forgo such care *as a matter of individual choice*. This is a matter of equality, both in terms of the right to life and with respect to the right to personal integrity and to make decisions regarding one’s own medical treatment. These principles are cornerstone elements of the human rights framework and of the principles of medical ethics established by Hippocrates in the 4th century B.C. and reaffirmed throughout the history of both ancient and modern medicine.

When a person is unconscious or becomes so ill that he/she can no longer express his/her wishes, treatment decisions are left to doctors and the patient’s family. However, if the patient has previously expressed his/her desire to accept or forgo life-saving treatment, those wishes must be respected under the principles of human rights and medical ethics and according to many national laws. Every person has the right to decide for herself or himself what represents unacceptable suffering or unacceptable conditions for his or her own life. While it may be difficult and unpleasant to think about circumstances in which you might choose to be allowed to die instead of prolonging your life, persons with disabilities are especially vulnerable in situations where other people make decisions based on perceptions of the quality of their lives. Even loving family members and well-meaning doctors may assume that you would declare a situation hopeless or intolerable, when in fact, you would wish to receive treatment.

The best way to ensure that your wishes are known and honored is to express them in writing in an “Advance Directive,” a document you develop to speak for you if you should be unable to speak for yourself when crucial medical decisions must be made.

WITHHOLDING MEDICAL TREATMENT

A Policy of Life and Death

In 2004 in the UK, the High Court issued a verdict in a case, brought by Mr. Oliver Leslie Burke, a 43-year-old man with cerebella ataxia. He challenged the guidelines set out in a pamphlet, "Withholding and Withdrawing Life Prolonging Treatments: Good Practice and Decision Making," published in 2002 by the General Medical Council (GMC), the oversight body for medical practice in the UK. The Disability Rights Commission intervened in the case on behalf of Mr. Burke when a hospital sought to withhold nutrition and hydration from him, based on the established policy of the GMC. In this case, *Regina vs. General Medical Council*, the Court ruled in favor of Mr. Burke receiving this life-sustaining treatment.

Jane Campbell, a disability rights activist who provided testimony in the case, offered her personal viewpoint on the matter at a Symposium entitled "Withholding Treatment," held by the Royal Society of Medicine:

When I heard the verdict I felt a surge of euphoria for two reasons. Firstly, for my own future safety, secondly, because the Court understood, perhaps for the first time, that doctors should not be asked or expected to pass sole judgment on what is "in the best interest" of the severely ill or disabled patient.

When I was born, doctors told my mother to take me home and enjoy me, as I would die within a year. As so often with severe impairment and medical diagnosis, there was no certainty, it is not an exact science. Fortunately, they were wrong. I have good reason to thank the many doctors and other hospital staff who got me through a childhood of chest infections and other life threatening illnesses.

Yet 40 years later, doctors treating an eighteen-month-old child, with the same impairment (Spinal Muscular Atrophy) decided they would not provide ventilation to help her through a chest infection. Her parents did not accept this decision and challenged it in court. There she was known as 'Baby C'. Her doctors argued that her "disability was too terrible to live a quality life." In addition she would need "total bodily care for the rest of her life" and this would be a "burden on state resources and family support." The Court ruled for the hospital having received advice from a range of doctors, who all categorically stated that no one with this diagnosis could live beyond the age of 2 and that if they did, life would be a living hell.

*Adults with SMA, including me, could have told a very different story, but we only found out about the case after the child's death.*¹³

13 Campbell, Jane. Presentation at the Royal Society of Medicine's Symposium on 'Withholding Treatment.' 10 Nov. 2004. <http://www.leeds.ac.uk/disability-studies/archiveuk/Campbell/Withholding%20Treatment1%20-%20Jane's%20final%20draft%208.11.04.pdf>



Different countries may have different requirements in order for an Advance Directive to represent a legal document, for instance having a witness who will testify that you were mentally competent when you wrote it. There are also many formats and styles for Advance Directives. You should try to find out what those requirements are in your country. However, even if you are not sure, a document that expresses your basic wishes and how you define “acceptable quality of life” is a powerful tool. If you share this document with family members, clergy, doctors, and others who may play an important role in treatment decisions, your decisions should be respected. Below is a very simple sample Advance Directive. You may wish for yours to be more detailed.

EXERCISE 8.5: Making a Commitment to Promote the Right to Health

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about the human right of people with disabilities to work, the group is ready to think about taking concrete action.
- Acknowledge that although there is still much planning and information gathering to do, commitment to creating change is also very important.
- Explain that you would like to ask each participant to name one individual action, however small, that she or he is willing and able to take in the next month to promote the human right of people with disabilities to exercise their right to the highest attainable standard of health.

For planning advocacy for the human rights of people with disabilities, see Part 3, “Advocacy! Taking Action for the Human Rights of People with Disabilities,” p. 229.

SAMPLE ADVANCE HEALTH CARE DIRECTIVE (LIVING WILL)

I, (Name) want everyone who cares for me to know what health care I want, when I cannot let others know what I want.

SECTION 1:

I want my doctor to try treatments that may get me back to an acceptable quality of life. However, if my quality of life becomes unacceptable to me and my condition will not improve (is irreversible), I direct that all treatments that extend my life be withdrawn.

A quality of life that is unacceptable to me means (check all that apply):

- ☐ Unconscious (chronic coma or persistent vegetative state)
- ☐ Unable to communicate my needs
- ☐ Unable to recognize family or friends
- ☐ Total or near total dependence on others for care
- ☐ Other:

Check only one:

- ☐ Even if I have the quality of life described above, I still wish to be treated with food and water by tube or intravenously (IV).
- ☐ If I have the quality of life described above, I do NOT wish to be treated with food and water by tube or intravenously (IV).

SECTION 2: (You may leave this section blank.)

Some people do not want certain treatments under any circumstance, even if they might recover.

Check the treatments below that you do not want under any circumstances:

- ☐ Cardiopulmonary Resuscitation (CPR)
- ☐ Ventilation (breathing machine)
- ☐ Feeding tube
- ☐ Dialysis
- ☐ Other:

SECTION 3:

When I am near death, it is important to me that:



USEFUL RESOURCES ON THE RIGHT TO HEALTH

- Constitution of the World Health Organisation:
http://www.who.int/governance/eb/who_constitution_en.pdf
- Disability Rights Advocates: http://www.dralegal.org/projects/health_access/index.php
- The François-Xavier Bagnoud Center for Health and Human Rights:
<http://www.hsph.harvard.edu/fxbcenter>
- General Comment No. 15 of Committee on Economic, Social and Cultural Rights:
<http://www.umn.edu/humanrts/gencomm/escgencomm5.htm>
- General Comment No. 14 of Committee on Economic, Social and Cultural Rights:
<http://www.umn.edu/humanrts/gencomm/escgencomm14.htm>
- Groce, Nora, *A Population at Risk: HIV/AIDS and Disability: Capturing Hidden Voices*. Findings of the Yale/World Bank Global Survey of HIV/AIDS and Disability. Washington, DC: The World Bank, 2004:
<http://sitesources.worldbank.org/disability/resources/health-and-wellness/HIVAIDS.pdf>
- *Removing Barriers to Health Care: A Guide for Health Professionals*. The Center for Universal Design and The North Carolina Office on Disability and Health:
<http://www.fpg.unc.edu/~ncodh/rbar>
- *The Right to Health: Fundamental Concepts and The American Disability Experience*. National Council on Disability, 2005: <http://www.ncd.gov/newsroom/publications/2005/righttohealth.htm>
- Special Rapporteur of the Commission on Human Rights on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health:
<http://www.ohchr.org/english/issues/health/right>
- World Medical Association Declaration of Lisbon on the Rights of the Patient:
<http://www.wma.net/e/policy/l4.htm>