# CHAPTER 9: THE RIGHT TO HABILITATION AND REHABILITATION

## UN Convention on the Rights of Persons with Disabilities

**Article 26, Habilitation and rehabilitation:**

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
   a. Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
   b. Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.
3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

## OBJECTIVES

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

- Define the right to habilitation and rehabilitation
- Explain the importance of the right to habilitation and rehabilitation for people with disabilities
- Understand the interrelationship between the right to habilitation and rehabilitation and other human rights
- Understand the process of developing habilitation and rehabilitation plans
- Identify ways in which the right to habilitation/rehabilitation has been promoted or denied
- Understand the provisions on habilitation and rehabilitation in the UN **Convention on the Rights of Persons with Disabilities** (CRPD).

## GETTING STARTED: THINKING ABOUT HABILITATION AND REHABILITATION

"**Habilitation**" refers to a process aimed at helping people gain certain new skills, abilities, and knowledge. "**Rehabilitation**" refers to re-gaining skills, abilities or knowledge that may have been lost or compromised as a result of acquiring a disability, or due to a change in one's disability or circumstances. The goals of habilitation and rehabilitation as defined in the Convention on the Rights of Persons with Disabilities (CRPD) are to "enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life." As with any other form of service or treatment, a rights-based approach to habilitation and rehabilitation requires the full participation and consent of persons with disabilities.

Habilitation and rehabilitation are very often linked with health-related issues and consequently addressed along with policies related to the right to health. In reality, rehabilitation is much more complex and far-reaching. While health-related rehabilitation can be a vital aspect of strategies to achieve these goals, many other elements are equally important, including those related to employment, education, or simply life skills. To ensure that habilitation and rehabilitation are understood to include the full range of measures necessary to equip persons with disabilities to attain their goals, the CRPD addresses the subject in a separate article.

Eliminating the barriers people with disabilities face in claiming their human rights requires a variety of strategies and tools. Many factors must combine to ensure that societies are as open to persons with disabilities as they are to other people (e.g., accessible environments, specialized programs and technologies, shifts in social and cultural attitudes, enforcement of non-discrimination laws, knowledge of human rights principles). However, efforts that focus on adapting the social, legal, political, and physical environments are often inadequate to create equal opportunities for each disabled person. An individual may require additional supports based on his or her unique circumstances and disability, such as assistive technologies, specific training, education, or skills development.

Unlike "**reasonable accommodation,**" habilitation and rehabilitation focus on equipping the individual with the specific knowledge, tools, or resources that he or she requires rather than ensuring that the general environment, program, practice or job includes the features needed for persons with disabilities to succeed on an equal basis with others. For instance, an employer may be required to provide an accessible workspace that accommodates a wheelchair user; however, the employer is not required to provide a wheelchair to the employee. A bank should have information on its services in accessible formats such as Braille, but the bank is not responsible for teaching a person with a visual impairment how to read using Braille. Responsibility is not always clear, however. For example if an office purchases new voice-recognition software to accommodate a person who is unable to use a standard computer keyboard, it would seem logical that the employer would teach that employee how to use the new software as part of the reasonable accommodation.

Habilitation and rehabilitation are crucial to ensuring that persons with disabilities are able to access all of their human rights. Without adequate habilitation and rehabilitation services, persons with disabilities may not be able to work, go to school, or participate in cultural, sports or leisure activities. At the same time, barriers to other human rights can prevent persons with disabilities from claiming the right to habilitation and rehabilitation. For example, services may be available, but if no accessible transportation exists, many people with disabilities will be

prevented from the benefit of these services. If information about habilitation and rehabilitation services is not available in accessible formats, people with certain disabilities may have never learned that they exist. These examples demonstrate how the right to habilitation and rehabilitation and other human rights are **indivisible, interdependent** and **interconnected.**

While persons with disabilities have the same rights as every other person, the ways people achieve their life goals - how they learn, how they communicate, how they interact with the physical environment, how they interact socially, and many other factors - differ for a variety of reasons, including disability. Habilitation and rehabilitation are processes designed to provide individualized strategies, tools, and resources to assist persons with disabilities in achieving the objectives they have set for themselves. These objectives may be as simple as taking the bus across town or as complex as becoming a world-famous rocket scientist! The important thing to remember is that ensuring access to habilitation and rehabilitation has been identified in human rights law as an obligation for States to enable persons with disabilities to claim their human rights.

## Who May Benefit From Rehabilitation?

Persons with disabilities are just one group that has been identified as entitled to rehabilitation programs and services. International law and policy has long recognized the need for specific populations to have access to rehabilitation in order to successfully integrate or reintegrate in society and lead independent, productive and happy lives.

**Child soldiers and children affected by war:**
The **Optional Protocol** to the **Convention on the Rights of the Child** (CRC) on the Involvement of Children in Armed Conflict calls for "the physical and psychosocial rehabilitation and social reintegration of children who are victims of armed conflict…"[1]

**Refugees:**
Article 14 of the **Convention Against Torture** (CAT) states that "Each State Party shall ensure in its legal system that the victim of an act of torture obtains redress and has an enforceable right to fair and adequate compensation, including the means for as full rehabilitation as possible."[2] The reporting guidelines for countries implementing the CAT require information on any measures to assist in the victim's rehabilitation and reintegration into the community.

**Land Mine Survivors:**
Article 6.3 of the Treaty to Ban Land Mines call on states to "provide assistance for the care and rehabilitation, and social and economic reintegration, of mine victims and for mine awareness programs."[3]

**Torture Survivors:**
In response to the report of the **Special Rapporteur** on Torture and other cruel, inhuman or degrading treatment or punishment, the UN General Assembly adopted a resolution in 2007 that calls on national legal systems to ensure that torture victims "receive appropriate social and medical rehabilitation."[4]

Rehabilitation is sometimes discussed in reference to whole countries as well as to our earth's environment after natural disasters or armed conflict. Rehabilitation is for anything or anyone who can benefit from assistance to ensure optimal functioning and realizing their full potential!

1 See: http://www.unhchr.ch/html/menu2/6/protocolchild.htm
2 See: http://www.unhchr.ch/html/menu3/b/h_cat39.htm
3 See: http://www.icbl.org/treaty/text
4 See: UN General Assembly Resolution 61/153, UN doc. A/RES/61/153. Available at: http://daccessdds.un.org/doc/UNDOC/GEN/N06/503/61/PDF/N0650361.pdf?OpenElement

## EXERCISE 9.1: Habilitation or Rehabilitation?

**Objective:** To understand what it means to enjoy the right to habilitation and rehabilitation
**Time:** 45 minutes
**Materials:** Chart paper and markers or blackboard and chalk

**1. Introduce:**
Remind participants of the distinctions between *habilitation* and *rehabilitation*.

**2. Create Examples:**
Divide participants into small groups; give each group 10 slips of paper and pens and these instructions:

- Working together as a group, make up two examples for each of these terms: *habilitation*, *rehabilitation* and *reasonable accommodation*.
- Write each example on a separate slip of paper along with a label indicating which term you are illustrating.
- Try to use a variety of disabilities (e.g., psycho-social and physical) and motivations (e.g., health, employment, education, social service).

**Sample:**

> You lost the ability to write after a stroke. Now you are learning to write again.
>
> **Rehabilitation**

**3. Test your knowledge:**
Collect the slips, fold them and place in a container. Divide the participants into two teams and explain the competition:

- A player from Team A will draw a slip from the container and read it aloud.
- The first player from Team B must identify the situation as *habilitation*, *rehabilitation* and *reasonable accommodation*. If the answer is correct, Team B wins a point.

Continue in this way, alternating teams until all the slips have been used. Tally a score and declare a winner.

**4. Define:**
Define some basic objectives of the following areas of habilitation and rehabilitation:

- health
- employment
- education
- social services.

**5. Discuss:**

- Are any of the above areas more important than others, in your opinion?
- Do you think that most people with disabilities in your community have access to adequate habilitation and rehabilitation services? Do you think that they know about their right to habilitation and rehabilitation? If not, why?
- What can be done to ensure that all people with disabilities have access to habilitation and rehabilitation?

## Peer Support in Habilitation and Rehabilitation

In the early 1960s, two students with quadriplegia were admitted to the University of California at Berkeley, but instead of living in dormitory with other students, they were required to live at the university hospital. As more students like them were admitted, they formed a group and called themselves "The Rolling Quads." The Rolling Quads questioned their living situation. Why were they forced to live in a hospital? There were many answers to this question. Dormitories on campus were not accessible to people using wheelchairs. University administrators expressed concern about students with disabilities needing medical care. The Rolling Quads used personal assistants or attendants, but there was no provision for personal assistants to share dormitory space. The Rolling Quads also brought up other topics. They could not move freely around the city of Berkeley. There were no curb cuts to go from one sidewalk to another. No accessible transportation existed. If a student's wheelchair broke down, there was no place to go to get it fixed.

The Rolling Quads decided to work together to advocate for their needs. As a result of their advocacy, the university opened the first Disabled Students Office. After a few years, many of the Rolling Quads were ready to graduate. To plan for the future they devised a course called "independent living," in which they discussed how to improve conditions for people with disabilities in the city of Berkeley, just as they had done with the University. Eventually, this group opened the first Center for Independent Living and helped to start a worldwide movement.

The Berkeley students acted on their own initiative, but they were not alone in their actions to champion disability rights. Similar groups were meeting all around the world, and these groups began communicating with each other. These peer groups came to believe that they knew more about life with a disability than the "experts." They decided that the experts about their own lives were really themselves. This viewpoint changed their way of looking at the world. If people with disabilities were their own experts then they were the ones most qualified to teach about their experiences and council other disabled people about living with a disability. They began to call themselves peer counselors.

The Rolling Quads took it upon themselves to identify their own goals for their lives at the University and beyond and made plans for how to achieve these goals. They helped one another through their shared experience. They knew what resources they needed and how to teach others to access those same resources. They took control of their own habilitation and rehabilitation![5]

5 Adapted from Brown, Steve. "Peer Counseling: Advocacy-Oriented Peer Support Part One." 1999. *Inde pendent Living Research Utilization.* http://www.ilru.org/html/publications/readings_in_IL/peer1.html

## WHAT DOES HUMAN RIGHTS LAW SAY ABOUT HABILITATION AND REHABILITATION?

Several international instruments address the subject of rehabilitation.

Article 23 of the Convention on the Rights of the Child (CRC) calls on States Parties to ensure "effective access" of children with disabilities to –

> *…education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.*[6]

The International Labour Organisation's (ILO) **Vocational Rehabilitation and Employment (Disabled Persons) Convention**, adopted in 1983, calls on members to implement national policies on vocational rehabilitation to ensure that "appropriate vocational rehabilitation measures are made available to all categories of disabled persons."[7] This convention states that the purpose of vocational rehabilitation is "to enable a disabled person to secure, retain and advance in suitable employment and thereby to further such person's integration or reintegration into society." Although the text does not provide detailed guidance on what vocational rehabilitation should include, it recognizes that the concept of rehabilitation had evolved significantly since the development of previous ILO standards in 1955 and refers to the need for adoption of new standards based on the **UN World Programme of Action Concerning Disabled Persons**.[8] In that non-binding instrument, rehabilitation was recognized to include the following range of services:

- Early detection, diagnosis and intervention
- Medical care and treatment
- Social, psychological and other types of counseling and assistance
- Training in self-care activities, including mobility, communication and daily living skills, with special provisions as needed (e g., for people with hearing impairment or visual impairment)
- Provision of technical and mobility aids and other devices
- Specialized education services
- Vocational rehabilitation services (e.g., vocational guidance, vocational training, placement in open or sheltered employment)
- Follow-up.

Rehabilitation was further refined and expanded upon in the **UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities**, which classifies rehabilitation as "fundamental concept in disability policy" and a "pre-condition for equal participation" and offers the following definition:

> *The term "rehabilitation" refers to a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence. Rehabilitation*

6 See http://www.unhchr.ch/html/menu3/b/k2crc.htm
7 See http://www.ilo.org/public/english/employment/skills/hrdr/instr/c_159.htm
8 See http://www.un.org/documents/ga/res/37/a37r052.htm

*may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation. The rehabilitation process does not involve initial medical care. It includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance vocational rehabilitation.*[9]

The Standard Rules call on States to ensure access by all persons with disabilities to comprehensive, individualized rehabilitation programs and stress the importance of participation by individuals with disabilities in the "design and organization of rehabilitation services concerning themselves." The Standard Rules reinforce the need for rehabilitation to be provided in the local community, although it also accepts of short-term residential programs for "certain training objectives." In addition States are instructed to draw upon the expertise of organizations of persons with disabilities when formulating or evaluating rehabilitation programs.

At the 58th World Health Assembly in 2005, the **World Health Organisation** adopted a resolution affirming its commitment to promoting comprehensive rehabilitation programs and services, noting the importance of "full physical, informational, and economic accessibility in all spheres of life, including to health and rehabilitation services, in order to ensure full participation and equality of persons with disabilities." The resolution recognizes that "people with disabilities are important contributors to society and that allocating resources to their rehabilitation as an investment."[10]

The **Convention on the Rights of Persons with Disabilities** (CRPD) is the first document to mention both habilitation and rehabilitation. Article 26 calls on States to "organize, strengthen and extend comprehensive habilitation and rehabilitation services and programs, particularly in the areas of health, employment, education and social services." The CRPD stresses that habilitation and rehabilitation should be multi-disciplinary and individualized to take into account the needs and strengths of the person and that services should be available to people as close to their own communities as possible. It recognizes the need for ongoing training of habilitation and rehabilitation professionals and the important role that assistive technologies and devices in habilitation and rehabilitation processes.

The CRPD also mentions rehabilitation in the articles on work, health, and freedom from exploitation, violence, and abuse, though no specifics are offered as to what rehabilitation entails in those contexts.

The principle of participation by persons with disabilities in the design, development, and implementation of habilitation and rehabilitation programs is implicit in the fundamental concepts of participation, autonomy, and decision-making included in CRPD Article 3 on General Principles. The principles contained in this article are considered foundational, which means they inform and apply to all of the human rights throughout the Convention. The first of the General Principles listed in Article 3 is:

a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;

Respecting the freedom of choice and the independence of persons with disabilities is an essential component of ensuring the right to habilitation and rehabilitation.

9 See http://www.un.org/ecosocdev/geninfo/dpi1647e.htm
10 See http://www.who.int/disabilities/publications/other/wha5823/en/index.html

### Some Startling Statistics about Habilitation and Rehabilitation

- People with disabilities are estimated to form 10% of the population in any country, and around 2% would need some form of rehabilitation services. Yet only 0.01% to 0.02% of the population in developing countries actually gets such services.[11]

- Fewer than 10% of landmine victims have access to proper medical care and rehabilitation services. In many countries landmine accidents happen in remote areas, where the victim cannot reach a hospital in time. The U.S. Department of State estimates that less than one in four landmine amputees are fitted with a proper prosthesis.

- In Australia, women with disabilities participate in the labor market at a lower rate than men with disabilities across all disability levels and types. Women with disabilities are less likely than men with disabilities to receive vocational rehabilitation or entry to labor market programs. Commonwealth Rehabilitation Services statistics for 1994/5 indicate only 35% of referred clients were female with women more likely to be rehabilitated to independent living (45%) than vocational goals (36%).[12]

## EXERCISE 9.2: Participating in the Design of Habilitation and Rehabilitation Programs

**Objective:** To practice developing an action plan for habilitation or rehabilitation
**Time:** 1 hour
**Materials:** None

**1. Introduce:**
Ask participants questions like these about the importance of the participation of people with disabilities:

- Why it is important for habilitation and rehabilitation programs to be "individualized"?
- Why should persons with disabilities play a role in developing programs for which they are the beneficiaries?
- How are habilitation and rehabilitation programs usually planned in your community?

**2. Discuss:**
Divide participants into small groups. Give these instructions:

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11 Zhao, Tizun and Kwok, Joseph "Evaluating Community Based Rehabilitation: Guidelines for Accountable Practice." Disability INFormation Resources (DINF). www.dinf.ne.sp/doc/Englsih/resource/2000221/2000210z.htm

12 "Submission from Women With Disabilities Australia (WWDA) to the Standing Committee on Employment and Workplace Relations Inquiry into Increasing Participation in Paid Employment." 2003. *Women with Disabilities Australia*. http://www.wwda.org.au/employsub.htm

- Invent a fictional but typical situation of a person who requires habilitation or rehabilitation services in one of the following areas: health, employment, education or social services.
- Choose somebody to play the role of the “client” (the person for whom the habilitation or rehabilitation is being provided).
- Other group members can designate themselves as other actors, such as service providers, counselors, doctors, family members, disability advocates, other people with disabilities, or others who should be involved in the design and implementation of a habilitation or rehabilitation plan.
- Use the following questions as a basic guide for developing an outline for the plan. Stress to participants that they are not being asked to create a complicated, detailed plan, but rather an outline that defines the goals, approach, and basic structure. Some questions should be answered by the solely or primarily by the client, while others will involve other actors.
    - What goal are you attempting to reach that requires assistance in the form of habilitation or rehabilitation?
    - What is the definition of success for your habilitation or rehabilitation scheme?
    - Why are you entitled to these services?
    - What human rights are affected by your need for habilitation or rehabilitation in this context?
    - Who should participate in the design of your program?
    - What is each person’s responsibility (including the client)?
    - What resources are required for the client to successfully reach his or her goals (e.g., training, assistive technologies)?
    - What qualifications, training, or education should instructors, counselors, health care practitioners or other team members have in order to provide the habilitation or rehabilitation services required.

**3. Report:**
Ask each group to introduce its “client,” and explain the collaborative process they used to design the habilitation or rehabilitation plan. Allow both the client and the spokesperson to describe their roles in planning. Briefly describe the plan.

**4. Analyze/Discuss:**
- What was the most difficult part of this process? What problems were encountered?
- What types of decisions were easy?
- What other questions or subjects, in addition to those listed above, did the groups identify as critical to address?
- What can persons with disabilities do if they feel like they are not being included in decisions regarding their own habilitation and rehabilitation programs?

## UN Agencies and Community Based Rehabilitation

In 1994 the International Labour Organization (ILO), United Nations Educational Scientific and Cultural Organization (UNESCO) and World Health Organization (WHO) produced a "Joint Position Paper on Community Based Rehabilitation" in order to promote a common approach to the development of community based rehabilitation (CBR) programs. The paper states:

> *CBR is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities.*
>
> *CBR is implemented through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services.*

The major objectives of CBR are:

1. To ensure that people with disabilities are able to maximize their physical and mental abilities, to access regular services and opportunities, and to become active contributors to the community and society at large.
2. To activate communities to promote and protect the human rights of people with disabilities through changes within the community, for example, by removing barriers to participation."

The ILO/UNESCO/WHO approach clearly recognizes that persons with disabilities are entitled to rehabilitation, but also that the communities themselves require training, assistance, and resources to reach their own goals of including all of their members and benefiting from the contributions that persons with disabilities can make.[13]

## HABILITATION AND REHABILITATION FOR PERSONS WITH INTELLECTUAL DISABILITIES AND PSYCHO-SOCIAL DISABILITIES

Persons with intellectual or psycho-social disabilities are particularly vulnerable to human rights violations committed in the name of "rehabilitation." The objective of habilitation and rehabilitation under the CRPD is to "enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life." These efforts must always be based on the goals and preferences expressed by the person who is receiving the rehabilitation service.

Persons with intellectual or psycho-social disabilities are often subjected to programs and therapies intended not to help them achieve what they want, but rather to change them in a way that the person may not wish to be changed. It would be unthinkable to force a person without an arm to wear an unwanted prosthetic limb or to insist that a blind person who

13 See http://www.ilo.org/public/english/employment/skills/download/jointpaper.pdf

does not like animals learn to work with a service dog. However, people with intellectual disabilities or psycho-social disabilities are assumed not to know "what is good for them" or to be incapable of defining reasonable goals for themselves. In these cases, doctors, family members, or others often employ rehabilitation approaches that further their own objectives and may violate the wishes of the individual with intellectual disabilities. Such "rehabilitation" violates fundamental human rights principles such as autonomy, freedom of expression, participation and inclusion, non-discrimination, and personal integrity. Furthermore, it directly contravenes the core purpose of habilitation and rehabilitation, which must be based on what the person decides is right and appropriate for himself and herself, independently or in the context of supported decision-making, if this support is requested by the person with the disability.

## EXERCISE 9.3: Making a Commitment to Promote Habilitation and Rehabilitation

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about the human right of people with disabilities to habilitation and rehabilitation, 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 habilitation and rehabilitation.

To plan advocacy for the human rights of people with disabilities, see Part 3, "Advocacy! Taking Action for the Human Rights of Persons with Disabilities," p. 229.

## USEFUL RESOURCES ON THE RIGHT TO HABILITATION AND REHABILITATION

- ILO Convention 159 (concerning Vocational Rehabilitation and Employment (Disabled Persons): http://www.ilo.org/ilolex/english/convdisp1.htm
- ILO Vocational Rehabilitation and Employment (Disabled Persons) Recommendation (No. 168): http://www.ilo.org/ilolex/english/recdisp1.htm
- WHO Disability and Rehabilitation Team (DAR): http://www.who.int/disabilities/en/
- WHO Disability and Rehabilitation Action Plan 2006-2011: http://www.who.int/disabilities/publications/dar_action_plan_2006to2011.pdf
- World Bank, Community-based rehabilitation (CBR): http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALPROTECTION/EXTDISABILITY/0,contentMDK:20192706~menuPK:418196~pagePK:148956~piPK:216618~theSitePK:282699,00.html