Human Rights. YES!

Action and Advocacy on the Rights of Persons with Disabilities

by Janet E. Lord, Katherine N. Guernsey, Joelle M. Balfe & Valerie L. Karr
Nancy Flowers, Editor

HUMAN RIGHTS EDUCATION SERIES

Topic Book 6

SHAFALLAH
Center for Children with Special Needs

A Publication of the University of Minnesota Human Rights Resource Center.
Developed and coordinated by BlueLaw, LLP, in partnership with Disabled Peoples' International.

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About the Human Rights Education Series

The Human Rights Education Series is published by the University of Minnesota Human Rights Resource Center. Edited by Nancy Flowers, the series provides resources for the ever-growing body of educators and activists working to build a culture of human rights in the United States and throughout the world. Other publications in the series include:

Human Rights Here and Now:
Celebrating the Universal Declaration of Human Rights
edited by Nancy Flowers

Economic and Social Justice:
A Human Rights Perspective
by David Shiman

Raising Children with Roots, Rights and Responsibilities:
Celebrating the UN Convention on the Rights of the Child
by Lori DuPont, Joanne Foley, and Annette Gagliardi

Lesbian, Gay, Bisexual, & Transgender Rights:
A Human Rights Perspective
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The Human Rights Education Handbook:
Effective Practices for Learning, Action, and Change
by Nancy Flowers

Lifting the Spirit:
Human Rights and Freedom of Religion or Belief
by the Tandem Project and Human Rights Resource Center

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ABOUT THE PROJECT PARTNERS

Advocating Change Together (ACT) is a grassroots disability rights organization run by and for people with developmental and other disabilities. ACT's mission is to help people across disabilities see themselves as part of a larger disability rights movement and make connections with other civil and human rights efforts.

Blue Law, LLP is a service-disabled, veteran-owned law firm specializing in international law and international development programming. Based in Washington, DC, Blue Law's human rights and disability practice group works with disabled peoples organizations, international human rights institutions, and governments to advance disability inclusion in international development programming worldwide.

Disabled Peoples' International (DPI) is the only global, grassroots, cross-disability network of national organizations and assemblies of persons with disabilities. The goals of DPI are to advance the human rights of persons with disabilities through full participation, equalization of opportunity and development; promotion of the economic and social integration of persons with disabilities; and development of and support to disabled peoples' organizations (DPOs). Established in 1981 and based in St. John's, Canada, DPI has a presence in more than 140 countries.

The Harvard Project on Disability (HPOD), located at Harvard Law School, is an interdisciplinary law and policy center dedicated to improving the circumstances of persons with disabilities, primarily through implementation of the United Nations Convention on the Rights of Person with Disabilities. HPOD advises governments and national human rights institutions regarding domestic disability laws and policies, provides capacity building and human rights training to international and local disabled persons and their representative organizations, and conducts academic research. HPOD acknowledges support from a grant by the Foundation Open Society Institute (Zug).

The University of Minnesota Human Rights Resource Center, an integral part of the University of Minnesota Human Rights Center, works to create and distribute human rights education via electronic and print media; to train activists, professionals, and students as human rights educators; and to build advocacy networks to encourage effective practices in human rights education.

ABOUT THE PROJECT FUNDER

The Shafallah Center for Children with Special Needs, located in Doha, Qatar, is a Center of Excellence designed to provide comprehensive services to children with developmental disabilities, their families and the community. Established as an initiative of the Chairperson of the Supreme Council of Family Affairs, Her Highness Sheikha Mozah Bint Nasser Bin Abdullah Al-Missned, the Shafallah Center reflects her belief in the vitality and importance of the family's and the child's role in society. The Center provides state-of-the-art services, educational facilities, and a dedicated staff to enable students to learn, grow, and integrate successfully into their community. The Shafallah Center's dedication to the human rights of all persons with disabilities is clearly demonstrated by its very generous support of all stages of the development of *Human Rights. YES!* educational materials

FOREWORD BY THE HIGH COMMISSIONER FOR HUMAN RIGHTS

United Nations Human Rights

OFFICE OF THE HIGH COMMISSIONER FOR HUMAN RIGHTS

On current estimates, one in ten people lives with a disability. Of these, a high proportion live in poverty, on the margins of society, and their rights are all too often breached. In many cases, people are simply unaware that they have rights and unaware of the opportunities that exist to combat inequality and bring about positive change. The adoption of the Convention on the Rights of Persons with Disabilities and its Optional Protocol has provided us with the means to shift disabling attitudes and environments in society and empower persons with disabilities to realize their rights. Now is the time to bring this new Convention home, to people, and I believe that "Human Rights. YES!" offers a much-needed tool to achieve this.

The curriculum is an accessible and easy-to-use training manual and provides a major resource for human rights advocates and practitioners to strengthen advocacy and human rights education. The division of the training material into three chapters – elaborating upon the human rights context of disability, a right-by-right explanation of the Convention and plans for future advocacy and action – comprehensively covers the human rights of persons, focusing in particular on the new Convention but drawing also from the body of law and experience of the broader human rights system. Importantly, each unit encourages participants in the course to make commitments to promote respect for the rights of persons with disabilities beyond the classroom. The chapter format offers practitioners the option of providing a full training package over an extended period, or shorter training sessions on specific human rights issues.

Human rights education through curricula such as "Human Rights. YES!" is an essential step in empowering people and communities. For persons with disabilities and their representative organizations, learning about human rights can help combat discrimination when it occurs and strengthen advocacy efforts to avoid it in the future. Significantly, through informed advocacy, we can help build the capacity and will of governments to undertake the law and policy reform needed to bring about change on the ground. For the broader community, the curriculum raises awareness of human rights and the ways that persons with disabilities can and do contribute to society – an important step in building more inclusive societies.

"Human Rights. YES!" is an indispensable addition to the human rights education tool-kit and I take pleasure in being associated with it. I congratulate the authors and sponsors for this initiative and I hope that it is widely used.

Louise Arbour
United Nations High Commissioner for Human Rights

ABOUT THE EDITOR

Nancy Flowers is a writer, editor, and human rights activist. She has worked to develop Amnesty International USA's education program and was a co-founder of Human Rights USA. Recent publications include *Compasito, a Manual for Children's Human Rights Education* (Council of Europe, 2007) and *Local Action/Global Change: Learning about the Human Rights of Women and Girls*, (Paradigm Press, 2007). She has served as consultant to governments, NGOs, and UN agencies and edits the University of Minnesota Human Rights Resource Center's Human Rights Education Series.

ABOUT THE AUTHORS

Joelle Balfe is an independent consultant with an extensive practice area that includes disability issues, international public health, and human rights law and policy. She has developed human rights education curricula and materials for a range of non-governmental organizations and spearheaded national and international advocacy campaign initiatives. Ms. Balfe provided core analytical and advocacy support to both governments and civil society participants in the development of the UN Convention on the Rights of Persons with Disabilities. Her diverse consulting practice provides analytical, communications, advocacy, and writing services to individuals, organizations, and institutions in the public and private sectors.

Katherine Guernsey is an attorney with a practice focusing on public international law, human rights, disability, and international development. Her clients include the World Bank Group and Disabled Peoples' International. She is also an adjunct professor at the American University School of International Service, where she teaches human rights. Ms. Guernsey served as legal counsel to a variety of disabled people's organizations and governmental delegations throughout the drafting of the UN Convention on the Rights of Persons with Disabilities, and continues to work on issues related to ratification and implementation of the Convention. She has designed and implemented human rights education and awareness-raising initiatives for people with disabilities in Central and South America, Africa, Europe, Asia and the Middle East.

Valerie Karr is an expert in the field of child education with a strong clinical background in special education and extensive experience in international education programming, including consultancies for UNESCO's inclusive education sector. Currently a Ph.D. candidate at Teachers College, Columbia University, Ms. Karr is a specialist in qualitative and quantitative program analysis, including assessment and evaluation and the development of measurement tools and strategies.

Janet Lord is a Partner in the international law and development firm Blue Law LLP and an Adjunct Professor of Law at the University of Maryland School of Law. A human rights educator with more than ten years of experience, Ms. Lord has designed and delivered human rights education programs in all regions of the world, most recently in Yemen, Egypt, and Liberia. She participated in all sessions of the negotiation of the UN Convention on the Rights of Persons with Disabilities, drafting proposed treaty text and advising civil society and governments alike on complex legal and technical matters. A leading expert on international human rights law and disability, Ms. Lord has implemented human rights programming for a number of national and international organizations, including the UN Office of the High Commission for Human Rights, UNDP, UN DESA, the US National Council on Disability, Disabled Peoples International, and IFES.

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The inspiration for *Human Rights. YES!* is inseparable from that which led to the drafting and adoption of the UN Convention on the Rights of Persons with Disabilities. The calls for the initiation of a convention-drafting process and the development of human rights education materials specifically addressing the rights of people with disabilities both arose from a 1999 UN-sponsored conference in Hong Kong. This impetus stimulated human rights education workshops in many countries while the convention text itself provided the coherent structure around which we could develop the kind of comprehensive educational resource first envisioned in Hong Kong.

The Shafallah Center for Children with Special Needs in Doha, Qatar, generously provided the financial support that made our vision for this project a reality. We acknowledge the Chairman of Shafallah, Hassan Ali Bin Ali, for his outstanding leadership and sincere commitment to human rights education on the rights of people with disabilities, which has made possible the development of this project and its broad dissemination in four languages in print, CD-ROM, and web-based formats. This project was formally launched at the Second Annual Shafallah Forum in Doha, Qatar in 2007. We likewise gratefully acknowledge Tom Coyne and Dominic Coyne, who provided essential coordination and all manner of support throughout the various phases of the project. The original cover art painting was generously provided by 14-year-old Qatari artist Muhammad Al Malki.

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Human Rights. YES! Review Board

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To everyone and every organization acknowledged, we thank you and the work that you do in support of international disability rights advocacy and education around the globe.

Janet Lord, Katherine Guernsey, Joelle Balfe, Valerie Karr, and Nancy Flowers
Baltimore, Maryland
2007

Introduction to *Human Rights. YES!*

The Purpose of *Human Rights. YES!*

The adoption of the UN Convention on the Rights of Persons with Disabilities by the UN General Assembly in 2006 presents both a challenge and an opportunity for the international disability rights movement. The human rights of persons with disabilities are now set forth in a legally binding treaty and provide a common language for engaged advocacy on a wide range of issues of importance to persons with disabilities. The challenge is to undertake broad-based education around the CRPD to ensure that persons with disabilities worldwide know and claim their rights to live self-determined lives in their communities with dignity.

Using *Human Rights. YES!*

This manual is intended to help all those who care about the human rights of persons with disabilities to become effective educators and advocates on human rights and disability, able to share both their passion and their knowledge. *Human Rights. YES!* draws on the experience of many educators and organizations, illustrating effective advocacy practices and distilling their accumulated insights in the development of participatory exercises.

Like most human rights education manuals, *Human Rights. YES!* is designed to be used as both a reference and tool: easy to read, easy to use, easy to photocopy, easy to relate to people's real lives. Each part and chapter stands alone and may be read and used independently depending on the needs of the reader. Throughout the manual, technical terms are printed in boldface type and defined in the Glossary.

Human Rights. YES! is unique in that it is written and designed for use by people with disabilities. However, adaptation for specific learners is recommended throughout the text. Facilitators should be sensitive to the needs of any particular audience and adapt the physical environment, activities, and all means of communication to make everyone's full participation possible. For more information on facilitation, see Annex 2, "Facilitating Human Rights Education," p. 291.

Part 1, "Understanding Disability as a Human Right," sets out some basic principles for thinking about human rights and disability. It provides a review of who is responsible for human rights and introduces the UN Convention on the Rights of Persons with Disabilities. It also summarizes common attitudes and perceptions about disability that may stand in the way of realizing human rights, and explores the way in which disability issues have been defined and researched. It concludes by setting forth a rights-based approach to disability and making the links between disability, human rights, and effective advocacy.

Part 2, "The Convention on the Rights of Persons with Disabilities," provides a comprehensive overview of the human rights set forth in the CRPD in seventeen chapters. Each chapter considers a set of human rights contained in the CRPD, providing an accessible explanation of each right, and incorporating participatory exercises to help people consolidate their understanding, articulate the issues in their own words and contexts, and think constructively about how to take action. Illustrative examples of advocacy strategies, helpful facts, and other topical information are also provided. Each chapter concludes with a short list of useful additional resources on the topics covered.

Chapter 1 Equality and Non-discrimination 24
Chapter 2 Accessibility. 36
Chapter 3 The Right to Participation in Political and Public Life 49
Chapter 4 Freedom of Expression and Opinion 60
Chapter 5 The Right to Life and Protection in Situations of Risk. 70
Chapter 6 Freedom from Torture and Other Forms of Abuse 83
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Chapter 17 The Rights of Other Populations. 219

Part 3, "Advocacy! Taking Action for the Human Rights of People with Disabilities," explains the essentials of effective human rights advocacy: awareness of rights; awareness of self; and action. Examples of advocacy actions are provided, along with exercises for adopting an advocacy action plan and an advocacy action plan template. Finally, Part 3 takes the reader through six steps of advocacy:

Step 1: Defining the change you want to make
Step 2: Articulating the change you want to make
Step 3: Preparing for action
Step 4: Making your action plan
Step 5: Taking action
Step 6: Following-up.

The **Annexes** contain a variety of useful resources:

- **Annex 1, Human Rights Documents**: Full text, plain-language text, and summary of the Universal Declaration of Human Rights and the Convention on the Rights of Persons with Disabilities and a list of major human rights instruments and their Internet addresses
- **Annex 2, Facilitating Human Rights Education**: Tips on interactive learning and accommodating learning for participants with disabilities, as well as model workshops
- **Annex 3, Resources**: A list of significant printed, electronic, and other materials
- **Annex 4, Glossary**: Definitions of human rights terms used in the text
- **Annex 5, Topic Index**: A list of principle subjects covered in the book

PART 1:

UNDERSTANDING THE HUMAN RIGHTS OF PERSONS WITH DISABILITIES

PART 1 CONTENTS:

Introduction to the Human Rights of Persons with Disabilities 2
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Who is Responsible for Human Rights? 9
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Defining and Researching Disability 15
Attitudes and Perceptions Regarding Disability 17
The Human Rights Approach to Disability 19
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PART I:
UNDERSTANDING THE HUMAN RIGHTS OF PERSONS WITH DISABILITIES

OBJECTIVES

The background information and exercises contained in this chapter will prepare participants to use this manual effectively by developing a fundamental understanding of:

- Basic human rights concepts
- The international human rights framework, in particular, the Convention on the Rights of Persons with Disabilities (CRPD) and other key disability-specific documents
- The challenges and barriers people with disabilities commonly face in claiming their human rights
- How to express issues and frame advocacy strategies in human rights terms.

INTRODUCTION TO THE HUMAN RIGHTS OF PERSONS WITH DISABILITIES

People with disabilities have the same rights as all other people. However, for a number of reasons they often face social, legal, and practical barriers in claiming their human rights on an equal basis with others. These reasons commonly stem from misperceptions and negative attitudes toward disability.

EXERCISE 1: The Impact of Myths and Stereotypes about Persons with Disabilities

Objective: To share lived experiences with discrimination based on myths and stereotypes and begin thinking about their impact on human rights
Time: 45 minutes
Materials: Optional: Copies of "Common Myths and Stereotypes about People with Disabilities"

1. Introduce:
Explain that discrimination is often based on mistaken ideas and stereotypes that one group holds about another. This exercise will examine the impact of these myths and stereotypes on the lives of people with disabilities.

2. Brainstorm/Analyze:
Divide participants into small discussion groups and ask them to develop a list of myths and stereotypes about people with disabilities. Ask each group to discuss these questions:

- What are some underlying reasons for these views (e.g., fears, cultural and religious attitudes, ignorance)?
- How do these views affect the way people with disabilities are regarded and/or treated by their families? By their communities? In public policy and law?

3. Report/Discuss:
Ask a spokesperson from each group to summarize their conclusions and discuss their findings.

- What seem to be the principal underlying reasons for these myths and stereotypes?
- What seem to be the most serious effects of these myths and stereotypes on persons with disabilities? On society?

Discuss these or similar questions:

- Which of these views are most prevalent in your community?
- How do these views result in discrimination and prevent people with disabilities from enjoying their human rights?
- How can these views be confronted?
- Why is it important to challenge such myths about people with disabilities?

Variation: Conclude the exercise by distributing the handout "Myths and Stereotypes about People with Disabilities." Compare this list with that generated by participants and ask questions like these:

- Were your lists similar to this one?
- Were there ideas on this list you did not include? Did this list omit ideas you included on your lists?
- How do you explain any differences between your list and this one?
- Do you disagree with any of the statements on this list?
- Did this list make you aware of new points of view?

Myths and Stereotypes about People with Disabilities

People with disabilities –

- cannot be self-sufficient/are excessively dependent;
- are to be pitied
- are helpless
- are cursed/disability is a punishment for evil
- are bitter because of their fate
- resent the non-disabled world
- have lives not worth living
- are better off at home
- cannot work
- cannot have a family/cannot be good parents
- are asexual
- need to be cured and helped by medical professionals
- need special, separate educational programs
- cannot be involved in cultural/recreational activities
- are unable to learn
- (People with intellectual disabilities) are naive, like children, and cannot make any decisions for themselves
- (People with psycho-social disabilities) are dangerous/a threat/violent
- must use alternative ways of communicating because they are stupid.

GETTING STARTED: THINKING ABOUT HUMAN RIGHTS

To provide a foundation for examining the human rights of people with disabilities, this chapter begins by examining fundamental human rights principles and the general human rights framework. It then looks at human rights in the context of disability.

What are Human Rights?

Human rights are based on human needs. They assert that every person is equally entitled not only to life, but to a life of dignity. Human rights also recognize that certain basic conditions and resources are necessary to live a dignified life.

Human rights have essential qualities that make them different from other ideas or principles. Human Rights are:

Universal: human rights apply to every person in the world, regardless of their race, color, sex, ethnic or social origin, religion, language, nationality, age, sexual orientation, disability, or other status. They apply equally and without discrimination to each and every person. The only requirement for having human rights is to be human.

Inherent: human rights are a natural part of who you are. The text of Article 1 of the **Universal Declaration of Human Rights (UDHR)** begins "*All human beings are born free and equal in dignity and rights*."

Inalienable: human rights automatically belong to each human being. They do not need to be given to people by their government or any other authority, nor can they be taken away. Nobody can tell you that you do not have these rights. Even if your rights are violated or you are prevented from claiming your human rights, you are still entitled to these rights.

Human rights relate to one another in important ways. They are:

Indivisible: human rights cannot be separated from each other;

Interdependent: human rights cannot be fully realized without each other;

Interrelated: human rights affect each other.

In simple terms, human rights all work together and we need them all. For example, a person's ability to exercise the right to vote can be affected by the rights to education, freedom of opinion and information, or even an adequate standard of living. A government cannot pick and choose which rights it will uphold for the people who live in that country. Each right is necessary and affects the others.

Human Rights Instruments

Human rights are outlined in a variety of international human rights documents, (sometimes called "**instruments**") some of which are legally binding and others that provide important guidelines but are not considered **international law**. This section looks at the overall human rights framework.

1. The Universal Declaration of Human Rights (UDHR)

The Universal Declaration of Human Rights (UDHR) was adopted by the United Nations in 1948. Many other documents have since been developed to provide more specific details about human rights; however, they are all based on the fundamental human rights principles laid out in the UDHR. The full text of the UDHR can be found in Annex 1, p. 244. Below is the official abbreviated version of the UDHR, which lists the key concept of each **article** in the Declaration.

The Universal Declaration of Human Rights (UDHR) (Official Abbreviated Version)

Article 1	Right to Equality
Article 2	Freedom from Discrimination
Article 3	Right to Life, Liberty, and Personal Security
Article 4	Freedom from Slavery
Article 5	Freedom from Torture and Degrading Treatment
Article 6	Right to Recognition as a Person before the Law
Article 7	Right to Equality before the Law
Article 8	Right to Remedy by Competent Tribunal
Article 9	Freedom from Arbitrary Arrest and Exile
Article 10	Right to Fair Public Hearing
Article 11	Right to be Considered Innocent until Proven Guilty
Article 12	Freedom from Interference with Privacy, Family, Home, and Correspondence
Article 13	Right to Free Movement in and out of the Country
Article 14	Right to Asylum in other Countries from Persecution
Article 15	Right to a Nationality and the Freedom to Change It
Article 16	Right to Marriage and Family
Article 17	Right to Own Property
Article 18	Freedom of Belief and Religion
Article 19	Freedom of Opinion and Information
Article 20	Right of Peaceful Assembly and Association
Article 21	Right to Participate in Government and in Free Elections
Article 22	Right to Social Security
Article 23	Right to Desirable Work and to Join Trade Unions
Article 24	Right to Rest and Leisure
Article 25	Right to Adequate Living Standard
Article 26	Right to Education
Article 27	Right to Participate in the Cultural Life of Community
Article 28	Right to a Social Order that Articulates this Document
Article 29	Community Duties Essential to Free and Full Development
Article 30	Freedom from State or Personal Interference in the above Rights

EXERCISE 2: The Interdependence of Rights

Objective: To examine the fundamental human rights contained in the UDHR and raise awareness of how these rights relate to each other
Time: 45 minutes
Materials: Chart paper and markers or blackboard and chalk
Copies of Effects Cascade for each small group
Copies of the simplified version of the UDHR

1. Explain/Illustrate:
Introduce the activity by observing that human rights are based on human needs and that everyone is entitled to and needs all their human rights. Explain that this activity helps to illustrate how rights are indivisible, interdependent, and interrelated and the far-reaching effects when just one right is denied.

Demonstrate how the "Effects Cascade" works:

1. Write a human right from the UDHR in the center of the big circle at the top of the cascade (e.g., right to education).
2. Ask, "If this right is denied, what are three possible effects?" Write any three effects mentioned in circles that extend with arrows from the central circle.
3. Then take each of the three mentioned effects (e.g., inability to get a good job) and ask "What human rights would be denied by this effect (e.g., right to an adequate standard of living). Write each right in a circle that extends with arrows from the effect.

Alternative: Ask each group to write the number of the UDHR article for each right mentioned in the cascade (e.g., "Inability to get a good job": Article 25, Right to Adequate Living Standard; Article 23, Right to Desirable Work).

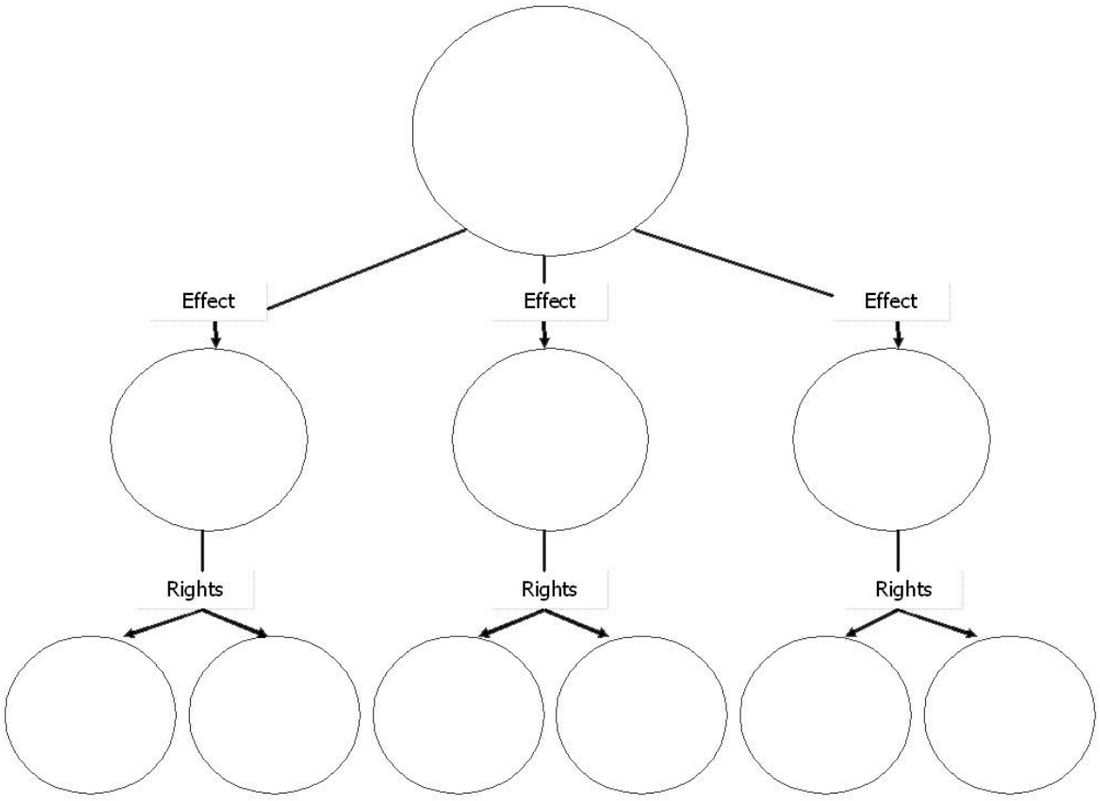
2. Complete:
Divide participants into small groups of 2-4 and give each a copy of the Effects Cascade. Ask each group to write a human right in the center of their chart. Encourage groups to choose a variety of different rights. Ask them to consider what effects result when a person with disabilities – or anyone – is denied this right.

Note to Facilitator: Participants may think of more than three effects, but encourage them to choose the three most far-reaching effects.

3. Discuss:
Ask a spokesperson from each group to present its chart. Discuss the results.

- Are you surprised by some of the effects when one right is denied?
- What happens when more than one right is denied?
- What results are most negative for people with disabilities?
- What does this activity suggest to you about the interdependence of rights (e.g., the importance of enjoying *all* human rights)?

SAMPLE EFFECTS CASCADE



2. International Human Rights Conventions

A **convention** (also known as a **treaty**) is a written agreement between States. It is typically drafted by a working group appointed by the UN General Assembly. Once the convention is drafted, it goes to the UN General Assembly for adoption. The next step is for countries to **sign** and **ratify** it. By signing a convention, a country is making a commitment to follow the principles in the convention and to begin the ratification process, but the convention is not legally binding on a country until it is ratified. Ratification is a process that takes place in each country, whereby the legislative body of the government takes the necessary steps to officially accept the convention as part of its national legal structure. Once a country signs and ratifies a convention, it becomes a **State Party** to that convention, meaning it has a legal obligation to uphold the rights the convention defines. Each convention must be ratified by a particular number of countries before it **enters into force** and becomes part of international law.

In the last sixty years, several human rights conventions have been developed that elaborate on the human rights contained in the UDHR. Nine of these instruments are considered “core” human rights conventions: they cover a major human rights issue and have a treaty-monitoring body that assesses and enforces how a State meets it obligations to that treaty.

Two of these conventions are called covenants and address broad human rights issues:

- The **International Covenant on Civil and Political Rights** (ICCPR, adopted 1966, entered into force 1976)[1].
- The **International Covenant on Economic, Social and Cultural Rights** (ICESCR, adopted 1966, entered into force 1976)[2].

The two Covenants and the UDHR combine to create a trio of documents known as the **International Bill of Rights.**

An additional seven UN human rights conventions address either thematic issues or particular populations.[3]

THE HUMAN RIGHTS FRAMEWORK

INSTRUMENT	ENTERED INTO FORCE
Universal Declaration of Human Rights (UDHR)	Not Applicable
International Covenant on Civil and Political Rights (ICCPR)	1976
International Covenant on Economic, Social, and Cultural Rights (ICESCR)	1976
Convention on the Elimination of All Forms of Racial Discrimination (CERD)	1965
Convention on the Elimination of all forms of Discrimination Against Women (CEDAW)	1979
Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)	1984
Convention on the Rights of the Child (CRC)	1989
Convention on Protection of the Rights of All Migrant Workers and Members of their Families	1990
International Convention for the Protection of All Persons from Enforced Disappearance	*
Convention on the Rights of Persons with Disabilities (CRPD)	*

*Not yet entered into force as of September 2007

These nine core human rights conventions form an interdependent **human rights framework**. It is useful to be familiar with them and to know which of these Conventions your country has ratified and is therefore legally obligated to enforce and implement.

1 See http://www.ohchr.org/english/law/ccpr.htm
2 See http://www.unhchr.ch/html/menu3/b/a_cescr.htm
3 See Annex 1, page 290 for internet addresses for these documents.

3. Regional Human Rights Conventions

In addition to the UN human rights framework, which applies globally, some regional institutions have developed human rights instruments specifically for the countries in their region. These include –

- **The African Charter on Human and Peoples' Rights**, developed by the Organization of African Unity, 1986[4]
- **The European Convention for the Protection of Human Rights and Fundamental Freedoms**, developed by the Council of Europe, 1953[5]
- **The Inter-American Convention on Human Rights**, developed by the Inter-American Commission on Human Rights, 1978.[6]

WHO IS RESPONSIBLE FOR HUMAN RIGHTS?

Governments:
Governments are the primary actors responsible for ensuring people's human rights. Governments must ensure that political and legal systems are structured to uphold human rights through laws, policies, and programs, and that they operate effectively. In some cases, international conventions and treaties are the main source of a State's legal obligations with respect to human rights. However, in many countries, national constitutions, bills of rights, and legal frameworks have been developed or amended specifically to reflect universal human rights principles and standards in international law, providing a double layer of protection and reinforcement of these principles on the national level.

Governments have a legal obligation to **respect**, **protect**, and **fulfill** human rights.

Respecting, Protecting, and Fulfilling Human Rights

Respect: The obligation to "respect" human rights means that States must not interfere with the exercise and enjoyment of the rights of people with disabilities. They must refrain from any action that violates human rights. They must also eliminate laws, policies, and practices that are contrary to human rights.

Protect: The obligation to "protect" human rights means that the State is required to protect everyone, including people with disabilities, against abuses by non-State actors, such as individuals, businesses, institutions, or other private organizations.

Fulfill: The obligation to "fulfill" human rights means that States must take positive action to ensure that everyone, including people with disabilities can exercise their human rights. They must adopt laws and policies that promote human rights. They must develop programs and take other measures to implement these rights. They must allocate the necessary resources to enforce laws and fund programmatic efforts.

4 See http://www1.umn.edu/humanrts/instree/z1afchar.htm
5 See http://conventions.coe.int/Treaty/en/Treaties/Html/005.htm
6 See http://www1.umn.edu/humanrts/oasinstr/zoas3con.htm

Although only governments have the official legal responsibility for respecting, protecting, and fulfilling human rights under international human rights law, human rights are not their exclusive responsibilities. Human rights are far more than legal requirements. They represent a moral code of conduct designed to promote understanding, equality, tolerance, fairness, and many other features essential to just and peaceful societies. Regardless of what behaviors may or may not be legally enforceable, a variety of actors, including individuals, groups, and institutions within society, also play important roles in the promotion and implementation of human rights.

Individuals:
Each person must know and understand their human rights in order to be able to claim them, defend them, and hold themselves, other people, their governments, and societies accountable for the actions that affect them. Because human rights are common to all people, even an effort by a single individual to assert his or her human rights represents an important initiative on behalf of every person. Likewise, actions of an individual that violate somebody else's human rights represent a threat to everyone's human rights.

Groups:
Social and cultural behavior has a profound effect on the ability of people to enjoy their human rights. The collective actions of groups – from families to entire societies – play a role in human rights. For instance, if parents decide that only male children will be allowed to go to school, they are effectively preventing their female children from claiming their human right to an education. If broad cultural values result in persons from racial minorities experiencing discrimination when they seek housing or public services, society itself is contributing to the violation of the human right to an adequate standard of living. On the positive side, groups that speak out against human rights violations and work to change harmful attitudes, policies or laws can be very effective advocates for human rights.

The Private Sector:
Members of society interact with the private sector every day, especially in countries with free-market economies. Private sector actors include people and entities of every kind: employers, providers of goods and services, entertainers, and builders of houses, banks and even government buildings. People depend on the private sector for many things. While private sector actors are often required to adhere to certain laws and standards that uphold human rights, it is impossible for governments to oversee every aspect of how the private sector operates. Businesses, organizations, and other private sector players must make their own commitment to ensuring that their practices do not violate people's human rights but, in fact, support and promote them.

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Persons with disabilities have long fought to have their human rights formally recognized in human rights law. In 2006 the United Nations General Assembly **adopted** the **Convention on the Rights of Persons with Disabilities** (CRPD), the first convention that specifically addresses the human rights of people with disabilities. The CRPD is the first global convention addressing disability.

From the first meeting to draft the CRPD, members of the global disability rights movement insisted that people with disabilities be included in deciding what the convention should say.

The disability community was able to exercise a greater level of participation and influence in the drafting of the CRPD than any other specific group has ever been able to achieve in a UN human rights treaty process. As a result, the CRPD covers the full spectrum of human rights of persons with disabilities and takes much stronger positions than it would have if governments alone had drafted it. In addition, disability organizations, individuals with disabilities, governments, and the United Nations forged important relationships during this drafting process.

Now that the human rights of persons with disabilities have been recognized in international law through the CRPD, the next step is for persons with disabilities in all countries to continue to advocate and work with their governments to ensure that the Convention is ratified and implemented. Every person who advocates for their rights under the CRPD becomes an important member of the global disability rights movement!

General Principles in the CRPD

One important feature of the CRPD is the inclusion of an article that sets forth general principles. The drafters of the CRPD wanted the Convention to recognize a core set of concepts that underlie disability rights issues and are of particular importance in the disability context. They believed that it was crucial to identify these explicitly at the beginning of the text to ensure that all of the rights expressed in the Convention are interpreted through the lens of these particular principles.

CRPD Article 3: General Principles

The principles of the present Convention shall be:

a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
b. Non-discrimination;
c. Full and effective participation and inclusion in society;
d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
e. Equality of opportunity;
f. Accessibility;
g. Equality between men and women;
h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Nearly all human rights conventions begin by recognizing respect for the human dignity and the inherent equality of all persons as the basis for human rights and fundamental freedoms. The CRPD General Principles include a number of other concepts that are particularly important to persons with disabilities, such as, non-discrimination, equality of opportunity, and respect for difference. Notably, the CRPD General Principles also stress the concepts of autonomy, independence, participation, and inclusion in society as essential to ensuring that the rights of persons with disabilities are respected, protected, and fulfilled. Although these concepts

are certainly implicit in the substance of other core human rights conventions (e.g., in relation to subjects such as freedom, self-determination and non-discrimination), none of the other conventions addresses autonomy, independence, or inclusion directly, or even uses those terms in their texts. By including these terms and defining them as general principles, the CRPD makes a bold statement regarding their importance to the human rights of persons with disabilities.

General Obligations in the CRPD

Following the Article 3 on General Principles, Article 4 on General Obligations clearly defines the specific actions governments must take to ensure that the rights of persons with disabilities are respected, protected, and fulfilled. Many of the general obligations in the CRPD are common to other human rights conventions. However, the general obligations of States with respect to the rights of persons with disabilities include certain unique requirements that are not mentioned in other human rights instruments. These include such things as promoting **universal design** for goods and services and undertaking research on accessible technologies and assistive technologies. It is crucial to understand these principles as foundational, overarching obligations that are applicable to every other subject within the CRPD.

One objective of this comprehensive Article 4 on General Obligations is to counteract the historic failure of States to truly understand their obligations to persons with disabilities as fundamental human rights obligations. States have tended to view these responsibilities as representing exceptional treatment or special social measures, not as essential requirements under human rights law. Clearly expressing them as general obligations in the Convention is an important step toward reversing this harmful way of thinking.

Other Cross-Cutting Articles in the CRPD

All human rights are indivisible, interdependent, and interrelated, and all of the articles in the CRPD are important and relate closely to one another. However, certain articles are fundamentally cross-cutting and have a broad impact on all other articles. These articles, sometimes referred to as **articles of general application,** are therefore placed at the beginning of the Convention to reinforce their importance. Article 3 on General Principles and Article 4 on General Obligations, discussed above, clearly fall into this category. The other articles of general application in the CRPD are:

Article 5: Equality and Non-Discrimination
Article 6: Women with Disabilities
Article 7: Children with Disabilities
Article 8: Awareness Raising
Article 9: Accessibility

As you become familiar with the rights included in the CRPD, you will develop a deeper understanding of how Articles 3 through 9 continually intersect with the principles and obligations throughout the Convention.

Specific Rights in the CRPD

Articles 10-30 address specific rights, such as the right to work, the right to political participation, and many others. A full list of the articles of the CRPD is included at the end of this chapter. In most cases, these topical articles correspond closely to articles found in other human rights conventions, except that they explain the particular right in the context of disability. A few articles, however, address subjects unique to the CRPD such as:

Article 19: Living independently and being included in the community
Article 20: Personal mobility
Article 26: Habilitation and Rehabilitation

They are areas of human rights in which persons with disabilities either have specific requirements that may not apply in other contexts, or in which persons with disabilities have traditionally experienced unique types of discrimination and human rights violations. While these articles do not create any new rights, they explain rights in the level of detail required for States to understand their responsibilities and in many cases do articulate new specific obligations or measures not previously included in international law.

REGIONAL DISABILITY RIGHTS CONVENTIONS

As of 2007, the only regional institution with a disability-specific convention is the Inter-American Commission on Human Rights, which developed the **Inter-American Convention on the Elimination of all forms of Discrimination against Persons with Disabilities** in 1999. However, most regional institutions have adopted **optional protocols,** treaties that modify another treaty, to existing conventions or have developed non-binding resolutions, recommendations, and/or plans that address disability rights. In some cases, persons with disabilities are specifically mentioned in the general regional human rights instruments.

KEY NON-BINDING INSTRUMENTS ON DISABILITY

World Programme of Action Concerning Disabled Persons:
The UN declared 1981 as the “International Year of Disabled Persons” (IYDP) with the theme of full equality and participation of persons with disabilities and a call for plans of action at the national, regional, and international levels. One important outcome of the IYDP was the development by the UN of the World Programme of Action Concerning Disabled Persons with the stated purpose “to promote effective measures for prevention of disability, rehabilitation and the realization of the goals of ‘full participation’ of disabled persons in social life and development and of equality.” To provide a timeframe for governments to implement the World Programme of Action, the UN declared 1983-1992 the United Nations Decade of Disabled Persons.

UN Standard Rules on the Equalization of Opportunity for Persons with Disabilities:
Many people believed that the World Programme of Action, although valuable, would not achieve the results needed to ensure that the rights of disabled persons were respected.

In 1987 the UN convened a meeting to consider drafting a convention on disability rights; however, at that time there was not enough support to move ahead. In 1990, the UN decided to develop another kind of instrument that would not be international law but rather a statement of principles signifying a political and moral commitment to equalizing opportunities for disabled people. The resulting **Standard Rules on the Equalization of Opportunity for Persons with Disabilities** (**Standard Rules**), adopted in 1993, was the first international instrument to recognize that the rights of disabled persons are greatly affected by the legal, political, social, and physical environment. Although superseded by the CRPD, the Standard Rules are still an important advocacy tool for the disability community, and many of its principles served as a basis for drafting that Convention.

The UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (The MI Principles):
These principles were developed in 1991 to establish minimum standards for practice in the mental health field. The **MI Principles** have been used as a blueprint for the development of mental health legislation in many countries. They include some very important concepts, such as the right to live in the community.

Many advocates in the field of psycho-social disability believe that this instrument establishes lower standards on some issues than is reflected in other human rights law and policy. In particular, there is concern about requirements for "informed consent" for treatment of people with psycho-social disabilities. Disability advocates should look carefully at the standards in this instrument and decide for themselves whether or not it should be used as an advocacy tool for the rights of persons with psycho-social disabilities.

EXERCISE 3: Tree of Rights

Objective: To identify how a range of human rights applies to persons with disabilities
Time: 45 minutes
Materials: Tree trunks sketched on large posters
10 cutouts each of branches/leaves/fruits on which to write
Chart paper and markers or blackboard and chalk
Handouts: UDHR (short version)
CRPD Article 3, General Principles; Article 4, General Obligations

1. Introduce:
Emphasize that like all human beings, people with disabilities are holders of human rights. Explain that in order to claim their human rights, people with disabilities must understand what those rights are and what must be done to respect, protect, and fulfill them.

2. Brainstorm/Construct:
Divide participants into small groups. Provide each group with a large poster size drawing of a tree trunk and paper cutouts of branches (10), leaves (10), and fruit (10). Explain the exercise:

- Participants should select 10 principles from the UDHR, write one principle on each branch, and attach the branches to the trunk to create a tree.

- Then on each branch attach:
  - one leaf that includes how that right applies to persons with disabilities (Note: Here it may be helpful for participants to refer to CRPD Articles 3 and 4, as the concepts in these CRPD articles underpin all rights as they relate to persons with disabilities.)
  - one piece of fruit that describes an action that can be taken by governments to ensure that right.

Example:	Branch:	Right to Equality before the Law (UDHR Article 7)
	Leaf:	Right to make decisions about where one lives
	Fruit:	Laws to ensure that people with disabilities are not automatically considered "legally incompetent" and are involved in legal decisions that affect them

3. Report/Analyze:
Post each tree on the wall. Have each group read a few of their branches and the associated leaves and fruits from its tree.

- Which UDHR principles did more than one group choose?
- How were the leaves and fruits different among those groups for the same UDHR principle?
- What were some of the more difficult rights to address? Was it difficult to decide what to write on the leaves? Why?

Select one or two examples and look at the relevant text from the full CRPD (See Annex, p. 253) to analyze what it offers in the context of that particular right.

4. Discuss:
The rights of people with disabilities are not different from the rights of everyone else, but they do often manifest themselves differently for people with disabilities.

- How does the CRPD help articulate the rights of persons with disabilities more specifically than the UDHR?
- How does it help guide governments in their responsibilities with respect to the human rights of persons with disabilities?

DEFINING AND RESEARCHING DISABILITY

Disability is a complex concept, and as yet there is no definition of disability that has achieved international consensus. Nevertheless, each person involved in advocating for disability rights must be able to explain to others what group of people they are talking about when they refer to persons with disabilities. How you define and express the concept of disability strongly impacts the understanding, attitude, and approach of others toward the human rights of persons with disabilities.

EXERCISE 4: Design a National Census Survey for Your Country

Objective: To examine how definitions of disability have a practical impact on advocacy and other efforts
Time: 45 minutes
Materials: Paper and pens/pencils; list of sample definitions

1. Introduce:
Explain that the purpose of a national census is to count the number of people in a country and to understand their distribution across different demographic categories. For instance, governments need to know the number of school-aged children in order to allocate the necessary resources to educate them.

2. Discuss:
Discuss the following questions either in small groups or the large group:

- Why is it important to know how many people with disabilities are in your country and where they are located? How does this relate to human rights?
- Is it important to identify what types of disabilities people have (e.g., mobility impairments, sensory disabilities, psycho-social disabilities)?

3. Analyze:
What definition of disability should be used to ensure the most accurate and inclusive consensus? Below are some examples of definitions or descriptions of disability used in various international and national contexts.

- What are the major differences between these definitions?
- Which ones seem to be the most useful? Inclusive? Accurate?
- Which ones seem the most limited? What do they leave out?

UN Convention on the Rights of Persons with Disabilities (CRPD):
Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Americans with Disabilities Act (ADA):
An individual with a disability is a person who: (1) has a physical or mental impairment that substantially limits one or more major life activities; or (2) has a record of such an impairment; or (3) is regarded as having such an impairment.

Definition from the 2002 Housing and Population Census conducted by the Government of Uganda:
A person with a disability is defined as one who is limited in the kind of or amount of activities that he or she can do, because of ongoing difficulty(ies) due to a long-term physical condition or health problem that has lasted six months or more**.** This includes all those difficulties that are expected to last more than six months.

4. Define/Present/Discuss:
There are many different contexts in which it is important to clarify the meaning of disability. As an advocate, you should be prepared to express your opinions about what disability means in various advocacy situations. Work with a partner to develop a definition that you yourself

would use in talking to others about disability rights. Present your definition to the whole group. Discuss the advantages and disadvantages of each definition. If possible allow time for revisions.

5. Research:

- Does your national census address the question of disability?
- If so, what definition of disability is used in your national census?
- What definition is used?
- Is this the same definition that is used in national legislation?
- How can you find out?
- What definition would you recommend to use in the census? In national legislation?

Census Questions on Disability

The World Bank has endorsed the following six questions, developed by the Washington Group on Disability, that a government might include in a national census to capture general disability prevalence in a census.

Because of a physical, mental or emotional health condition…

1. Do you have difficulty seeing even if wearing glasses?
2. Do you have difficulty hearing even if using hearing aid/s or are you deaf?
3. Do you have difficulty walking or climbing stairs?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty with self-care (e.g., washing all over or dressing)?
6. Do you have difficulty communicating, understanding or being understood?

Question response categories: No, Some, A lot, and Unable[7]

ATTITUDES AND PERCEPTIONS REGARDING DISABILITY

Although they are entitled to every human right, persons with disabilities often face serious discrimination based on attitudes, perceptions, misunderstandings, and lack of awareness. For example, the misconception that people with disabilities cannot be productive members of the workforce may lead employers to discriminate against job applicants who have disabilities, even if they are perfectly qualified to perform the work. Or it might mean that buildings where jobs are located are not constructed in a way that people with mobility impairments can access them.

Such limitations can affect other population groups as well. For example, in some societies attitudes toward women prohibit them from owning property or participating in public life. Members of racial or ethnic minorities are often forbidden to speak their own language or practice their religion. A person with a disability who also belongs to another group that

7 *Center for Disease Control, National Center for Health Statistics, Washington Group on Disability Statistics.* 2007. http://www.cdc.gov/nchs/citygroup.htm

experiences discrimination (e.g., a disabled woman who belongs to an ethnic minority) may face multiple layers of discrimination and barriers to realizing human rights.

In addition to attitudes and perception coming from external sources, each individual's attitude directly affects how he or she exercises human rights. A person who believes a disability makes her or him somehow different in respect to human rights will claim – or not claim – those rights very differently.

Destructive Attitudes and Concepts

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 Charity Model of Disability:
Another major misperception is that people with disabilities are helpless and need to be cared for. It is much easier for people to offer pity and charity than to address the fear or discomfort they themselves feel when it comes to people with disabilities. It is also often easier to do something for somebody than to make sure that they have the resources to do it for themselves.

The result of both the medical and charity approach is to strip people with disabilities of the power and responsibility for taking charge of their own lives and asserting their rights on an equal basis with others.

Positive Attitudes and Concepts

Disability as a Natural Part of Human Diversity:
Everyone is different, whether that difference relates to color, gender, ethnicity, size, shape, or anything else. A disability is no different. It may limit a person's mobility or their ability to hear, see, taste, or smell. A psycho-social disability or **intellectual disability**, may affect the way people think, feel, or process information. Regardless of its characteristics, disability neither subtracts from nor adds to a person's humanity, value or rights. It is simply a feature of a person.

Reasonable Accommodation:
A person with disabilities may require a reasonable accommodation, such as a wheelchair or more time to accomplish a task. A reasonable accommodation is simply a resource or a measure designed to promote full participation and access and to empower a person to act on his or her own behalf. This approach is not the same as trying to fix the person or fix the disability (the Medical Model) or assuming that people with disabilities are incapable of acting for themselves (the Charity Model).

The Social Model of Disability:
This model focuses on eliminating the barriers created by the social and physical environment

that inhibit the ability of persons 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 APPROACH TO DISABILITY

The social model of disability, which focuses on the responsibility of governments and society to ensure access, inclusion, and participation, sets the stage for the emergence of the Human Rights Approach to Disability, which focuses on the inherent human rights of persons with disabilities. This approach:

- 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 political, legal, social, and physical environments support the human rights and full inclusion and participation of people with disabilities.

The UN **Office of the High Commissioner for Human Rights (OHCHR)** has summarized the rights-based approach as follows:

> "A human rights approach asks what are the long term or underlying reasons why a section of society is vulnerable, marginalized or experiences discrimination.
>
> A human rights approach then provides strategies based in international human rights law and standards which address these root causes of discrimination."

In particular the OHCHR stresses the following ideas:

> **Empowerment:** A human rights approach to disability aims to empower people with disabilities to make their own choices, advocate for themselves, and exercise control over their lives.
>
> **Enforceability and Remedies:** A human rights approach to disability means that people with disabilities should be able to enforce their rights at the national and international levels.
>
> **Indivisibility:** A rights-based approach to disabilities must protect both the civil and political rights as well as economic, social, and cultural rights of people with disabilities.
>
> **Participation:** A human rights approach to disabilities says that people with disabilities must be consulted and participate in the process of making decisions that affect their lives.[8]

8 "Draft Guidelines: A Human Rights Approach to Poverty Reduction Strategies" 10 Sept. 2002. *UNHCHR Homepage*. http://www.unhchr.ch/development/povertyfinal.html

Barriers to exercising human rights can stem from attitudes, prejudice, a practical issue, a legal obstacle, or a combination of factors. But a disability itself does not affect or limit a person's entitlement to human rights in any way. Defining persons with disabilities first and foremost as rights holders and subjects of human rights law on an equal basis with others is an extremely powerful approach to changing perceptions and attitudes, as well as providing a system for ensuring the human rights of persons with disabilities.

EXERCISE 5: Language & Rights

Objective: To understand the role that language can play in supporting both positive and negative attitudes about the role of people with disabilities in society
Time: 45 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Introduce:
Explain that language may be used in different ways to support both negative and positive attitudes about disability. This language may be found in the words used for people with disabilities, the words that describe their disability, or the words used to describe their role in the family or community. Attitudes may also be reflected in the words that people avoid using.

2. Discuss:
Break into small groups. Ask each group to generate examples of language used in their society to describe people with disabilities, their disability, or their role in family or community.

3. Report/Analyze:
Ask each group to report their findings. List these terms on chart paper in a table as shown below. Discuss the following questions:

- How do the terms used to describe disability in your local language reflect people's attitudes toward disability and people with disabilities?
- How does this language reflect the negative models of disability (e.g., the Medical Model, the Charity Model)? How does it support and maintain these negative models?
- How does this language reflect positive approaches? How does it support and maintain positive attitudes?
- How does such language affect people with disabilities?
- What can be done to alter negative language?
- What are the advantages of the human rights approach to disability? How can it be promoted?

LANGUAGE DESCRIBING DISABILITY		
The Person with Disabilities	The Disability	The Role of the Person with Disabilities

HUMAN RIGHTS ADVOCACY

Every person is entitled to claim her or his human rights and to demand that they be protected, respected, and fulfilled. When you advocate in human rights terms, and use the human rights framework to support your advocacy, no one can challenge that you are asking for special treatment or something undeserved. All stakeholders have a role to play to see that the new Convention on the Rights of Persons with Disabilities is fully implemented.

Human Rights.YES! was designed to support you in this effort. This first section has provided a comprehensive study of human rights principles, legal documents, and social attitudes related to disability. By providing detailed information on specific themes related to disability rights, Part 2 seeks to equip disability advocates with the knowledge they need to effect change in both national laws and policies and in the social and cultural environments. Part 3 offers specific training on advocacy strategies and techniques, including defining advocacy objectives, developing advocacy action plans, and measuring your advocacy success.

Just because human rights law exists does not make human rights a reality in people's lives. Positive attitudes and good intentions are not enough either.

Without individual efforts, a firm social and cultural commitment reinforced by group action, and strong implementation and enforcement by governments, human rights cannot be guaranteed!

PART 2:

THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

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CHAPTER 1: EQUALITY AND NON-DISCRIMINATION

UN Convention on the Rights of Persons with Disabilities

Article 5, Equality and Non-discrimination:

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

Article 2, Definitions (excerpts):

"Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.

Article 3, General Principles:

The principles of the present Convention shall be:

(a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
(b) Non-discrimination;
(c) Full and effective participation and inclusion in society;
(d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
(e) Equality of opportunity;
(f) Accessibility;
(g) Equality between men and women;
(h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

OBJECTIVES

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

- Define the right to equality and non-discrimination
- Explain the importance of the right to equality and non-discrimination for people with disabilities
- Understand the interrelation between equality and non-discrimination and other human rights
- Identify ways in which the right to equality and non-discrimination of people with disabilities has been promoted or denied
- Understand the provisions related to equality and non-discrimination in the UN **Convention on the Rights of Persons with Disabilities** (CRPD).

GETTING STARTED: THINKING ABOUT EQUALITY AND NON-DISCRIMINATION

The terms “equality” and “non-discrimination” address some of the most fundamental concepts in human rights, yet many people use them without thinking about what they really mean. Understanding equality and non-discrimination is essential if they are to be used effectively in human rights advocacy.

Equality

In its simplest sense, the word “equality” may be defined as meaning “the same as,” “equivalent,” “matching,” or “identical.” When applied to people, however, the term is not intended to mean that all people are identical or exact copies of each other, for that is clearly not the case! In a human rights context, “equality” is used to mean that we are all the same in one fundamental way: regardless of our differences we all possess inherent worth. We are all equally entitled to human rights simply because we are human, and the qualities that make us unique and different should not make us superior or inferior in regard to rights. When put into practice, the principle of equality therefore requires every individual and the societies in which they live to value and accommodate human differences, including - differences based on disability.

A number of different approaches can be taken when thinking about and applying the principle of equality. The first is often referred to as “**formal equality**,” and can occur when laws or policies call for different groups of people to be treated the same, perhaps by saying that they should not be discriminated against. Although such an approach seems logical and it certainly has an important role to play, it is not enough by itself to ensure that people with disabilities or other groups can enjoy true equality. Additional steps may need to be taken in order to account for the different circumstances that people with disabilities face and to address the artificial barriers to their inclusion that have been created by society. For example, calling for people with disabilities to be treated in the same way as other people will not be effective in removing physical, informational, communication, and attitudinal barriers, nor will it help individuals who need differential treatment in the form of specific disability accommodations.

Another approach to equality is what is often referred to as "**equality of opportunity**." This approach recognizes that people may face limitations in their lives resulting from factors and circumstances entirely outside of their control, such as their race, gender, disability, and social status. These factors alone, and in combination with attitudinal and other barriers, can make it impossible for people with disabilities to live as they wish and contribute to society as they might want. Ensuring equality of opportunity therefore requires specific actions to be taken to move beyond formal equality, and ensure that people with disabilities can enjoy the same opportunities as other people. Such actions might include ensuring accessibility of transportation, combating stereotypes and attitudes that lead to discrimination against people with disabilities, and providing reasonable accommodations in educational, employment, and other contexts.

The third approach can be referred to as "equality in fact," "**substantive equality**," or "de facto equality." This approach seeks to ensure equality of results and not just equality of opportunity, as just saying that people are "equal" is not usually enough to make them so. In other words, de facto equality sees each person as equally entitled to full enjoyment of their human rights regardless of their actual contributions or capacity to contribute to society.

Although a properly implemented "equality of opportunity" approach is typically sufficient to ensure that most people with disabilities are able to enjoy their human rights as they wish, an additional commitment by the State to "de facto equality" can be of great assistance in ensuring enjoyment of human rights by people with disabilities. For example, ensuring that people with disabilities are not discriminated against by employers may not be enough to ensure that people with disabilities enjoy the right to work if at the same time they are not otherwise qualified for the jobs for which they apply. Thus, to ensure de facto equality in employment settings, it may be necessary for States to provide training opportunities for people with disabilities so that they can more readily compete against other job applicants.

Non-discrimination

It is perhaps easier to start thinking about what "non-discrimination" means by first considering the meaning of "discrimination." In its most basic sense to "discriminate" means to "distinguish," to "differentiate," or to "treat differently," and is neither positive nor negative in tone. However, the term takes on a more negative meaning when used to describe how people treat each other. To say that somebody has been "discriminated against" typically means that they have not only been treated differently but also unfairly. This unfair treatment could be blatant such as a law expressly discriminating against people with disabilities, or it could occur in a more subtle manner, such as where a rule is neutral but acts to adversely affect people with disabilities. Such subtle forms of discrimination can be particularly insidious because people may believe that the lack of blatant discrimination makes rules or laws fair, even though their effects are damaging.

These two types of discrimination are sometimes referred to as "direct" and "indirect" discrimination, though the labels are less important than the damage caused by such discrimination and the actions needed to counter it. As will be discussed later, international human rights law prohibits all such discrimination when it is on specific grounds, such as disability, race, sex, national origin, and other specified bases. The principle of "non-

discrimination" therefore encompasses the commitment not to engage in such forms of discrimination and to take steps to counter more subtle and indirect forms of discrimination. States must also ensure that they address issues of discrimination regardless of whether the discrimination occurs just between individuals or in a more systemic way, such as through legislation, policies, and regulations.

Perhaps one of the most potentially confusing aspects of non-discrimination is that it does not always prohibit States from treating people differently, and in some cases requires that they do! This is because the principles of non-discrimination and equality interact with each other. For example, the historic and long-term discrimination against people with disabilities as a group has led to people with disabilities not enjoying full equality with other people. In order for this situation to be reversed, States need to undertake actions that are known in different countries and contexts as "specific measures," "**affirmative action**," "fair discrimination," "reverse discrimination," or "positive discrimination." However they are labelled, the objective of these actions is to achieve equality, and they often do so by treating people with disabilities in a way that accords them some comparative advantage. For example, efforts to encourage businesses to appreciate the value of employees with disabilities and to employ more people with disabilities, may favour people with disabilities over other people. The need for workplace disability accommodations may also lead to employees with disabilities receiving specific treatment that differs from that of other employees. Although such actions effectively treat people differently, they are not considered "discrimination," because the goal is to overcome disadvantages, achieve equality, and promote rather than violate enjoyment of human rights. Indeed, under Article 2 of the Convention on the Rights of Persons with Disabilities, the failure to provide for reasonable accommodation would be considered a form of disability-based discrimination prohibited under the Convention.

The principles of equality and non-discrimination not only interact with each other, they are also fundamentally **indivisible**, **interrelated**, and **interdependent** with all other human rights. For example, if a State passed a law denying people with disabilities the right to work, this would not only constitute a violation of the right to work, but it would also represent an explicit form of discrimination and a violation of equality. Indeed, it is not truly possible to say that any human right has been fully enjoyed if equality or non-discrimination have been denied. For this reason some people would say that full enjoyment of human rights by people with disabilities necessarily occurs through implementation of the principles of equality and non-discrimination, together with access to specific rights. For example, it is not enough to say that people with disabilities should not be discriminated against in enjoying the right to education if no educational services are provided. Similarly, it is not enough for the State to provide educational services if people with disabilities face discrimination when using them. Thus, States are required to address both equality and non-discrimination and also access to human rights, in order for people with disabilities to truly enjoy their human rights in a manner that is inclusive and respectful of human dignity.

Approaches to Equality, Non-discrimination, and Disability in National Law

Recognizing and respecting the importance of these fundamental principles, many national constitutions contain specific references to the obligation of the State to respect and uphold the principles of equality and non-discrimination. Increasingly, constitutional documents also contain references to disability as a prohibited grounds for discrimination. The following represent some examples of such provisions from different countries (Bold typeface has been added to references to "disability"):

Charter of Rights and Freedoms of Canada
Equality Rights

15. (1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical **disability**.
(2) Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical **disability**.

Constitution of Fiji
Section 38, Equality

(1) Every person has the right to equality before the law.
(2) A person must not be unfairly discriminated against, directly or indirectly, on the ground of his or her:
(a) actual or supposed personal characteristics of circumstances, including race, ethnic origin, colour, place of origin, gender, sexual orientation, birth, primary language, economic status, age or **disability**; or
(b) opinions or beliefs, except to the extent that those opinions or beliefs involve harm to others or the diminution of the rights or freedoms of others; or on any other ground prohibited by this Constitution.

Constitution of South Africa
Chapter 2: Bill of Rights
9. Equality

1. Everyone is equal before the law and has the right to equal protection and benefit of the law.
2. Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons, or categories of persons, disadvantaged by unfair discrimination may be taken.
3. The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, **disability**, religion, conscience, belief, culture, language and birth.
4. No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.
5. Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair.

Constitution of Uganda
Equality and freedom from discrimination.

21. (1) All persons are equal before and under the law in all spheres of political, economic, social and cultural life and in every other respect and shall enjoy equal protection of the law.
(2) Without prejudice to clause (1) of this article, a person shall not be discriminated against on the ground of sex, race, colour, ethnic origin, tribe, birth, creed or religion, or social or economic standing, political opinion or **disability**.
(3) For the purposes of this article, "discriminate" means to give different treatment to different persons attributable only or mainly to their respective descriptions by sex, race, colour, ethnic origin, tribe, birth, creed or religion, or social or economic standing, political opinion or **disability**.
(4) Nothing in this article shall prevent Parliament from enacting laws that are necessary for-
(a) implementing policies and programmes aimed at redressing social, economic or educational or other imbalance in society; or
(b) making such provision as is required or authorised to be made under this Constitution; or
(c) providing for any matter acceptable and demonstrably justified in a free and democratic society.
(5) Nothing shall be taken to be inconsistent with this article which is allowed to be done under any provision of this Constitution.

EXERCISE 1.1: What Does it Mean to Enjoy Equality and Non-discrimination?

Objective: To understand what it means to enjoy equality and non-discrimination
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Brainstorm/Discuss:
Brainstorm, listing responses to:

- What does the phrase "equality" mean to you?
- When you think of "enjoying full equality and non-discrimination," what do you think that would mean in terms of –
  - How you live your life?
  - How you treat other people?
  - How other people treat you?
  - What opportunities you have access to?
  - What life experiences you can enjoy?
  - What about how others live and experience their lives?

Review the definitions of formal equality, equality of opportunity, and de facto equality. Ask for examples of each from participants' personal experiences or observations.

2. Imagine:
Divide participants into small groups. Give these instructions:

Make up a fictional account of a person with a disability who enjoys *formal equality* of opportunity (e.g., at school, in the workplace, in the community) but does not yet enjoy *de facto* equality with others in that setting. Give the person a name, specific age, disability, and living context. Consider:

- What barriers have been removed or actions taken to ensure that this person enjoys formal equality of opportunity?
- What barriers have *not* been removed?
- How would de facto equality be different for this person?

3. Present/Discuss:
Ask each group to "introduce" their imagined person. After each presentation discuss:

- What additional actions are needed to ensure de facto equality for that person?
- Who is responsible for taking those actions and how could they be achieved?

South Africa's Equality Courts and Human Rights Commission Promoting the Human Rights of People with Disabilities

As part of the Promotion of Equality and Prevention of Unfair Discrimination Act of 2000, South Africa created approximately 60 "Equality Courts." The mandate of these courts is to eradicate "systemic discrimination and inequalities," addressing hate speech, racial harassment, and discrimination in the areas of race, gender, and disability. The courts are fully empowered to adopt positive orders and require respondents to take specific action to rectify situations of discrimination affecting complainants.

The Equality Unit of the South African Human Rights Commission (SAHRC) has participated in bringing several disability-related cases before the Equality Courts, as part of its mission to "promote the achievement of substantive equality" in South Africa. Indeed one of the first cases reviewed by the Equality Courts was a case supported by the SAHRC and brought by an attorney with a disability, addressing the lack of wheelchair access to South African court buildings. (This case is addressed in more detail in Chapter 12, "Access to Justice," p. 158.) The case resulted in the government's agreement to ensure proper access for people with disabilities to court facilities across the country, and an on-going monitoring process to ensure compliance. A further decision was reached in 2006, regarding access by people with disabilities to the Kabega Park police station. Not only was the police station required to undergo renovations to ensure its accessibility, temporary disability accommodations (e.g., moving certain offices to the ground floor until wheelchair access could be made available to other floors) was required in the interim. Furthermore, the national and area police commissioners were required to submit written letters of apology to the complainant, recognizing their inappropriate attitudes towards people with disabilities.[1]

EXERCISE 1.2: Understanding Barriers to Equality and Non-Discrimination

Objective: To identify barriers to equality and non-discrimination faced by people with disabilities
Time: 45 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Brainstorm/Discuss:

- Can you think of examples of discrimination and inequality that might be common to different people with disabilities in their everyday lives? List these.
- In your examples of discrimination and inequality, does the discrimination occur only on the grounds of disability? What other kinds of discrimination might people with disabilities experience?
- Does discrimination only affect people with disabilities? What about their friends or family?

1 "Equality Update". Nov/Dec 2006. *South Africa Human Rights Commission.* http://www.sahrc.org.za/sahrc_cms/downloads/Equality Update_Dec.pdf;
"Equality Court Victory for People with Disabilities". 24 Feb. 2004. *South African Government Information*. http://www.info.gov.za/speeches/2004/04022415461001.htm

2. Analyze:
Break into pairs or small groups, and using the list of examples of discrimination and inequality generated, ask each group or pair to choose one example and discuss among themselves:

- Who is responsible for the discrimination and inequality?
- Why might the person or persons responsible engage in the discrimination and violations of equality? Are they even aware they are behaving in a discriminatory way?
- What are the root causes of the discrimination and inequality?

3. Role Play:
Ask each group or pair to report on their analysis and to role play at least one of the barriers or root causes of discrimination and inequality that a person with a disability might face.

4. Discuss:

- What are the consequences when the root causes of discrimination and inequality are not addressed? To the person with disability? To society as a whole?
- Which root causes/barriers have the greatest effect on people with disabilities? On society as a whole?
- What can be done to eliminate these most significant causes and/or barriers to full enjoyment of the principles of equality and non-discrimination?
- What can be done to make people aware that they are behaving in ways that continue discrimination against people with disabilities?

WHAT DOES HUMAN RIGHTS LAW SAY ABOUT EQUALITY AND NON-DISCRIMINATION?

Numerous provisions addressing equality and non-discrimination are found throughout international human rights law instruments, reflecting the importance of these principles to the enjoyment of human rights. Indeed, the Preamble of the **Universal Declaration of Human Rights** (UDHR)[2] talks about the "equal rights of men and women," and Article 1 begins by saying that "All human beings are born free and equal in dignity and rights." Article 2 of the UDHR then goes on to list the grounds upon which no "distinction" or discrimination is permitted, including "race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status." Article 7 addresses equality before the law and equal protection of the law: in other words the right of everyone to have the law fairly applied without discrimination. Further references to "equality" are found throughout the rest of the UDHR in the context of specific rights, such as the equal rights of men and women regarding marriage.

The basic provisions found in the UDHR are reflected again in the **International Covenant on Economic, Social and Cultural Rights** (ICESCR)[3] and the **International Covenant on Civil and Political Rights** (ICCPR).[4] Both the ICESCR and ICCPR contain articles ensuring the equal rights of men and women (Article 3 in each Covenant), and prohibitions of discrimination (Article 2 in each Covenant) on the same grounds as those listed in the UDHR. Article 26 of the ICCPR addresses the issue of equality before the law and equal protection of the law.

Similar provisions are reflected again in other international human right treaties. For example, Article 2 of the **Convention on the Rights of the Child** (CRC) expressly prohibits

2 See http://www.unhchr.ch/udhr
3 See http://www.unhchr.ch/html/menu3/b/a_ccpr.htm
4 See http://www.unhchr.ch/html/menu3/b/a_cescr.htm

discrimination on a number of bases, including disability, regardless of whether it is the child or parent who is disabled.[5] In some cases the overall purpose of the treaties is to combat specific types of discrimination. For example, the express intent of the **International Convention on the Elimination of All Forms of Racial Discrimination** (CERD)[6], and the **Convention on the Elimination of All Forms of Discrimination Against Women** (CEDAW)[7] is to combat discrimination on the basis of race and against women respectively.

The non-legally binding **UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** (Standard Rules)[8] has a strong focus on the concept of equality of opportunity, even incorporating the concept into its title! All of the Rules included in the Standard Rules are intended to promote achievement of full participation and equalization of opportunities for people with disabilities.

The Convention on the Rights of Persons with Disabilities (CRPD) contains three articles of particular relevance to the principles of equality and non-discrimination: Articles 2, 3, and 5. Although it does not elaborate on the concepts, Article 3 (General Principles) clearly establishes equality and non-discrimination as two of the most important principles of the Convention, which along with other principles such as respect for difference and autonomy, should be applied to interpretation and implementation of all other substantive articles in the CRPD.

Article 5 addresses equality and non-discrimination in more detail, specifying that States must recognize the equality of people with disabilities before the law and the equal protection and benefit of the law. Article 5 also bans discrimination on the basis of disability and obligates States to guarantee "equal and effective legal against discrimination on all grounds." Although the additional grounds on which people with disabilities should not be discriminated against are not listed in Article 5, they appear in paragraph (p) of the Preamble, which lists them as:

> *… race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status.*

Though the list of prohibited grounds is similar to that included in the ICESCR, ICCPR and other international human rights instruments, it is broader than some in that it also references "ethnic" origin, "indigenous" origin, and "age" as grounds upon which people with disabilities should not be discriminated.

Article 5 represents the first time that an international human rights convention expressly bars discrimination on the basis of disability. That is not to say that disability-based discrimination is permitted under the prior human rights conventions simply because their lists of prohibited grounds do not include the term "disability." Arguably, the references in the ICESCR, ICCPR and other treaties to "other status" preclude discrimination on the basis of disability. However, Article 5 of the CRPD leaves no question that discrimination on the basis of disability is prohibited, though Article 5 does not define this term.

Instead, this definition is provided in Article 2, where other definitions (including "**reasonable accommodation**") are also elaborated. Article 2 indicates that "discrimination on the basis of disability" means any "distinction, exclusion or restriction on the basis of disability" that has the "purpose or effect of" damaging or denying the enjoyment or exercise of human rights by people

5 See http://www.unhchr.ch/html/menu3/b/k2crc.htm
6 See http://www.unhchr.ch/html/menu3/b/9.htm
7 See http://www.unhchr.ch/html/menu3/b/e1cedaw.htm
8 See http://www.ohchr.org/english/law/opportunities.htm

with disabilities. It also specifies that the failure to provide reasonable accommodation is itself a form of discrimination.

As well as prohibiting discrimination both on the basis of disability and other grounds, Article 5 requires States to ensure provision of reasonable accommodation, in order to "promote equality and eliminate discrimination." It also specifies that any measures undertaken to ensure or speed up the "de facto equality" of people with disabilities, should not be considered discrimination under the Convention. Unlike similar provisions in other treaties (such as Article 4 of CEDAW), Article 5 does not set a time limit on the use of such measures or refer to them as "temporary" measures because the reality is that such measures will need to continue indefinitely for many people with disabilities to enjoy de facto equality.

Taken as a whole, States' obligations with regard to equality and non-discrimination include:

1. Obligation to respect: States must refrain from engaging in any act, custom or practice that is inconsistent with the principles of equality and non-discrimination (e.g., they may not pass or maintain laws that discriminate against people with disabilities);
2. Obligation to protect: States must take all appropriate measures to eliminate discrimination and violations of equality by any non-State actors, such as persons, organizations or private enterprises (e.g., the State should ensure that employers do not discriminate against people with disabilities in hiring and employment settings);
3. Obligation to fulfill: States must be proactive in their adoption and implementation of measures to give effect to the principles of equality and non-discrimination (e.g., through the use of "fair discrimination" or "affirmative action").

EXERCISE 1.3: Understanding Equality and Non-discrimination

Objective: To review and understand the equality and non-discrimination provisions of the CRPD
Time: 45 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Review:
Divide the participants into small groups. Ask each group to work together to paraphrase Articles 5 and 2 in common language, and give some examples of how they could be enjoyed and make a difference for people with disabilities in their community. Alternatively, have some groups address Article 5 and others address Article 2.

2. Paraphrase:
Read Articles 5 and 2 aloud, pausing at each natural section to ask different groups for their paraphrase. Discuss the meaning of the sections until everyone can agree on a paraphrase. Write the final paraphrase of the articles on chart paper.

3. Give examples:
Ask for examples of how the rights to equality and non-discrimination could be enjoyed and make a difference for people with disabilities.

4. Discuss:
How can Articles 5 and 2 of the CRPD be used to set national disability rights agendas and formulate platforms of action for submission to political parties or government decision-makers?

Things to Remember About Equality and Non-discrimination

Here are some of the main things to remember about these important principles of human rights:

- Equality and non-discrimination are central to the enjoyment of all rights;
- Effective access to human rights is central to the enjoyment of equality and non-discrimination;
- Equality means that we all have the same inherent worth, regardless of our differences. There are different approaches to equality:
  - Formal equality
  - Equality of opportunity
  - Substantive or "de facto" equality.
- Non-discrimination concerns avoiding and correcting unfair treatment on the basis of disability, regardless of whether the unfair treatment is blatant or subtle;
- Under the CRPD:
  - Equality and non-discrimination are two of the most important principles;
  - States cannot discriminate on the basis of disability, and they must act to stop non-State actors discriminating on the basis of disability;
  - Failure to provide reasonable accommodation is a form of discrimination on the basis of disability;
  - States must take positive action to promote and ensure de facto equality of people with disabilities.

EXERCISE 1.4: Making a Commitment to Promote Equality and Non-discrimination

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about the right to equality and non-discrimination for people with disabilities, 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 right to equality and non-discrimination of people with disabilities to ensure their full enjoyment of all human rights;
- If there is time, draft an action plan that promotes equality and non-discrimination, identifying actors who have responsibility to promote equality and non-discrimination and what can be done to ensure that they meet their obligations.

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.

ADDITIONAL RESOURCES ON EQUALITY AND NON-DISCRIMINATION

- General Comment No. 18 of the Human Rights Committee: http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/3888b0541f8501c9c12563ed004b8d0e?Opendocument
- General Comment No. 5 of Committee on Economic, Social and Cultural Rights: http://www.unhchr.ch/tbs/doc.nsf/(Symbol)4b0c449a9ab4ff72c12563ed0054f17d?Opendocument
- Gerard Quinn and Theresia Degener, et. al., “Human Rights Are for All: A Study on the Current Use and Future Potential of the UN Human Rights Instruments in the Context of Disability” (OHCHR, February 2002): http://www.ohchr.org/english/issues/disability/study.htm
- Report of the United Nations High Commissioner for Human Rights on progress in the implementation of the recommendations contained in the study on the human rights of persons with disabilities: http://www.ohchr.org/pacific/docs/Report_UN_HC_Disability.pdf

CHAPTER 2: ACCESSIBILITY

UN Convention on the Rights of Persons with Disabilities

Article 9, Accessibility:

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to 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, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

(a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
(b) Information, communications and other services, including electronic services and emergency services.

2. States Parties shall also take appropriate measures to:

(a) Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
(b) Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
(c) Provide training for stakeholders on accessibility issues facing persons with disabilities;
(d) Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;
(e) Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
(f) Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
(g) Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
(h) Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

Article 2, Definitions (excerpts):

"Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;

"Universal design" means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

OBJECTIVES

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

- Define accessibility and the related concepts of **reasonable accommodation** and **universal design**
- Explain the importance of accessibility for people with disabilities
- Understand the interrelation between accessibility and other human rights
- Identify ways in which the accessibility of people with disabilities has been promoted or denied
- Understand the provisions related to accessibility in the UN **Convention on the Rights of Persons with Disabilities** (CRPD).

GETTING STARTED: THINKING ABOUT ACCESSIBILITY

Any discussion of the human rights of people with disabilities necessarily includes the issue of "accessibility." No one can enjoy a human right to which they do not have access, and the barriers that currently prevent people with disabilities from fully enjoying their human rights are abundant. Indeed, it is these barriers that are part of the concept of "disability" itself. As noted in the Preamble of the CRPD:

> (e) *Recognizing* that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

The forms that barriers to accessibility take can be many and varied, including:

- Physical: These barriers include environmental barriers, especially those that exist in the built (in other words, human-made) infrastructure. They are some of the first barriers that people think of when considering access for people with disabilities, as they are the most obvious. For example, many people are now aware of the importance of ramps for wheelchair access to buildings with stairs or the need for curb-cuts in side-walks to facilitate street-level access. Other physical barriers may be less obvious, however. For example, many people are unaware of the barriers faced by little people, who frequently have to interact with a built-environment primarily designed for "average-sized" people. In addition, people may not be sufficiently aware of the need for tactile or high colour-contrast surfaces to assist people with visual impairments as they navigate streets and buildings.

- Informational: Both the form and content of information can constitute barriers to access for people with disabilities. For example, publications or websites in small print or without adequate visual contrast may be inaccessible to people with low vision. Television that does not include captioning, subtitles, or in-set sign language interpretation will be inaccessible to people who are deaf. Similarly, television programming may also be inaccessible to people who are blind unless audio-description is available. Information that is not in Braille or other appropriate tactile forms may be inaccessible to people who are blind. In addition to form, the content of information is also of critical importance. For example, information that is not provided in plain language is unlikely to be accessible to many people with intellectual disabilities.

- Institutional: These include legislation, practices, or processes that actively prohibit or fail to facilitate access by people with disabilities. For example, in some countries people with psycho-social disabilities are expressly prohibited from participating in voting, while other people with disabilities may be unable to vote because of the absence of legislation or practice that ensures that they can both gain physical access to polling venues or voting booths and have access to the ballot and other voting information once they are there.

- Attitudinal: Perhaps the most pervasive barrier is the attitudes of many people. Sometimes people's myths and stereotypes about people with disabilities can cause societies unconsciously to create accessibility barriers. In other cases barriers are created or maintained simply because people are unaware of their existence and the detrimental effect they have on the lives of persons with disabilities. For example, a restaurant owner may mistakenly believe that their restaurant is accessible to wheelchair users because there are "only a couple of steps" at the entrance, and may not appreciate the need for people to be able to enter and exit safely and independently. Such lack of awareness can have especially detrimental consequences in the area of technology. Although technology has the potential to enhance access for people with disabilities, technological advances that occur without incorporating accessibility features can create barriers. For instance, at a time when people increasingly rely upon mobile phones and the internet as sources of information and means of communication, many of the devices and software programmes available are not usable by people who are deaf, blind or deafblind, leading to further marginalization and exclusion of these groups.

Ensuring accessibility is of critical importance because it directly affects the enjoyment of the full range of human rights by people with disabilities. In other words, lack of access can prevent people with disabilities from fully enjoying any human right. In addition, specific barriers to access can have a negative effect on the enjoyment of multiple human rights. For example, the lack of accessible transportation not only prevents enjoyment of the right to liberty of movement, but it can also prevent people with disabilities from travelling to places of work, education, health care, rehabilitation, culture, sports, and other venues where different human rights can be enjoyed. The lack of accessible information about political processes not only inhibits the ability of people with disabilities to enjoy the right to participate in political and public life, but it can also make it difficult to make informed choices about issues affecting other human rights. For instance, if a voter with a disability is deciding how to vote in a referendum determining how a local authority provides emergency services (e.g., police, fire, ambulance, rescue services), it will be essential for that person to have access to the information they need to make an informed choice. These examples demonstrate that human rights are indivisible, interdependent, and interconnected.

Ultimately, accessibility is fundamental to ensure the inclusion and participation of people with disabilities as full and equal members of society. Regardless of the human right in question, discussion of how that right can fully be enjoyed must include consideration of access – not just for some but for all people with disabilities.

EXERCISE 2.1: Getting Started Thinking About Accessibility

Objective: To simulate an informational accessibility barrier
Time: 20 minutes
Materials: Paper and pens

1. Brainstorm:
As a group, make a list of basic grocery items that a person in your community might purchase on a day-to-day basis. Write or draw these items on separate pieces of paper.

2. Simulate:
Split the group into pairs. Have one person from each pair select one of the pieces of paper on which a grocery item is listed. Without speaking, that person must now communicate what that item is to his or her partner.

Alternate Version: Play this like charades where two teams guess what the player is trying to communicate.

3. Discuss:
- How easy was it for participants to communicate the items to their partners?
- Did either person experience any frustration during the exercise?
- If so, what was the source of that frustration?
- What does this exercise illustrate about the barriers to accessibility that people with disabilities face on a daily basis?

Approaches to Accessibility: Understanding Universal Design

As indicated in Article 2 of the CRPD, the use of universal design is intended to ensure access "by all people, to the greatest extent possible, without the need for adaptation or specialized design." Universal design is especially important in situations where it is difficult to predict exactly what each individual user's accessibility needs will be. When creating a new product, service, or program or when constructing a building, sports arena, or park, following universal design principles can ensure access by as many potential users as possible.

These principles include:

- **Equitable use:** The design is useful and marketable to people with diverse abilities;
- **Flexibility in use:** The design accommodates a wide range of individual preferences and abilities;
- **Simple and intuitive:** The use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level;
- **Perceptible information:** The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities;
- **Tolerance for error:** The design minimizes hazards and the adverse consequences of accidental or unintended actions;
- **Low physical effort:** The design can be used efficiently and comfortably with a minimum of fatigue; and
- **Size and space for approach and use:** The appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.[1]

EXERCISE 2.2: What Does It Mean to Enjoy Accessibility?

Objective: To understand what it means to enjoy accessibility
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk
Paper and pens

1. Brainstorm/Imagine:

Ask participants to brainstorm some typical life activities that most people in your community do (e.g., going shopping, going to work, going to school, talking to friends, taking public transportation, eating in a restaurant, attending a religious service, attending a cultural or sports event). List these.

Next ask them to name some typical people with disabilities, including people with physical, sensory, learning, intellectual, psycho-social, and multiple disabilities. As suggestions are given, ask each participant to write them down on a separate slip of paper using the format "You are …" and adding more description including an imagined sex and age for the suggested person (e.g., "You are a middle-aged man who uses a wheelchair"; "You are a twenty-year-old woman

1 "Principles of Universal Design". 2007. *The Center for Universal Design.* http://www.design.ncsu.edu/cud/about_ud/udprinciples.htm

who is bipolar"; "You are a teenage girl with Downs Syndrome"; "You are a man of seventy who is deaf and dyslexic"). Encourage everyone to contribute at least one example.

Collect the slips of descriptions, fold them, and place in an open container.

2. Analyze:
Divide participants into pairs and ask each pair to choose two activities from the list (more than one couple may have the same activity). Then ask each couple to draw one of the descriptive slips.

Give these instructions:

a. The slip you drew is your "identity" for the rest of the exercise;
b. Imagine what it would be like for "you" to participate in the activities you have chosen;
c. What barriers to access might you encounter? Consider -
    - Physical barriers
    - Informational barriers
    - Institutional barriers
    - Attitudinal barriers
d. What would it take for you to be able to participate? What accessibility features would you need?

To the Facilitator: You may need to remind participants of the differences in the different kinds of barriers and illustrate each.

3. Report:
Ask each group to describe who they "are" and what activities they chose. Then ask each to name the accessibility features they would need to be able to participate in their activities. List these needs on a chart like the one below and retain it for use in Exercise 2.2. Be sure to ask for informational, institutional, and attitudinal as well as physical barriers.

Barrier	Accessibility Feature Needed

4. Discuss:

- Did the group's definition of "accessibility" differ depending upon the person you have in mind, or does it stay the same for all people?
- How would you define "accessibility" so that it fits all these cases?
- How does having accessibility make a difference in the lives of individual people with disabilities? In the life of the community?
- How does *not* having accessibility make a difference in the lives of individual people with disabilities? In the life of the community?

Approaches to Accessibility: Understanding Reasonable Accommodation

One approach to accessibility involves application of the principles of **universal design**, which focuses on the overall usability of the product, service or environment itself. However, universal design is not yet used everywhere and may not always succeed in providing access for every individual. In these instances, a second approach to accessibility, that of reasonable accommodation, is needed. As defined in the CRPD and as practiced in a number of countries, "**reasonable accommodation**" describes a process through which necessary and appropriate modifications, adjustments, or provisions are made, in order to accommodate the accessibility needs of a particular person. In other words it is a specific response to the unique accessibility needs of an individual.

Reasonable accommodation requires discussions between the provider and the user in order to ensure that the accommodation meets the access needs of the user and can be implemented by the provider. The provision of the accommodation is not required where doing so would impose a "disproportionate or undue burden" on the person providing the accommodation. What is considered reasonable will vary depending upon the size and resources of the person or organization providing the accommodation. The reasonableness of an accommodation will also vary over time, as new solutions to accessibility issues become available. In general what providers assume is feasible usually falls below the level of what is possible.

Because of the typically individualized nature of the accommodations, reasonable accommodation is a process that is often used in educational and employment settings, where long-term accessibility solutions for specific individuals may be necessary to facilitate their enjoyment of the rights to education or work. For example, in an educational setting someone with a learning disability might be accommodated through the provision of a dedicated note-taker or perhaps the allowance of extra time on exams. In an office environment, reasonable accommodation might include ensuring that the workspace is navigable for a wheelchair user or providing special software or other assistive technologies to facilitate computer use by someone with a visual impairment.

The approach of reasonable accommodation differs from that of universal design. Universal design treats all users the same and reasonable accommodation treats specific users differently. However, the goal of both approaches is the same: full accessibility that ensures the full inclusion of all people with disabilities in society on an equal basis with others.

EXERCISE 2.3: Understanding Barriers to Accessibility

Objective: To identify barriers to accessibility faced by people with disabilities
Time: 30 minutes
Materials: List of life activities generated in Exercise 2.2

1. Discuss:
Using the list of needed accessibility features generated in Exercise 2.2, ask participants to assess to what extent these accommodations are available in this community. Record responses on a chart like that below.

To the Facilitator: If participants don't know the answer, put a question mark and discuss where this information could be obtained.

Accessibility Feature	Never Available	Somewhat Available	Generally Available	Usually Available	Always Available

2. Discuss:
- What accessibility features are most available in the community? Why do you think this is?
- What accessibility features are least available? Why?
- Are people with certain disabilities provided with more accessibility features than others? Which? Why?
- Are people with certain disabilities provided with fewer accessibility features than others? Which? Why?

To the Facilitator: In asking why some accessibility features are more generally available than others, always seek to establish whether advocacy by people with disabilities has brought about some of these accessibility features.

3. Evaluate:
- What accessibility features are most needed in your community? Be sure to think broadly about all the different people with disabilities who might need accessibility features, so that no groups of people are left out.
- What can be done to see that these needs are met?

WHAT DOES HUMAN RIGHTS LAW SAY ABOUT ACCESSIBILITY?

Accessibility as it has been discussed above is not elaborated in any detail in international human rights law until the 1993 UN **Standard Rules on the Equalization of Opportunities for Persons with Disabilities**. However, there are references to "access" and related concepts that can be found in earlier documents. For example, Article 21 of the **Universal Declaration of Human Rights** (UDHR) refers to the right of everyone to "equal access to public service in his country." Article 26 of the UDHR also refers to the need for tertiary, professional and higher education to be "equally accessible to all on the basis of merit."

The **International Covenant on Civil and Political Rights** (ICCPR) contains one express reference to "access" in Article 25, which address the right of people to "have access, on general terms of equality, to public service in his country."[2] Similarly, the **International Covenant on Economic, Social and Cultural Rights** (ICESCR) only references accessibility in the context of equal access to education in Article 13.[3] Nevertheless, General Comment No. 5 of the **Committee on Economic, Social and Cultural Rights**, the treaty body that monitors implementation of the ICESCR, specifically highlights the need for States Parties to the ICESCR to ensure that people with disabilities enjoy full access to transportation, health care services, places of work, housing, health care, education, cultural and recreational venues, and other programs, services, and places relevant to the enjoyment of economic, social, and cultural rights.

The **Convention on the Rights of the Child** (CRC) contains more frequent references to the concept of access, including in Article 17 (access to information), Article 24 (access to health care services and education about health and nutrition), Article 28 (access to education), and Article 37 (access to legal assistance if deprived of liberty).[4] In addition, Article 23 specifically addresses the rights of children with disabilities, and notes the need for 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.*

The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules) provides more elaboration on accessibility for people with disabilities in Rule 5, addressing physical, informational, and communication accessibility. For example, Rule 5 calls on States to remove obstacles to participation in the physical environment and promote accessibility through the development of standards and guidelines, training of architects and other construction professionals, and the consultation of organizations of people with disabilities. Rule 5 also calls for information to be provided in different accessible formats, for the media (e.g., television, radio, newspapers) to provide accessible services, for new computer and other technologies to be made accessible initially or be retrofitted later, and for sign language and other interpreters to be made available to those who need them.

The Convention on the Rights of Persons with Disabilities (CRPD) is the first legally binding international instrument to provide in-depth articulation of the responsibilities of governments to thoroughly address accessibility so that people with disabilities may "live independently and participate fully in all aspects of life." Specifically, Article 9 requires States to ensure that people with disabilities are able to access a comprehensive range of venues, facilities, and services on an equal basis with others. In providing examples, Article 9 references a variety of places and services, such as "buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces," as well as "information and communications" and emergency services, all of which have the potential to impact a wide variety of other human rights. Furthermore, Article 9 includes "other facilities and services open or provided to the public, both in urban and in rural areas," ensuring that accessibility is not only addressed in cities, but also for people with disabilities living in rural communities.

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2 See http://www.unhchr.ch/html/menu3/b/a_ccpr.htm
3 See http://www.unhchr.ch/html/menu3/b/a_cescr.htm
4 See http://www.unhchr.ch/html/menu3/b/k2crc.htm

In order to achieve accessibility, Article 9 requires States to identify and eliminate obstacles and barriers to accessibility. The provisions that elaborate the specific measures to be undertaken are quite detailed and attempt to capture the wide range of access needs of different people with disabilities in different contexts. They include:

- Developing and monitoring implementation of minimum accessibility standards and guidelines
- Providing training on accessibility for stakeholders
- Promoting design, development, production, and distribution of information and communications technologies that address accessibility early in their development, and that are provided at minimum cost
- Promoting access to new information and communications technologies and systems, "including the internet"
- Providing signage for the public in Braille and other easy to read and understand forms
- Providing live assistance (such as guides, readers, and sign language interpreters)
- Promoting other "appropriate forms of assistance and support" to ensure access to information.

As with other articles in the CRPD, the scope of Article 9 is not limited just to State actors, such as local and national governments, government agencies, and government corporations. Article 9 also implicates private actors, requiring States to "ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities." In other words, although the Convention is not directly legally binding upon private actors (as only States can be bound by international treaties), it obligates States to act to ensure that private actors over whom they have control act in a manner consistent with the goals and obligations of Article 9. Such private actors might include restaurants, taxi companies, supermarkets, and other businesses offering facilities and services to the public.

It should be noted that Article 9 is located towards the beginning of the CRPD. As with Articles 1-8, Article 9 is intended to inform and assist in the interpretation and implementation of all the human rights elaborated in the CRPD. For example, if someone were seeking to implement Article 13, Access to justice, an important starting place would be Article 9 when considering how to improve the accessibility of, for example, courthouses or the criminal justice system. This approach also explains why accessibility concepts are often not addressed in great detail or sometimes not at all in specific articles of the CRPD: the drafters of the CRPD intended Article 9 to be the common reference point for all issues of accessibility.

Taken as a whole, States' obligations with regard to accessibility include:

1. Obligation to respect by refraining from engaging in any act, custom or practice that creates barriers to accessibility;
2. Obligation to protect by ensuring that non-State or "private" actors (such as businesses that offer services and facilities to the public) do not create or fail to remove barriers to access for people with disabilities;
3. Obligation to fulfill by affirming that States must take proactive action (such as indicated in the provisions outlined in Article 9) to ensure accessibility for people with disabilities.

In short, international human rights law strongly supports accessibility for people with disabilities, so that people with disabilities may live independently and fully participate in all aspects of life.

EXERCISE 2.4: Understanding Accessibility

Objective: To review and understand the accessibility provisions of the CRPD
Time: 45 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Review:
Divide the participants into small groups. Ask each group to work together to paraphrase Article 9 in common language and give some examples of how it could be enjoyed and make a difference for people with disabilities in their community. Given the length of Article 9, you may want to ask different groups to address specific sections, especially if you feel that particular sections have already been addressed through previous exercises.

2. Paraphrase:
Read Article 9 aloud, pausing at each comma or natural section to ask different groups for their paraphrase. Discuss the meaning of the section until everyone can agree on a paraphrase. Write the final paraphrase of Article 9 on chart paper.

3. Give examples:
Ask for examples of how accessibility could be enjoyed and make a difference for people with disabilities.

4. Discuss:
How can Article 9 of the CRPD be used to set national disability rights agendas and formulate platforms of action for submission to political parties or government decision-makers? What would it mean in your country?

EXERCISE 2.5: Making a Commitment to Promote Accessibility

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about accessibility for people with disabilities, 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 accessibility of people with disabilities to ensure their full enjoyment of all human rights. (One example of an action might be investigating whether there are national accessibility standards governing the built environment, government websites, etc. If standards exists, participants may wish to see whether they are enforced, and if not, they may wish to engage in advocacy to encourage the government to adopt such standards.)

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.

The BBC: Taking a Holistic Approach to Accessibility

The BBC is perhaps best known internationally for its television and radio news and entertainment programs. However, when the BBC undertook a review of its commitment to accessibility for people with disabilities, it looked beyond subtitles and audio description in its programming. Recognizing the diversity of services that it provides, as well as its role as an employer, the BBC committed itself to a comprehensive review of all of its activities, including:

- Provision of television licenses
- Development, production and broadcasting of news, educational and entertainment programming
- Provider of web-based information
- Participant in the switch-over from analogue to digitally-based broadcasting
- Customer-service provider
- Public actor subject to the UK's Disability Discrimination Act.

As part of its overall commitment to disability, race, and gender diversity, the BBC adopted a "Disability Equality Scheme" (DES), which was developed through consultation with organizations of people with disabilities as well as employees with disabilities. Through surveys and focus groups, the BBC gathered information on the accessibility of its current activities, where people felt there were problems, and ways in which it could improve its performance in the future. For example, most people surveyed indicated that they did not face barriers in purchasing their television licenses, but they did face problems accessing customer service departments and felt that the organization did not always understand the issues facing people with disabilities.

The DES (which runs from December 2006-2009) sets forth a detailed action plan and procedures for performance monitoring, assessment, and review. The DES operates in conjunction with the BBC's "Broader Approach to Promoting Disability Equality." Together, the policies address access for viewers and customers with disabilities and also address accessibility in other areas, such as employment of staff with disabilities; employment of program makers, writers, actors and presenters with disabilities; utilization of digital, internet and other technologies to promote disability access and inclusion; and training and educational materials to promote staff awareness.[5]

5 "The BBC's Disability Equality Scheme". 30 Apr. 2007. *BBC Home*. http://www.bbc.co.uk/info/policies/diversity.shtml#DES1

USEFUL RESOURCES ON ACCESSIBILITY

- Access Exchange International: Accessible Transportation Around the World: http://www.globalride-sf.org/index.html
- American Council of the Blind - helpful resources for blind and visually impaired persons: http://www.acb.org/resources/index.html
- The Center for Universal Design: Environments and products for all people: http://www.design.ncsu.edu/cud/about_ud/udprinciples.htm
- *Design for Accessibility: A Cultural Administrator's Handbook*. National Assembly of State Arts Agencies: http://www.nea.gov/resources/Accessibility/pubs/DesignAccessibility.html
- General Comment No. 5 of Committee on Economic, Social and Cultural Rights: http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/4b0c449a9ab4ff72c12563ed0054f17d?Opendocument
- *International Best Practices in Universal Design: A Global Review.* Canadian Human Rights Commission: http://www.chrc-ccdp.ca/whats_new/default-en.asp?id=376
- Manila Declaration on Accessible Information and Communication Technologies (ICT): http://www.un.org/esa/socdev/enable/maniladecl.htm
- UN Global Audit of Web Accessibility: http://www.un.org/esa/socdev/enable/gawanomensa.htm
- W3C Web Accessibility Initiative – policies addressing web accessibility: http://www.w3.org/WAI/Policy/

CHAPTER 3: THE RIGHT TO PARTICIPATION IN POLITICAL AND PUBLIC LIFE

UN Convention on the Rights of Persons with Disabilities

Article 29, Participation in political and public life:

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and undertake to:

(a) Ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:
   (i) Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;
   (ii) Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums, without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;
   (iii) Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;

(b) Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:
   (i) Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;
   (ii) forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

OBJECTIVES

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

- Define the right to participation in political and public life
- Explain the importance of participation for achieving disability rights
- Understand the interrelationship between the right to participation and other human rights
- Identify ways in which the rights of people with disabilities to participate in political in political and public life and decision-making generally has been promoted or denied
- Describe the provisions regarding participation in the **Convention on the Rights of Persons with Disabilities** (CRPD)
- Highlight possible advocacy strategies to advance the right of people with disabilities to participate in decision-making, including in political and public life.

GETTING STARTED: THINKING ABOUT PARTICIPATION IN POLITICAL AND PUBLIC LIFE

People with disabilities have too often been excluded from participating in the decisions that affect their lives. Their absence from decision-making processes reinforces barriers to full participation in society.

The enjoyment of the right of people with disabilities to participate in decision-making, including participation in political and public life, is interrelated to their enjoyment of other human rights. For example, if a person with a disability is denied her or his right to education, the right to participate in political processes is also compromised because education provides the basis for active citizenship. Access to information is another precondition to the right to vote and to participate in decision-making in society. Similarly, if a disabled person has no access to transportation, she or he may not be able to register to vote, to cast a ballot at a polling station, or to participate in a public hearing on an important community issue that affects her. Discriminatory laws may permanently deny people with disabilities of their legal rights and thus deny them their legal capacity, as in the case of processes that strip the rights of persons with psycho-social disabilities to make decisions about medical interventions. These examples demonstrate how human rights are **indivisible**, **interdependent**, and **interconnected**.

The right to political participation may be denied to people with disabilities for a variety of reasons. Discriminatory laws may restrict or even prohibit altogether the right to vote, particularly for people with a psycho-social or intellectual disabilities. Stereotypes about disability may also serve to exclude people with disabilities from being included in public outreach by political parties or for consideration as candidates for public office. Lack of access to information, such as when public meetings are held or voting requirements, can also be a barrier to participation. Communication barriers frequently exclude people who are deaf or hard of hearing from decision-making processes, such as medical decision-making. In the context of international development, donor organizations or service providers may wrongly assume that people with disabilities are unable or uninterested in taking part in the planning and implementation of development projects. These and numerous other barriers serve to reinforce the exclusion and isolation of people with disabilities in political and public life, and, more generally, their participation in decision-making in all areas where their interests are affected, whether in the public or private realm.

Examples of Barriers to Participation in Decision-making

- Attitudes about the value of inclusion of people with disabilities in decision-making processes
- Lack of accessible information about public meetings and consultations, political parties, voting, and registration
- Lack of transportation to public meetings, registration, and polling stations
- Physical barriers to public buildings, including courts, voting registration centers, and polling stations
- Polling stations in rooms too small to accommodate people using wheelchairs and voting boxes placed on high tables
- Lack of accessible information on voting procedures for voters with sensory disabilities
- Poorly trained election workers
- Hostility and/or exclusion of people with psycho-social disability and intellectual disabilities in decision-making processes
- Lack of alternative voting devices or accessible voting methods for people with sensory disabilities
- Lack of mobile voting mechanisms for people who cannot leave their homes or who are currently residing in hospitals/institutions.

EXERCISE 3.1: What Rights to Participation in Decision-making Does the CRPD Affirm?

Objective: To review and understand the rights to participation and public life affirmed by the CRPD
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Review:
Divide participants into small groups and assign each group different parts of Article 29, such as Articles 29(a)(i) and 29(b). Ask each group to work together to:

- paraphrase their assigned section in common, clearly understandable language, and
- give some examples of how that right could be enjoyed and make a difference for people with disabilities.

2. Paraphrase/Give examples:
Read each section of Article 29 aloud and ask the assigned group to give their paraphrase. Discuss the meaning of the section until everyone can agree on a paraphrase. Write the final paraphrase of each section Article 29 on chart paper.

After each section ask for examples of how that right could be implemented and make a difference for people with disabilities.

3. Discuss:
How can Article 29 of the CRPD be used to set national disability rights agendas and formulate platforms of action for submission to political parties or government decision-makers?

WHAT DOES HUMAN RIGHTS LAW HAVE TO SAY ABOUT THE RIGHT TO PARTICIPATE IN POLITICAL AND PUBLIC LIFE?

The right to participate in political processes is a well-established principle of human rights law and is expressed in Article 21 of the **Universal Declaration of Human Rights** (UDHR).[1] Article 25 of the **International Covenant on Civil and Political Rights** (ICCPR) provides that–

[E]very citizen shall have the right and the opportunity… without reasonable restrictions…to vote and to be elected at genuine periodic elections which shall be universal and equal suffrage and shall be held by secret ballot, guaranteeing the free expression of the will of the electors.[2]

The CRPD elaborates on the right of people with disabilities to participate in the political life of their societies and provides specific guidance to States on implementing this right. Participation in the context of the CRPD extends beyond voting and encompasses the right of disabled persons to participate in decision-making processes where their interests are affected, on an equal basis with others. Specifically, Article 29 guarantees the right of people with disabilities:

- to vote, on a non-discriminatory basis, in elections
- to access an effective impartial and non-discriminatory procedure for the registration of voters
- to have equal and effective access to voting procedures and facilities in order to exercise their right to vote
- to cast their ballot in secret
- to have assistance in order to exercise their right to vote or to stand for election as a candidate for public office
- to participate in the conduct of public administration, including the administration of political parties and civil society
- to participate in the work of international organizations, including serving as a representative of government in international organizations
- to form and join disabled peoples organizations at all levels.

States Parties to the CRPD are required to ensure the right to participate in political processes, including voting, and to provide, *by means of positive State action*, that citizens with disabilities actually have the opportunity to exercise their political rights. The CRPD makes participation a fundamental principle in Article 3 (General Principles) and calls for "[f]ull and effective participation and inclusion in society." Article 4 states a general obligation for States to "closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations" in the "development and implementation of legislation and policies." Together with Article 29, Article 3 (General Principles) and Article 4 (General Obligations) specify one of the clearest expressions in international human rights law of the right to participation in decision-making when one's interests are affected.

1 See http://www.unhchr.ch/udhr
2 See http://www.unhchr.ch/html/menu3/b/a_ccpr.htm

In summary, States have the obligation to *respect, protect, and fulfill* the rights of people with disabilities to participate in political and public life and decision-making more generally where their interests are affected. In meeting their obligation to *respect* the rights of people with disabilities to participation in political and public life, States must refrain from limiting or interfering with the access of people with disabilities to exercise their right to participation. States must also refrain from enforcing discriminatory practices as a State policy and abstain from imposing discriminatory practices relating to participation. Obligations to *protect* include, along other things, the duties of States to adopt all appropriate legislative, administrative and other measures to facilitate the enjoyment of participation rights. This may include, for example, introducing accessible voting procedures and facilities, ensuring equal access to political rights. Finally, the obligation to *fulfill* participation rights requires States to, among other things, adopt policies that detail plans for realization of these rights. States Parties to CRPD must, for example, ensure the appropriate training of election officials and support information campaigns that are accessible to people with disabilities. The obligation to fulfill further requires States to adopt positive measures that enable and assist people with disabilities to enjoy their political participation rights.

Measures to Enhance Participation in Political Life and Decision-making by People with Disabilities

- Training of elected representatives on disability issues (e.g., Parliamentarians, local council members)
- Capacity building among organizations for persons with disabilities to enhance their role in public decision-making processes of all types
- Disability awareness campaigns
- Outreach campaigns highlighting the right of people with disabilities to vote and be elected
- Public forums with political parties to present a unified disability platform
- Development of an election access task force to work with election officials and national election commissions on access issues
- Inclusion of the voice and image of people with disabilities in civil and voter education materials
- Development of Tactile Ballot Guides for blind voters, allowing their votes to be cast independently and in secret
- Training of election officials on accessibility
- Inclusion of people with disabilities in election observation and inclusion of access issues on all election observation forms
- Participation in the planning of development programs and lobbying development organizations for inclusion
- Encouragement of government ratification of the UN Convention on the Rights of Persons with Disabilities.[3]

3 "Global Initiative to Enfranchise People with Disabilities." *International Foundation For Election Systems (IFES)*. http://www.electionaccess.org

PARTICIPATION IN VOTING AND OTHER ELECTORAL PROCESSES

The CRPD provides that people with disabilities have the right to vote, which means that they have the right to register to vote, to receive voting information, and to cast their ballot on election day. States are required to provide procedures and facilities for voter registration and polling that are accessible to people with disabilities. States are also required to ensure that all voters have the right to vote in secret. Although the right to register to vote and to vote on polling day extends to all people, it is subject to the usual eligibility requirements such as age and nationality. Certain disqualifications may apply to otherwise eligible voters, including sentencing by a competent court in criminal proceedings. Other disqualifications may be based on a declaration of legal incompetence or incapacity by a court, which often impacts people with intellectual and psycho-social disabilities. In the absence of such disqualifications, no person can be barred from exercising his or her right to vote, provided she or he meets the other eligibility requirements. In practice, disqualifications relating to mental capacity are much abused; they are applied arbitrarily and without court declarations. In this context, therefore, education of voters, registration and polling officials, and people with disabilities themselves is particularly important.

Voting procedures and facilities must be accessible to people with disabilities. Polling stations must be free of physical barriers that might prevent a person with a physical disability from registering or voting. For example, stairs are barriers for people who use wheelchairs or have mobility impairments and can also present dangers to blind voters and voters with visual impairments. Communication barriers can prevent voters with hearing impairments from exercising their right to register and to vote. Sign language interpreters or written material, highlighted with clear illustrations may provide accommodations for such voters. Plain language materials may assist voters with intellectual disabilities in exercising their right to vote. The training of election officials is essential to enable voters with disabilities to be appropriately accommodated and treated in a non-discriminatory manner.

All people have the right to vote in secret, an absolute right that may not be restricted. In many countries, however, voting and registration procedures are not made accessible to people with disabilities to allow for their secret voting, especially for blind voters. Blind voters may exercise their right to vote in secret with a tactile ballot guide or with a voting machine that has audible instructions. Many countries have introduced accessible procedures that provide blind voters with the right to vote in secret. (See text box below).

Tactile Ballot Guides for Blind Voters

In the 2005 Liberian elections, the National Elections Commission, together with the International Foundation for Election Systems (IFES), printed Tactile Ballot Guides to enable blind voters to mark their ballot independently, thereby preserving their rights to vote in secret. Election officials were trained on the use of this guide so that they could assist blind voters wishing to use them. A coalition of organizations for persons with disabilities held voter education sessions throughout Liberia in which they explained to blind voters how to use the guides. IFES has facilitated the introduction of Tactile Ballot Guides in many countries, including Armenia, Ghana, and Yemen.

People with disabilities also have the right to assistance in the exercise of their registration and voting rights. For example, they may select a friend or family member to accompany them to the polls. The right to assistance is particularly important where registration and polling stations are not fully accessible. Service animals may also facilitate political participation rights.

In many countries around the world, organizations for persons with disabilities have played important advocacy roles to enhance the accessibility of electoral processes for all and also to raise awareness about disability issues more generally. Electoral processes present opportunities for persons with disabilities to raise the visibility of disability issues, to engage with political parties, and to assess the extent to which national elections commissions are working to ensure access and realizing the right of people with disabilities to exercise their right to vote. Electoral processes also present opportunities for disabled people's organizations to work with other civil society groups on voter awareness and education and on observation and monitoring. In this way, organizations for persons with disabilities can connect with other civil society groups to share information and advocacy goals and to learn the advocacy strategies and priorities of other groups.

EXERCISE 3.2: Voting Access for People with Disabilities

Objective: To consider how voting processes can ensure the participation of people with disabilities
Time: 45 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Discuss:
Divide participants into small discussion groups. Ask each group to discuss the following questions, encouraging them to consider these questions as they may apply to people with different kinds of disabilities (e.g., physical, sensory, and psycho-social):

- What barriers do you think might exist in exercising rights to political participation in your community (e.g., in voting, in holding public office, in accessing information)?
- If you do not know of any barriers to voting, how and where could you find out?
- What has been your own experience or observation relating to barriers faced by people with disabilities in voting?

2. Report:
Ask each group to summarize their discussion and role play a situation identified in their discussion. Record the situations of barriers as they are mentioned.

3. Discuss:
Emphasize to the group that discrimination is often based on mistaken ideas and stereotypes that one group holds about another.

- How would you confront perceptions about people with psycho-social disabilities in voting?
- How could you increase the visibility of people with disabilities in an election process?
- How could you ensure that election observers think about accessibility issues in their monitoring role?
- What steps could you take to reach disabled voters in voter awareness programs?

Alternative:
As a whole group, draw together suggestions into an Election Access Tips Document covering some or all of the following actions to improve accessibility in voter registration: voter education, places of registration and voting, ballot casting, and voter observation. Use in disability rights advocacy and distribute to national election commissions, NGOs active in elections work and voter observation, and international democracy and governance groups engaged in voter education, election administration, and observation.

EXERCISE 3.3: Voter Observation and Monitoring

Objective: To consider how people with disabilities and their allies can monitor and evaluate election procedures
Time: 45 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Explain:
Emphasize to the group that people with disabilities can play a significant role in election observation, ensuring the transparency of an election, as well as identifying barriers to voting. Election observers observe and monitor the balloting process and the counting of results. Observation includes, among other issues:

- location of polling stations and their accessibility to the population which includes:
  a. the opening and closing of polling stations at stated times
  b. the arrangement of voting booths
  c. the orderly movement of voters
- the presence of well-trained and competent officials who are knowledgeable about the procedures and responsive to requests for assistance
- an established procedure for identification and verification of voters
- secrecy of the act of balloting such as
  a. the marking of ballot papers out of the sight of officials and observers
  b. provision for secret balloting for blind voters
- security of the ballot box and integrity of the counting process and results, such as
  a. ensuring that ballot boxes are empty before voting begins and secure and sealed when polling stations are closed and during any transit procedure
  b. ensuring that votes are tallied in a process that inspires confidence.

2. Discuss/Draft:
Divide participants into small discussion groups. Ask each group to discuss these questions:

- How can a disability dimension be included in election observation?
- What steps can be taken to ensure that election observers are aware of election access issues?
- How can election observation results be used to improve election access in future elections?

Ask each group to design their own voter observation forms and/or procedures with questions relating to election access for people with disabilities.

3. Report/Discuss:
Ask a spokesperson from each group to summarize the group's discussion conclusions and present the group's draft election observation form. Record ideas on chart paper as they are mentioned.

4. Take Action:
Use the tool you have created, participate in election observation, help train observers, and report on your election observation!

RIGHT TO STAND FOR ELECTION AND HAVE EQUAL ACCESS TO PUBLIC SERVICE

People with disabilities have the right to stand for election to public office. While States may limit that right to those who have reached a minimum age, restrictions must be justifiable and reasonable. Disability should never apply as a restrictive condition.

People with disabilities likewise enjoy equal access to public service and government jobs at all levels, including working at local government offices as well as serving as government representative at international levels such as the United Nations. Indeed, a number of disabled elected representatives as well as governmental public servants participated in the UN negotiations that resulted in the adoption of the CRPD. Such inclusion helps to ensure that government at all levels takes into account the needs of people with disabilities.

In some countries, disabled peoples organisations have advocated for positive measures in order to ensure that their interests are effectively represented in their legislatures. In Uganda, for example, the Constitution requires that a certain percentage of seats in Parliament be accorded to representatives with disabilities. In other countries, a certain number of parliamentary seats may be appointed by the executive. This policy has resulted in the presidential appointment of representatives with disabilities to Parliament, in Namibia for example. In other cases, people with disabilities may have representation through a Disability Advisor linked to the Executive, as in the case of the Swedish Disability Ombudsman or Namibian Disability Advisor, or through a Council on Disability, as in the case of the United States National Council on Disability.

RIGHT TO FORM AND JOIN ORGANIZATIONS

The CRPD recognizes the right of people with disabilities to form and join disabled peoples organizations for the purpose of representation at all levels. This right reflects the human right of anyone to found an association with others around a particular issue or to join an existing association. Forming an association and joining as a member must be voluntary: no one can be forced to join any association. States must provide a legal framework for establishing association and must protect this right against interference.

Disabled peoples organizations are explicitly referenced in the CRPD because they refer to organizations established by and for people with disabilities themselves. Associations established and run by people with lived experience of disability are best placed to ensure that the voice of people with disabilities is heard in decision-making processes. Disabled peoples organizations played an important role in the process by which the CRPD was drafted and will continue to play critical roles in the implementation of the treaty.

Parliamentary Participation and People with Disabilities

Canada: Following the election of a disabled person to the House of Commons, modifications were made to the House's Standing Orders to "permit the full participation in the proceedings of the House of any Member with a disability." This allows the Speaker to exempt such a member from the requirement to stand for debate and voting. Disabled MPs are now allowed to be accompanied by an assistant on the floor of the House.

Uganda: Uganda's new constitution, written in 1995, requires that five of the national members of Parliament *have personal experience with disability*. The Local Government Act of 1997 provides for the election of one disabled woman and one disabled man to every village, parish sub-county, and district council. The 47,000 representatives sitting on directly elected bodies are easily the largest group of disabled politicians anywhere in the world. Disabled MPs have served on a variety of Parliamentary committees, including Presidential Appointments, Rules and Privileges, Legal and Parliamentary Affairs, Commissions, Statutory Authorities and State Enterprises, Social Services, as well as Public Service, Gender, and Local Government. Serving in the Parliament is easier now that rules have been changed to permit guide dogs and sign language interpreters in meeting and parliamentary sessions.

Sri Lanka: Section 23(2) of Sri Lanka's constitution has a section titled "Specific Inclusion of People with Disabilities" that states: "No person with a disability shall, on the ground of such disability, be subject to any liability, restriction or condition with regard to access to, or use of, any building or place which any other member of the public has access or is entitled to use, whether on the payment of any fee or not."

Article 89 of the Sri Lankan constitution titled "Exclusion Based on Mental Disability" states:

> *No person shall be qualified to be an elector at an election of the President, or of the Members of Parliament or to vote at any Referendum, if he is subject to any of the following disqualifications, namely…(c) if he is under any law in force in Sri Lanka found or declared to be of unsound mind…" Article 91, subsection (1) states: "No person shall be qualified to be elected as a Member of Parliament or to sit and vote in Parliament (a) if he is or becomes subject to any of the disqualifications specified in article 89…*

Tanzania: Margaret Agnes Mkanga is a MP representing women and people with disability in the national legislature in Tanzania. Her major task is to mediate, discuss and advise the government on how it can improve the welfare of people with disability through formulation of better policy. As the only MP representing people with disability, Ms. Mkanga travels around the country to participate in consultations with different organizations working on disability issues, visiting groups of people with disabilities in rural and urban communities.

South Africa: Eleven MPs in the South African parliament have disabilities. Prior to the 1994 elections, activists with disabilities looked for the political base to advance their cause. They used the Disability Rights Charter that they had produced as a bargaining chip to pressure the ruling African National Congress (ANC) to establish a disability unit. Within three years a national disability strategy was adopted, and the unit was moved to the Office of the Deputy President.

EXERCISE 3.4: Making a Commitment to Promote Participation Rights

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about the human right of people with disabilities to participate in political and public life, and other decision-making processes 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 disability to participate in political and public life.

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.

USEFUL RESOURCES ON PARTICIPATION IN POLITICAL AND PUBLIC AFFAIRS

- *Americans with Disabilities Act Checklist for Polling Places***.** Civil Rights Division, Disability Rights Section, U.S. Department of Justice, February 2004: http://www.ada.gov/votingck.htm
- Global Initiative to Enfranchise People with Disabilities, International Foundation For ElectionSystems (IFES): http://www.el ectionaccess.org
- Goodwin-Gill, Guy S., *Free and Fair Elections.* Inter-Parliamentary Union, 2006.

CHAPTER 4: FREEDOM OF EXPRESSION AND OPINION

UN Convention on the Rights of Persons with Disabilities

Article 21, Freedom of expression and opinion and access to information:

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

(a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;
(b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;
(c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
(d) Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;
(e) Recognizing and promoting the use of sign languages.

Article 2, Definitions (excerpts):
For the purposes of the present Convention:

"Communication" includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology;

"Language" includes spoken and signed languages and other forms of non-spoken languages.

OBJECTIVES

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

- Define the right to freedom of expression and opinion
- Explain the importance of the right to freedom of expression and opinion for people with disabilities
- Understand the interrelation between the right to freedom of expression and opinion and other human rights
- Identify ways in which the right to freedom of expression and opinion of people with disabilities has been promoted or denied

- Understand the provisions related to freedom of expression and opinion in the UN **Convention on the Rights of Persons with Disabilities** (CRPD).

GETTING STARTED: THINKING ABOUT FREEDOM OF EXPRESSION AND OPINION

The human right to freedom of expression and opinion addresses a number of specific but interrelated concepts, each of which can be subjected to differing degrees of restriction by States:

1. Freedom of opinion

Everyone has the right to hold any opinion or view, regardless of how popular, unpleasant, or controversial others might find that opinion. This is a right that is absolutely protected and cannot be subjected to any form of restriction by States, as to do so would be to permit State interference into people's very minds and thoughts. Essentially, we all have the right to think as we please and not to be told what or how to think.

2. Freedom of expression

The right to freedom of expression has two distinct parts:

a. Right to impart or share information and ideas of all kinds
b. Right to seek and receive information.

Clearly the right to freedom of expression includes the right to exchange information and articulate ideas and opinions, as well as to obtain information so that ideas and opinions can be developed.

Unlike the right to freedom of opinion, the right to freedom of expression carries with it certain responsibilities and *can* be subjected to restrictions by the State. This is because the expression of ideas or exchange of information can sometimes be harmful to others, such as when people incite hatred against others, or say untrue things that could harm the reputation of another person. For this reason the State is permitted to impose some restrictions on the right to expression in the interests of public safety, order, health, morals, or protection of the fundamental rights and freedoms of others. However, such restrictions must be provided by law and actually necessary to protect those interests. In addition, any restrictions imposed by the State should not be so great as to effectively erase the right.

The right to freedom of expression and opinion is critical to the enjoyment of other human rights by people with disabilities. For example, it would be hard to imagine the forming and effective functioning of disabled peoples organizations or trade unions, without the ability of members to participate in the sharing and exchange of information and ideas. Similarly, the ability of people with disabilities to participate in political and public life, such as through voting and public service, would be severely hampered if candidates could not express their views and voters could not access information about the issues. The formation and exchange of ideas is also essential to the right to education, where research and debate are critical components of many academic environments. In the same way, the development and exchange of ideas is critical to the development of culture and can provide an important means of expression. Indeed, unless people with disabilities enjoy the right to freedom of expression and opinion, no State can comply with its legal obligation under the Convention on the Rights of Persons with Disabilities,

which in Article 3(3) calls for consultation with and active involvement of people with disabilities in the implementation of the CRPD.

Violations of other human rights can also negatively impact the enjoyment of the right to freedom of expression and opinion by people with disabilities. For example, lack of access to education can hamper the opportunities for people with disabilities to acquire knowledge and learn skills that contribute to developing of ideas and sharing of those ideas with other people. Violation of the right to privacy may discourage people with disabilities from expressing their ideas in letters or other forms that they feel may be subject to search or confiscation. Such concerns may be heightened for people who do not enjoy the right to live independently and in the community but live in institutional settings where the right to privacy may not be sufficiently respected by staff or others living there.

Despite the importance of the right to freedom of expression and opinion, people with disabilities face numerous barriers to full enjoyment of this right. For instance, many people with disabilities lack access to information in accessible formats. Although numerous formats and technologies already exist, these accessible formats are often not widely available, especially in developing countries where accessible technologies are unaffordable for many people with disabilities. This is certainly true for mainstream media, where not all television programmes are broadcast with subtitles, captioning, or inset sign language interpretation for deaf viewers, or audio description for viewers who are blind or have visual impairments. Few newspapers are available in Braille in a timely manner for readers who are blind, and fewer still offer content in plain language suitable for people with intellectual disabilities. Despite the growing use of the Internet as a source of news and a means of research, many websites remain inaccessible to people with disabilities. Emerging technologies, such as digital broadcasting and broadband, have the potential to enhance the accessibility features available to people with disabilities. However, this potential will only be realised if decision-makers responsible for how information is distributed are aware of the need to address accessibility and are willing to listen to the views of product users who have disabilities.

As with other human rights, one of the greatest barriers to enjoyment of the right to freedom of expression and opinion can be the attitudes of others. Prevailing social attitudes and stereotypes often create an environment in which the opinions of people with disabilities are not welcome. Even when they do express themselves, their ideas and opinions may not be accepted as worthy of consideration on an equal basis with those of others. People with intellectual and psycho-social disabilities commonly face pressure from others to conform not only in their way of thinking, but also in their methods of expressing themselves, to a manner considered “more acceptable.” Some people with psychosocial disabilities have noted that forced treatment involving psychotropic medications can interfere substantially with a person’s thought processes, making it difficult to think clearly and formulate opinions. In some cases the actual objective of using these therapies is to alter the way people with psycho-social disabilities think and express themselves, so that their behavior and beliefs do not offend or upset other people. This treatment is often defended by the argument that it is in the person’s best interests to avoid thoughts, ideas, and opinions that are “not rational.”

In summary, the right to freedom of expression and opinion is essential to the ability of people with disabilities to develop as individuals and to participate in societies on an equal basis with others. However, full enjoyment will remain elusive for people with disabilities as long as access, attitudinal, and other barriers exist.

Making Information Available in Plain Language

In 2002 Jean Ross and Janet Pringle of the Vocational and Rehabilitation Research Institute (VRRI) gave a speech to the Plain Language Association International (PLAIN) called "Hey, I can read that! Perspectives on plain language and people with developmental disabilities." Jean Ross, who self-identifies as someone with a developmental disability, spoke of some of the reasons why it is important for information to be available in plain language:

> *It's not fair when things we need to know are not written so we can read them. We feel left out. We have to wait for our support workers, or our family to tell us things. Sometimes they don't have time or they forget. We should be able to read them for ourselves*

Jean and other people with developmental disabilities work with people like Janet in order to "translate" information into plain language. This helps to make the content of the information accessible to as many people as possible. (The information might still need to be available in alternative formats, such as Braille, in order to make it fully accessible to all people with other disabilities.) After the information has initially been translated, the group works together to figure out what the information is trying to say and whether it does so in a way that can be understood by everyone. Jean describes the process as this:

> *Janet asks two or three of us to work with her. We read the papers out loud, a little bit at a time. Some of us cannot read at all. Those people listen. Some, like me, can read well. We talk about what each bit means, and we say when we do not understand. Sometimes Janet has to help us find better words and sometimes we find them ourselves. We all take part. No one is ever put down. We all have to feel safe together or it would be too hard to say when we did not understand something. But we know when we say we do not understand; we help lots of others who do not understand.*[1]

1 Ross, Jean and Pringle, Janet. "Hey, I can read that! Perspectives on plain language and people with development disabilities." 27 Sept. 2002. *Plain Language Association International (PLAIN) Fourth Biennial Conference Proceedings.* http://www.plainlanguagenetwork.org/conferences/2002/perspect/perspect.pdf ; see also: The Vocational and Rehabilitation Research Institute (VRRI): http://www.vrri.org

EXERCISE 4.1: Enjoying the Right to Freedom of Expression and Opinion

Objective: To understand what it means to enjoy the right to freedom of expression and opinion
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Brainstorm/Discuss:
Think about the typical life activities in which people with disabilities in your community are engaged. List these responses. (Save this list for further use in Exercises 4.2 and 4.3.

2. Analyze:

- Examine this list of life activities and list participants' responses:
  - In which instances do people with disabilities need access to information in order to participate fully?
  - What kind of information do they need?
  - Who is responsible for providing it?
- Examine this list of life activities and list participants' responses:
  - In which instances do people with disabilities need to be able to develop and communicate opinions in order to participate fully?
  - What different methods of communication can you think of that people with disabilities might use?

3. Prioritize:

1. Divide participants into small groups. Ask them to look at the list of needs identified in the Step 2 analysis and decide on the five most important needs of people with disabilities in order to enjoy the right to expression and opinion.
2. Bring the group back together and ask them to share and compare their prioritized lists. Combine these lists to form a list that everyone can agree upon.
3. Explain that this is a first step in the process of advocacy planning for the right to expression and opinion. Encourage participate to keep their prioritized lists for later use.

United Nations Global Audit of Web Accessibility

The United Nations commissioned Nomensa, a company specializing in technology accessibility, to conduct a survey of websites from around the world in order to obtain an indication of the "accessibility of websites that persons with disabilities might access as part of their daily lives." The survey examined 100 websites from 20 countries, focusing on five sectors: travel, finance, media, politics, and retail. It found that the vast majority of those websites did not currently meet internationally established accessibility standards and that many would need considerable work to upgrade them. Indeed, only 3 of the 100 websites met the basic accessibility rating. The following excerpts from the report represent some of the survey's findings, and indicate barriers to access experienced by a variety of people with disabilities:

- 93% did not provide adequate text descriptions for graphical content, causing problems for visually impaired people;
- 78% used foreground and background color combinations with poor contrast, making it difficult for people with mild visual conditions such as color blindness to read information;
- 97% used link text that did not clearly indicate the destination of the link, causing confusion for people with learning difficulties; and
- 92% did not provide a keyboard shortcut allowing people to bypass large blocks of content, causing difficulty and frustration for people with physical impairments.[2]

EXERCISE 4.2: Understanding Barriers to Freedom of Expression and Opinion

Objective: To identify barriers to freedom of expression and opinion faced by people with disabilities
Time: 40 minutes
Materials: List of life activities generated in Exercise 4.1

1. Analyze:
Using the list of life activities generated in Exercise 4.1, ask each participant (or pair of participants) to choose one activity from the list and to evaluate the barriers people with disabilities might face in either accessing information or expressing their thoughts, opinions, and preferences when they participate in that activity.

2. Role Play:
Ask each participant or pair to report on their analysis and to role play at least one fictional example of the barriers a person with disabilities might face in accessing information and/or expressing and communicating their opinions when they participate in that particular life activity.

2 "United Nations Global Audit of Web Accessibility, Executive Summary." Nov. 2006. *United Nations Department of Economic and Social Affairs: Social Policy and Development.* http://www.un.org/esa/socdev/enable/documents/execsumnomensa.doc ; see also: United Nations DESA Enable Global Audit page: http://www.un.org/esa/socdev/enable/gawanomensa.htm
Nomensa: http://www.nomensa.com/about.html

3. Discuss:

- What are the consequences when people with disabilities are excluded from accessing or imparting information in the life activities examined?
- To the person with disability?
- To society as a whole?
- Which barriers have the greatest effect on people with disabilities?
- What can be done to eliminate these most significant barriers to accessing or imparting information?

WHAT DOES HUMAN RIGHTS LAW SAY ABOUT FREEDOM OF EXPRESSION AND OPINION?

Article 19 of the **Universal Declaration of Human Rights** (UDHR) provides a concise description of the right to freedom of expression and opinion that captures the essential elements, including the right to hold opinions "without interference," as well as the right to receive and impart information and ideas "through any media and regardless of frontiers."[3] Thus, there are no geographic restrictions on the right, and the right can be enjoyed regardless of the methods or media used.

The **International Covenant on Civil and Political Rights** (ICCPR)[4] provides further elaboration of the right, addressing in more detail when and how States may place restrictions on its enjoyment. Article 19 of the ICCPR does not permit restrictions on the freedom of people to hold opinions, but does permit restrictions on the right to freedom of expression, in order to respect the "rights or reputations of others," national security, public order, public health, or morals. As noted by the **Human Rights Committee** in its General Comment on the right, any such restrictions must be provided by law and necessary to protect the interests permitted by the article. They "may not put in jeopardy the right itself" or be imposed arbitrarily.

Other international human rights conventions do not provide the same level of detail about the freedom of expression and opinion as that given in the ICCPR. For example, Article 5 of the **International Convention on the Elimination of All Forms of Racial Discrimination** (ICERD)[5] merely notes that States must prohibit and eliminate racial discrimination and guarantee equality in enjoyment of the "right to freedom of opinion and expression." Article 13 of the **Convention on the Rights of the Child** (CRC)[6] largely repeats the ICCPR provisions, though Article 12 states that children should be able to express their views on matters concerning them and that those views should increasingly be taken into account as the child grows in maturity and competence.

The non-legally binding **UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** (Standard Rules)[7] does not specifically address the right to freedom of expression and opinion. However, several of its rules address preconditions to equality of participation that are relevant to the enjoyment of this right:

- Rule 1 addresses awareness-raising, which can positively impact the attitudinal barriers faced by people with disabilities when trying to exercise their right to freedom of expression and opinion;

3 See http://www.unhchr.ch/udhr
4 See http://www.ohchr.org/english/law/ccpr.htm
5 See http://www.ohchr.org/english/law/cerd.htm
6 See http://www.unhchr.ch/html/menu3/b/k2crc.htm
7 See http://www.un.org/ecosocdev/geninfo/dpi1647e.htm

- Rule 4 addresses support services and the provision of assistive devices and services that could be useful to people with disabilities in enjoyment of the right;
- Rule 5 addresses accessibility, including access to information and communication;
- Rule 10 notes the need to ensure accessibility of literature, films, and theatre for people with disabilities to fully enjoy culture.

Article 21 of the **Convention on the Rights of Persons with Disabilities** (CRPD) does not address the parameters of the right to freedom of expression and opinion in the same detail as the ICCPR. Instead it examines specific issues impacting the ability of people with disabilities to enjoy the right on an equal basis with others. The article places great emphasis on the need for information, including information distributed by the mass media or for distribution to the general public by both public and private actors to be available in accessible formats and technologies. It also calls for States to accept sign language, Braille, and other means and modes of communication that people with disabilities choose to use whenever they have "official interactions." In recognition of the importance of sign language, Article 21 also calls for States to recognize and promote the use of sign language. It should be noted that the terms "language" and "communication" used in Article 21 are defined further in Article 2.

Taken as a whole, States' obligations with regard to the right to freedom of expression and opinion include:

1. Obligation to respect the right by refraining from engaging in any act, custom, or practice that creates barriers to people's enjoyment of the right (e.g., not prohibiting people who are deaf from communicating in sign language).
2. Obligation to protect the right by ensuring that non-State or "private" actors, such as businesses that distribute information to the general public, do not create or fail to remove barriers to enjoyment of the right (e.g., repairing inaccessible web pages).
3. Obligation to fulfill the right by requiring States to take proactive action to ensure enjoyment of the right by people with disabilities.

In short, international human rights law strongly supports the right to freedom of expression and opinion for people with disabilities, so that they may participate fully in all aspects of life on an equal basis with others.

EXERCISE 4.3: Understanding Freedom of Expression and Opinion

Objective: To review and understand the right to freedom of expression and opinion provisions of the CRPD
Time: 45 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Review:
Divide the participants into small groups. Ask each group to work together to discuss one of the sections of Article 21.

- What does each section require be achieved?
- Who is responsible to meet this requirement?
- What challenges might there be to implementation?
- How can these challenges be overcome?

2. Discuss:
Have the groups report on the outcomes of their discussions.

3. Give examples:
Ask for examples of how each of the provisions of Article 21 could be applied to the real life examples listed and discussed in Exercise 4.1 and 4.2.

4. Discuss:
- How can Article 21 of the CRPD be used to set national disability rights agendas and formulate platforms of action for submission to political parties or government decision-makers?
- What would it mean for people with disabilities if the CRPD were realized in your country?

The National Association for the Deaf: Advocating for Freedom of Expression and Opinion

The National Association for the Deaf (NAD) is one of the associations advocating for the rights of deaf and hard of hearing people in the United States. It has engaged in a number of advocacy campaigns supporting the increased accessibility of mainstream media for deaf and hard of hearing people, and has also advocated for improved ease of communication for deaf and hard of hearing people. For example, it has participated in the following activities:

- Working with Congress and the Federal Communications Commission to establish new rules on captioning for television broadcasters, in order to increase the number of captioned television programs
- Participating in the Coalition for Movie Captioning (CMC), an umbrella organization of disabled people's organizations that advocates for movies in theatres to be available with quality captions, including on the day and date of release of new movies
- Bringing complaints against companies who refuse to allow customers to communicate with them via telephone relay – a service that enables people to type over the telephone system, facilitating communication between both deaf and hearing people
- Advocating that broadcasters and others who provide information in emergency situations ensure that such information is accessible to people who are deaf or hard of hearing.
- Campaigning for the right of deaf children to learn sign language and for parents of deaf children to be supported should they choose for their child to learn sign language (e.g., through access to sign language learning programs if the parents are hearing).[8]

8 *National Association of the Deaf.* http://www.nad.org

EXERCISE 4.4: Making a Commitment to Promote Freedom of Expression and Opinion

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about the right to freedom of expression and opinion for people with disabilities, 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 right to freedom of expression and opinion of people with disabilities to ensure their full enjoyment of all human rights.

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.

USEFUL RESOURCES ON FREEDOM OF EXPRESSION AND OPINION

- American Council of the Blind, helpful resources for blind and visually impaired persons: http://www.acb.org/resources/index.html
- General Comment No. 10 of the Human Rights Committee: http://www1.umn.edu/humanrts/gencomm/hrcom10.htm
- Inclusion Daily Express: www.inclusiondaily.com/archives/04/09/15/091504sacourtaccess.htm
- Manila Declaration on Accessible Information and Communication Technologies (ICT): http://www.un.org/esa/socdev/enable/maniladecl.htm
- National Association of the Deaf: http://www.nad.org
- The Plain Language Association International (PLAIN): http://www.plainlanguagenetwork.org
- United Nations DESA Enable Global Audit: http://www.un.org/esa/socdev/enable/gawanomensa.htm
- United Nations Global Audit of Web Accessibility, Executive Summary (2006): http://www.un.org/esa/socdev/enable/documents/execsumnomensa.doc
- The Vocational and Rehabilitation Research Institute (VRRI): http://www.vrri.org
- W3C Web Accessibility Initiative – policies addressing web accessibility: http://www.w3.org/WAI/Policy

CHAPTER 5: THE RIGHT TO LIFE AND PROTECTION IN SITUATIONS OF RISK

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Article 10, Right to Life:

States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

Article 11, Situations of Risk and Humanitarian Emergencies:

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

OBJECTIVES

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

- Define the right to life
- Define the right to protection in situations of risk and humanitarian emergencies
- Understand the interrelationship between the right to life and protection in situations of risk and other human rights
- Identify ways in which the right to life of people with disabilities and protection in situations of risk have been promoted or denied
- Describe the provisions regarding the right to life and protection in situations of risk and humanitarian emergencies in the UN **Convention on the Rights of Persons with Disabilities** (CRPD).

For disabled people like me who are constantly up against society's belief that our lives are of less quality, the right to life article is literally a matter of life and death. To participate in its development is of vital importance.

— Jane Campbell, British Disability Rights Advocate speaking about the right to life provision in the UK Human Rights Act

GETTING STARTED: THINKING ABOUT THE RIGHT TO LIFE AND PROTECTION IN SITUATIONS OF RISK

Disability is profoundly linked to the right to life. People with disabilities are frequently denied their right to life, as well as their right to protection in situations of risk in many contexts, such as natural disaster, armed conflict, and other humanitarian emergencies.

Harmful cultural practices may directly violate the right to life of people with disabilities. Where resources are limited, preferential treatment of boys in the provision of food and medical attention directly impacts girls with disabilities and their right to life. In some cultures and societies, women and girls with disabilities are, like other women, subjected to practices such as widow burning and dowry killings. The practice of female genital mutilation often results in death from hemorrhaging and can create life-threatening conditions later for women during childbirth.

Other practices likewise implicate the right to life of people with disabilities. The practice of euthanasia in many countries takes the form of withholding life-saving treatment to a newborn child with a disability. Disability organizations have exposed cases where adults or children with disabilities have died at the hands of medical personnel who unilaterally decided that their life was "not worth living." These cases have included the imposition of a "do not resuscitate order" (DNR order) on the medical chart of patients with non life-threatening health care conditions. (See text box below). A DNR order is intended to prevent attempts at Cardiopulmonary Resuscitation (CPR) if a patient goes into cardiac or respiratory arrest.

Barriers to Enjoyment of the Right to Life

- Attitudes that life with a disability is "not worth living"
- Life-threatening conditions in institutions and orphanages
- Harmful cultural practices such as female genital mutilation, dowry killing and widow burning
- Selective abortion based on disability
- Infanticide and neglect of newborn infants with disabilities
- Imposition of "do not resuscitate" (DNR) orders
- Withholding of life-sustaining treatment for people with disabilities in hospital settings
- Domestic violence, particularly against women and girls with disabilities
- Failure to be inclusive of people with disabilities in disaster management, programs for refugees and internally displaced persons, and other humanitarian programs
- Lack of access to adequate food, clean water, shelter and basic survival needs

Disability advocates have invoked the right to life in order to oppose physician-assisted suicide. Other practices of concern include abortion on the basis of disability. In developing countries, the mortality rate of children with disabilities is frequently disproportionately high because such children may not receive adequate health care, including immunization from childhood

diseases. Health care providers frequently underestimate the quality of life enjoyed by people with disabilities. Consequently, people with disabilities are sometimes not given life-saving interventions that would otherwise be provided to patients.

The enjoyment of the right to life by people with disabilities is inextricably linked to the enjoyment of other human rights. For example, if a person with a disability has no access to health care or rehabilitation services, their right to life may well come under threat. Subjecting people with disabilities to dangerous working environments or to conditions that amount to forced labor is likewise potentially life threatening.

Access to information is another precondition to the enjoyment of human rights and, in some instances, is directly related to the enjoyment of the right to life. Thus, the failure of officials to provide important information in accessible formats (e.g., HIV/AIDS prevention programs or emergency evacuation procedures in times of natural disaster) may infringe upon the right to life of people with disabilities. These illustrations demonstrate that human rights are indivisible, interdependent, and interconnected. What is clear is that without respect for the right to life, all other human rights are without meaning.

Guiding Principles on "Do Not Resuscitate" Orders

The following Guiding Principles were developed by the British Columbia Association for Community Living to ensure that people with developmental disabilities are not subjected to the inappropriate use of "do not resuscitate" orders (DNR orders):

- A disability is not a terminal illness;
- The decision of whether someone is at the end stages of life must be made independently of the person's disability;
- All people at the end stages of life have the right to care and comfort measures, with an emphasis on alleviating pain;
- DNR orders should only be considered when someone is in the irreversible terminal stages of an illness or when the process of giving CPR could potentially cause significant trauma to the individual;
- Physicians should seek consent for a DNR order from the individual or an authorized substitute decision-maker before the order is placed on a person's medical chart;
- People with developmental disabilities who are receiving treatment for a treatable health care condition should be given CPR, unless the process of giving CPR could potentially cause significant trauma to the individual.[1]

EXERCISE 5.1: Threats to Life

Objective: To understand threats to the right to life of people with disabilities
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1 "Do Not Resuscitate Orders Policy." *British Columbia Association for Community Living.* http://www.bcacl.org/index.cfm?act=main&call=788F8794

1. Introduce:
Explain that people with disabilities face many threats to their life, not necessarily from their disability but because of it. These may include the dangers of living in institutions, decisions made by the medical profession, social attitudes, and public policies like eugenics. Endemic poverty may also threaten their quality of life and health, along with armed conflict or natural disaster.

2. Discuss:
Divide participants into pairs and ask each pair to:

- Share some examples from their own experiences or the experiences of people in their communities of such dangers to survival;
- Try to explain the cause of such threats to the survival of people with disabilities;
- Refer to "Barriers to the Enjoyment of the Rights to Life" (see text box above) or formulate a new list from responses of group.

3. Report/Analyze:
Ask each pair to report the causes they recognized for such threats to life. List these on a chart/ blackboard as they are reported.

- Ask participants if these causes can be grouped into categories (e.g., poverty, cultural or societal attitudes, medical decisions, public policies);
- What actions could be taken to address these causes and protect the right to life of people with disabilities? Are there preventive measures that may be taken to reduce life-threatening situations? Are there advocacy strategies that might help?

WHAT DOES HUMAN RIGHTS LAW HAVE TO SAY ABOUT THE RIGHT TO LIFE AND PROTECTION IN SITUATIONS OF RISK?

The right to life is the most fundamental of all human rights. Article 3 of the **Universal Declaration of Human Rights** (UDHR) provides that "[e]veryone has the right to life, liberty and security of person."[2] Article 6(1) of the **International Covenant on Civil and Political Rights** (ICCPR) provides:

> *Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.*[3]

The right to life is not absolute, however. For example, the death of a combatant during a lawful act of war under international humanitarian law does not violate the right to life. In certain limited circumstances, such as self-defense, a law enforcement official may take the life of someone. Some jurisdictions permit capital punishment for serious crimes, a practice which Article 6 of the ICCPR acknowledges but also narrowly limits in those countries where the practice exists.

When a state recognizes the right to life in international law, it assumes various duties. The **UN Charter** prohibits the threat or use of force by any State against another State, except in exercise of the inherent right of self-defense.[4] The **Human Rights Committee,** which monitors

2 See http://www.unhch.ch/udhr/lang/eng.htm
3 See http://www.ohchr.org/english/law/ccpr-one.htm
4 See http://www.un.org.aboutun/charter

the ICCPR, has stated in **General Comment** 6 that "States have the supreme duty to prevent wars, acts of genocide and other acts of mass violence causing arbitrary loss of life."[5] The State's obligations include making every effort to avert the danger of war and to strengthen international peace and security. These obligations constitute the most important condition for the safeguarding of the right to life. States may not limit the right to life during times of war or emergency and are required to provide protection and safety to persons who are non-combatants as a matter of **international humanitarian law**.

States must also refrain from action that may intentionally take away life**.** The **Human Rights Committee** has condemned the practice of infanticide for infants with disabilities and noted that it "is gravely concerned at reports that new-born handicapped infants have had their lives ended by medical personnel."[6] The **Committee on the Rights of the Child** urged States to "review and amend laws affecting disabled children which are not compatible with …the Convention, for example legislation which denies disabled children an equal right to life, survival and development (including, in those countries which allow abortion, discriminatory laws on abortion affecting disabled children, and discriminatory access to health services…)."[7]

The Human Rights Committee has stressed that the protection of the right to life requires that States adopt positive measures designed to protect life. These may include measures to increase life expectancy, decrease infant and child mortality, combat disease, and provide rehabilitation, adequate food, clean water shelter, and other basic survival needs. Rule 2.3 of the **UN Standard Rules** requires that "States should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society."[8]

The CRPD reflects these concerns about the right to life of people with disabilities. In Article 10, the CRPD recognizes the inherent right to life for people with disabilities and, in addition, requires States to "take all necessary measures" to ensure the enjoyment of that right by people with disabilities, on an equal basis with others. Article 11 of the CRPD requires positive measures of protection and safety for people with disabilities affected by situations of humanitarian emergencies and risk. Article 11 is closely connected to Article 10 insofar as war and other acts of mass violence continue to take the lives of thousands of innocent human beings every year.

In sum, States have the obligation to **respect**, **protect**, and **fulfill** the right to life of people with disabilities and their right to protection and safety in situations of risk and humanitarian emergency. In meeting their obligation to *respect* the right to life of people with disabilities, States must refrain from directly or indirectly infringing on disabled peoples' enjoyment of the right to life. States must also refrain from policies that enforce discriminatory practices that may impact their right to life, including in times of humanitarian emergency.

The obligation to *protect* includes, among other things, the adoption of all appropriate legislative, administrative, and other measures to prevent threats to the life of people with disabilities by state officials, as well as third parties. Protective measures could include careful monitoring of all settings where people with disabilities live or receive services, whether publicly or privately operated. Transitioning people with disabilities into community-living situations with appropriate

5 See http://www.umn.edu/humanrts/gencomm/hrcom6.htm

6 Concluding Observations of the Human Rights Committee for The Netherlands. UN Doc. CCPR/CO/72/NET (2001). http://www1.umn.edu/humanrts/hrcommittee/netherlands2001.html

7 See http://www.unhchr.ch/html/menu2/6/crc/doc/days/disabled/pdf

8 See http://www.ohchr.org/english.law/opportunities.htm

supports and out of institutions would also constitute protective measures. In the context of humanitarian crisis situations, protective measures could include disaster preparedness planning with the participation of people with disabilities and the provision of services that are inclusive of people with disabilities, such as appropriate evacuation procedures and refugee assistance programming.

The obligation to *fulfill* the right to life and protection in situations of risk requires States to, among other things, adopt positive measures to ensure the enjoyment of the right to life. Such measures might include information campaigns that seek to dispel the myth that people with disabilities have lives "not worth living" or training programs for disaster preparedness and relief workers that include the care of people with disabilities in the general population.

EXERCISE 5.2: What Rights to Life and Protection in Situations of Risk Does the CRPD Affirm?

Objective: To review and understand Articles 10 and 11
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Review:
Assign either Article 10 or Article 11 of the CRPD to small groups of participants. Ask each group to discuss and paraphrase its article in common language and give some examples of how that right could be enjoyed and make a difference for people with disabilities.

2. Paraphrase/Give examples:
Read each section of Articles 10 and 11 aloud and ask the assigned group to give their paraphrase. Discuss the meaning of the section until everyone can agree on a paraphrase. Especially ask:

- What does "inherent" mean?
- What might "necessary measures" refer to in each article?
- Ask for examples of armed conflict, humanitarian emergencies, and natural disasters, focusing on those experienced by this community.

Write the final paraphrase of Articles 10 and 11 on chart paper and post.

After each section ask for examples of how that right could be enjoyed and make a difference for people with disabilities. What "necessary measures" might be implemented by States to ensure the right to life and protection in situations of risk? Encourage participants to be as specific as possible.

3. Discuss:
How can Articles 10 and 11 of the CRPD be used to set national disability rights agendas and formulate platforms of action for submission to political parties or government decision-makers? What types of actors might disabled peoples organizations target for advocacy around the right to life and protection in situations of risk (e.g., Ministries of Health, humanitarian and disaster assistance organizations, the United Nations High Commissioner for Refugees)?

THREATS TO LIFE IN INSTITUTIONS

People with disabilities living in institutions are at high risk for human rights abuse, including infringements on the right to life. Placing people in large-scale institutions, instead of providing for living arrangements within the community, is isolating and makes close monitoring of conditions nearly impossible. Mental Disability Rights International (MDRI) has documented egregious violations of the right to life for children and adults with psycho-social and other types of disabilities who are housed in dismal and dangerous institutions. The human rights reports published by MDRI reveal unhygienic conditions of detention, excessive use of physical restraints, lack of adequate food, water, clothing and medical care, and other life dangerous and life-threatening conditions, including instances of patients freezing to death. People with disabilities face other dangers in institutional settings. In emergency situations, institutions have so often failed to take appropriate action when doing so could have averted threats to life. Recent cases in Russia and Hurricanes Katrina and Rita in the United States reveal that all too frequently, people with disabilities are simply left behind. (See text box). MDRI and many other disability rights organizations advocate for the closure of such facilities and enjoyment of the right to live independently and in the community, with appropriate supports (See also Chapter 6, "Freedom from Torture and Other Forms of Abuse," p. 83).

Lives Lost in Minnesota Institutions: The Remembering with Dignity Campaign

Remembering with Dignity is a coalition of disability rights and advocacy organizations founded in 1994 working to honor people who lived and died in Minnesota's state institutions. The goals of the campaign include:

- Restoring over 12,500 unmarked graves in institution cemeteries. Graves currently identified with only a numbered cement block – or with no marker at all – will be honored and marked with the person's name, date of birth and date of death.
- Collecting and recording oral histories of people with disabilities, particularly those who have lived in institutions.
- Organizing people with disabilities to ensure full integration in community life and to prevent a return to institutionalization.
- Raising public awareness about people with developmental disabilities.
- Demanding an apology from the State of Minnesota for its treatment of people with disabilities kept in institutions.

Campaign Achievements:

- Obtained release of the names of people buried in the Faribault cemeteries by working with the Department of Human Services, Attorney General's Office, Disability Law Center and Faribault Regional Center.
- Reconstructed incomplete lists of the earliest burials at the former Faribault State Hospital. There is now a more complete record of the individuals who were buried anonymously there.
- Between 1997 and 2005, the state legislature approved the granting of $725,000 for marking 12,500 graves of people buried in state hospital cemeteries.
- Placed over 2500 gravestones at cemeteries of former state hospitals.
- State cemetery in Cambridge was officially named the "Garden of Remembrance".
- Introduced a resolution asking the state legislature for a formal public apology to Minnesotans who were institutionalized and apology from the Governor in recognition of harms caused by massive institutionalization.[9]

9 "Remembering with Dignity, Read the Apology Resolution." 2005. *Advocating Change Together (ACT)*. http://www.selfadvocacy.com/programs_rwd_apology.htm

EXERCISE 5.3: Advocating for Community-Based Living

Objective: To consider strategies for addressing threats to the right to life of people with disabilities living in institutions and advocacy on community-based living
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Introduce:
Explain that people with disabilities are still housed in large scale institutions in many parts of the world and that community-based living is still a new phenomenon in many places. Disability groups such as Mental Disability Rights International in the US and the Mental Disability Advocacy Center in Hungary are working to expose abuses in institutional settings and promote community-based living.

2. Discuss:
Divide participants into pairs and ask them to:

- Share examples of situations in their own community/country/region where people with disabilities are not being provided with the opportunity to live in the community;
- Identify threats to the life and survival of persons with disabilities living in institutions;
- Identify the barriers that continue to prevent people with disabilities from living in the community.

3. Report/Analyze:
Ask each pair to report on the situations identified, the threats to life/survival, and the barriers that prevent community living. List these on the chart as they are reported.

- What actions could be taken to address these issues and protect the right to life of people with disabilities?
- What type of advocacy might be most effective (e.g., education, dialogue, documenting and reporting, media campaigning, court action)?
- Who needs to be informed in order to take action?

Russian Fire Safety Failures

Russia records nearly 18,000 fire deaths a year, several times the per capita rate in many other countries. In some of the worst cases, people with disabilities are the most affected. For example, in Russia on three days in December 2006:

- On December 9, 46 women died in a fire in Moscow in a drug rehabilitation institution in southern Moscow. Doors were allegedly locked, and the metal barred windows could not be opened.
- On December 11, eight people died in a fire at a psychiatric institution in the town of Taiga, Siberia.
- Also on December 11, a fire broke out in an institution for children with psycho-social and intellectual disabilities, but all escaped serious injury.[10]

10 "Russia: Government must establish independent investigation into hospital fires." 12 Dec. 2006. *Disability World*. http://www.disabilityworld.org/01_07/russianfires.shtml

EUGENICS AND NAZI-ERA MASS KILLING

While people with disabilities throughout the ages and in most societies have faced stigma and discrimination on account of their differences, the rise of the **eugenics movement** in America and Europe during the late nineteenth century led to the specific targeting of people with disabilities for widespread abuses, and ultimately, mass murder in Nazi Germany. Eugenicists warned that the birthrate of the "fit" and "talented" members of society had declined to an alarming extent, while less-desirable members of society continued to multiply. In the most egregious cases, people with disabilities were singled out for mass murder, as in the Nazi genocidal programs targeting people with disabilities living in institutions. (See text box) Children with disabilities were targeted for systematic killing under a separate Nazi program that preceded the mass murder of adults with disabilities. A decree mandated the reporting of all newborns and infants under three years of age with suspected "hereditary diseases" including, among others, Down's Syndrome, deafness, blindness, paralysis, and congenital physical disabilities. A variety of particularly horrific killing methods were used, including massive lethal injection to the heart, poison administrated over an extended period of time, gassing with cyanide or chemical warfare agents, starvation, and exposure. The latter two methods were sometimes selected so that doctors could attribute the death to "natural causes" or routine illness such as pneumonia. Estimates suggest that at least 5,000 children with disabilities were killed under the euthanasia program during World War II. More recently, human rights reports have exposed eugenics-like programs in North Korea where people with disabilities are sent to dismal internment camps and are categorized and then separated according to their disability. For example, camps exist for persons of short stature who are rounded up and relocated and are prohibited from marrying or having children. People with mental disabilities are detained in camps known as 'Ward 49' where they endure particularly harsh and life threatening conditions.[11]

SITUATIONS OF RISK: NATURAL DISASTER AND ARMED CONFLICT

Recent humanitarian emergencies – both natural disasters such as the Asian Tsunami and crises resulting from armed conflict such as Kosovo, Liberia, and Iraq – disclose the failure of large-scale assistance operations conducted by international agencies to respond appropriately to the needs of disabled beneficiaries. A UN commissioned review of overall humanitarian responses and the Tsunami Evaluation Coalition report found that transparency, communication, and accountability to affected populations was notably lacking in relief efforts.[12] These reviews suggest that humanitarian organizations were largely unprepared and ill-equipped to address even the most basic needs of people with disabilities in the provision of shelter, food, water, and health care services.

Likewise, Hurricanes Katrina and Rita in the United States demonstrated the failure of US federal-level disaster preparedness for meeting the needs of persons with disabilities. During Hurricane Katrina and its aftermath, people with disabilities were trapped in their homes for days and provided with completely inadequate medical care in shelters. Many disabled people died as a result. Later, they were often unable to access assistance programs. For example,

11 "North Korea Puts Disabled in Camps." 10 Nov. 2006. *Disabled People's International*. http://v1.dpi.org/lang-en/resources/details?page=753

12 Cosgrave, John. "Tsunami Evaluation Coalition: Initial Findings." Dec. 2005. *Tsunami Evaluation Coalition*. http://www.tsunami-evaluation.org/NR/rdonlyres/576D8E84-27DB-44DC-8663-83AB9D5BF614/0/lowresA520060221.pdf

shelters provided to survivors were not accessible to people who use wheelchairs.[13]
Armed conflict, whether international or national in character or localized conflict involving militias and gangs, presents a major threat to human life and security. Conflict is a source of disabling conditions of all kinds and can exacerbate or create secondary disabilities for people with disabilities. There are many adverse effects of conflict on people with disabilities, including the break-up of support networks of family and community, displacement or abandonment, and destruction of health, rehabilitation, and transportation infrastructure. The devastating impact of armed conflict on the mental and psycho-social well-being of the affected population is also a major risk factor.

Operation T-4

In 1933, the German Ministry of Justice proposed legislation authorizing physicians to grant "mercy deaths" in order to "end the tortures of incurable patients, upon request, in the interests of true humanity." The legislation was never formally enacted, yet its objectives – not euthanasia but the mass killing of people with disabilities – were implemented in the form of a program known as Operation T-4.

Under the top secret T-4 program, patients in all government- and church-run sanatoria or nursing homes with a wide range of physical, sensory, and mental disabilities perceived to be hereditary in nature were targeted for extermination. Included were those with blindness, deafness, epilepsy, intellectual disabilities, autism, depression, bipolar disorder, mobility impairments, or congenital disabilities. The pool of victims later expanded to include sick residents of poorhouses and old age homes.

The T-4 program served as a testing ground for the Nazi killing machine. At the outset T-4 victims were killed by lethal injection, but they soon became the first victims of an experimental gas chamber at Brandenberg Prison. In a test run in January 1940, patients diagnosed with mental disabilities were gassed to death in an experiment intended to show the effectiveness of poison gas over other methods of killing. Nazi techniques of outfitting killing chambers with false showerheads and bathroom tiling developed under the T-4 program were later used extensively in the notorious death camps like Auschwitz and Birkenau.[14]

Although many international documents recognize that persons with disabilities are a particularly at-risk population in times of humanitarian crisis, few specific policies and practices have resulted in humanitarian action. Nonetheless, international humanitarian assistance organizations, including both UN specialized agencies and large private voluntary organizations, do identify their work as "rights-based" and protection-oriented. Few of these groups have any disability-specific policies and staff members are ill-equipped to accommodate people with disabilities in their programming. Advocacy by disabled peoples organizations is an essential tool in ensuring that humanitarian assistance programs take into account the specific needs of people with disabilities in their preparation for and response to humanitarian crises. People with

13 See http://www.nobodyleftbehind.org

14 Lord, Janet E. "The Application of the Laws concerning Genocide and Crimes against Humanity to People with Disabilities" in *Encyclopedia of Genocide and Crimes against Humanity*, (Dinah L. Shelton, ed., Macmillan Reference USA, 2004).

disabilities and their representative organizations must participate in all programs designed to reach affected populations in times of crisis.

EXERCISE 5.4: People with Disabilities in Situations of Risk

Objective: To consider the needs of persons with disabilities in natural disasters and identify strategies to enhance the protection of people with disabilities in emergency preparedness
Time: 45 minutes
Materials: Chart paper and markers or blackboard and chalk (optional)

1. Brainstorm:
Ask participants to identify natural disasters that can take place in their community (e.g., blizzard, tornado, hurricane, earthquake). List these. Ask the group to create three profiles of people with disabilities in their communities. Encourage diverse profiles, including different ages, disabilities (including psycho-social disability), ethnic minority status, and living arrangements (e.g., living alone, in an institution, with family). Collect the profiles and select a diverse sample to use in role plays.

2. Imagine:
Divide participants into small groups and give each group a profile with these instructions: Your group is going to role play what might happen in a typical natural disaster.

- Choose one of the typical disasters identified in Step 1 to role play using the profile you have received. What really happens in your community in these crises (e.g., loss of electricity, gas or water, loss of most forms of communication, loss of assistance devices such as artificial limbs, crutches, hearing aids, eye glasses, loss of means of transportation, inability to meet basic needs such as food, water, shelter, latrines, and health care services)?
- One person should play the person with disability and others should develop support (or non-support) roles (e.g., family member, neighbor, police, relief worker, medical personnel).
- You may choose to role play a worst-case scenario, a best-case scenario, or both.

3. Present:
Ask each group to present its role play. Afterward, form a panel of those who took the role of the person with disability and "interview" them about their experiences.

- What kinds of responses were or would have been helpful in this situation?
- What kinds of responses were or would have been unhelpful?

4. Discuss:
Emphasize that although people with disabilities have a human right to life and that States must take specific measures to ensure their protection and safety in emergencies, the needs of people with disabilities are often overlooked in real crises or situations of armed conflict.

- What can be done to ensure protection of this right?
- Who is responsible to see that this protection is provided?
- Does your community have a disaster preparedness plan?
- Does it include such protections? What can you do to help first responders and aid workers to better include disability issues in their work?
- **Optional:** Have each group present a disaster preparedness plan that takes into account the needs of persons with disabilities or a checklist of tips for humanitarian

workers. (For examples of checklists, see text box below and the following website: http://www.nobodyleftbehind.org).

Checklist for Community Disaster Preparedness for Persons with Mobility Impairments

- Do get involved in public disaster planning in your community.
- Don't wait until a disaster, and people with disabilities are left behind.
- Do get prepared at home and then expand preparedness to public settings.
- Don't assume evacuation plans exist for people with disabilities.
- Do form an "Accessibility Committee" at work and other public places.
- Don't assume you will be evacuated with everyone else.
- Do explore evacuation options with emergency managers and others.
- Don't overlook alternatives, such as evacuation chairs.
- Do share the plan with all those in the building/area and then practice it.
- Don't wait until the disaster to raise awareness on disability issues.
- Do learn about disasters and share that knowledge.
- Don't forget to check shelter accessibility and service animal provisions.
- Do talk to local emergency managers about disability rights.
- Don't wait to train and educate others about the plan procedures.
- Do initiate talking to managers, responders and Red Cross/Red Crescent.
- Don't forget to develop a network of supporters who can assist you.
- Do remember to participate so that "Nobody is Left Behind"![15]

DISABILITY ADVOCACY ON THE RIGHT TO LIFE

Disability advocacy has, in recent years, begun to address how a growing "right to die" or "assisted suicide" movement may impact the right to life of people with disabilities. These movements claim to provide people with significant and/or terminal illnesses or disabilities the right to choose death according to their own timing and place. The major question of concern for disability advocates is whether death in such cases is really a free and informed choice or merely a response to external pressure and negative messages about the "burden" of disability or assumptions about quality of life. Some disability organizations, such as the US-based group, Not Dead Yet,[16] are confronting the "right to die" movement and challenging the apparent devaluation of the life of a person with a disability. Such organizations oppose attempts to legalize physician-assisted suicide and address other medical and bioethics issues. Other disability advocates are addressing the right to life in other contexts, such as working to ensure that people with disabilities have access to quality health care, including immunization programs or health education. Still others are working on ensuring that emergency preparedness addresses the needs of people with disabilities in a variety of situations of risk. In these, and many other contexts, activists with disabilities must work in cooperation with other stakeholders to advocate on right-to-life issues.

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15 "Individual Disaster Preparadness, Disaster Do's and Don'ts Checklists." *Nobody Left Behind: Disaster Preparadness for Persons with Mobility Impairments.* http://www.nobodyleftbehind2.org

16 Not Dead Yet. *notdeadyet.org.* 2005. http://www.notdeadyet.org/docs/about.html

EXERCISE 5.5: Making a Commitment to Promote the Right to Life and Protection in Situations of Risk

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about the human right of people with disabilities to life and protection in situations of risk, the group members are 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 the right to life and protection in situations of risk.

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

USEFUL RESOURCES ON THE RIGHT TO LIFE AND PROTECTION IN SITUATIONS OF RISK:

- *An ADA Guide for Local Governments: Making Community Emergency Preparedness and Response Programs Accessible to People with Disabilities*. US Department of Justice: http://www.ada.gov/publicat.htm#Anchor-Emergency.
- British Columbia Association for Community Living: http://www.bcacl.org/index.cfm?act=main&call=788F8794
- International Disability Rights Monitor, *Disability and Tsunami Relief Efforts in India, Indonesia and Thailand* (Center for International Rehabilitation: September 2005): http://www.disability.ws/idrm
- Mental Disability Rights International: http://www.mdri.org
- National Organization on Disability, Disaster Readiness Tips for People with Disabilities Series: http://www.nod.org
- Nobody Left Behind Research Project, Research and Training Center on Independent Living, Lawrence, Kansas: "Final Report of the Nobody Left Behind: Preparedness for Persons with Mobility Impairments Research Project" (M.H. Fox et al. 2007): http://www.nobodyleftbehind.org
- Not Dead Yet: http://www.notdeadyet.org
- UN Human Rights Committee, General Comment No 6, the Right to Life (Article 6), 16th Session, 1982: http://www.unhchr.ch/tbs/doc.nsf/084ab9690ccd81fc7c12563ed0046fae3?Opendocument

CHAPTER 6: FREEDOM FROM TORTURE AND OTHER FORMS OF ABUSE

UN Convention on the Rights of Persons with Disabilities

Article 15, Freedom from torture or cruel, inhuman or degrading treatment or punishment

1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.
2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

Article 16, Freedom from exploitation, violence and abuse

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.

3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.

4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

OBJECTIVES

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

- Define the right to be free from torture or cruel, inhuman, or degrading treatment or punishment
- Define the right to be free from exploitation, violence, and abuse
- Explain the importance for people with disabilities of the rights relating to freedom from torture and other forms of violence
- Understand the interrelationship between the right to be free from torture and other forms of violence and other human rights
- Identify ways in which the prohibitions against torture and other forms of violence have been violated and efforts to prevent such violations
- Describe the provisions regarding the right to be free from torture or other cruel, inhuman, or degrading treatment or punishment and the right to be free from exploitation, violence, and abuse.

GETTING STARTED: THINKING ABOUT THE RIGHT TO BE FREE FROM TORTURE AND OTHER FORMS OF VIOLENCE

People with disabilities are particularly at risk for exposure to torture and other forms of cruel, inhuman, or degrading treatment or punishment. Likewise, people with disabilities are vulnerable to exploitation, violence, and abuse. Many violations of these kinds against people with disabilities go unnoticed given their frequent occurrences in institutionalized settings or other places which are isolated and hidden from public scrutiny, such as private and group homes, detention centers, and prisons. Like all human beings, people with disabilities have the right under human rights law to be free from all of forms of violence and abuse.

The enjoyment of the right of people with disabilities to be free from torture and other forms of violence is also related to the enjoyment of other human rights. For example, if a person with a disability is subjected to torture, his or her right to life may well be compromised and his or her right to health – both physical and mental – is surely at risk. Where children with disabilities are subjected to violence and abuse in educational settings, their right to health and their right to an education are violated. (For more on the rights of children with disabilities, see Chapter 15, p. 191). Subjecting people with disabilities in institutional settings to degrading conditions where they receive little or no care, have no means to fulfil their basic necessities of personal hygiene, or have no access to meaningful activities of interest violates a number of human rights, not only the right to be free from inhuman and degrading treatment, but also the right to an adequate standard of living, the right to recreation, and the right to health. These examples demonstrate that human rights are **indivisible**, **interdependent**, and **interrelated**.

Typical Forms of Violence and Abuse against People with Disabilities

- The World Health Organization reports that violence against persons with disabilities occurs at three times the rate of their peers without disabilities.
- Maltreatment of children with disabilities is reported to be 1.7 times the maltreatment rate for children without disabilities.
- In the U.S.A., the Center for Research on Women with Disabilities concluded that students with disabilities experience higher rates of sexual harassment than students without disabilities. In addition, girls with disabilities experience sexual harassment at higher rates than boys with disabilities.
- A Canadian study found that 60% to 80% of women receiving psychiatric care in institutions experienced violence.
- More than 90% of persons with developmental disabilities will experience sexual abuse at some point in their lives.
- 12% of men with disabilities experienced serious neglect and 9% reported physical violence at the hands of care providers.
- An estimated 1 in 25 elderly people are victims of violence each year.[1]

Human rights law draws some distinctions between torture on the one hand, and cruel, inhuman, or degrading treatment or punishment on the other. Where an action does not meet the precise definition of torture, it may be considered cruel, inhuman, or degrading treatment or punishment, depending on the form, severity and purpose of the conduct. Advocates need to understand the legal differences when they are making claims and reporting violations. It is also important to understand, however, that the lines between torture and cruel, inhuman, or degrading treatment or punishment may be difficult to draw in any given case. In part, it requires assessing the intensity and duration of pain and the particular circumstances of the individual. What some courts may agree amounts to torture in one case, may be characterized differently in another, albeit similar case.

Torture is one of the most serious violations of human rights. The right to be free from torture and other forms of physical and mental ill-treatment is absolute, and may not be suspended or restricted under any circumstances. Because of the risk of torture and other ill-treatment occurring during police custody, a number of procedural safeguards have been put in place in international human rights law documents that aim to substantially reduce the risk of torture occurring.

Torture is a frequent cause of disability, and when torture is inflicted on a person with a disability, it may lead to secondary disabilities or the onset of a serious medical condition. Interrogation techniques amounting to torture which are damaging to anyone, may be compounded for a person with certain disabilities or for those with medical conditions. In addition, the failure of an interrogator to recognize a person's disability could be mistaken for non-cooperation, as in the case of a prisoner who is unable to hear or process a question or communicate an answer as a result of a disability.

1 Rousso, Harilyn. *Girls and Women with Disabilities: An International Overview and Summary of Research*. (Disabilities Unlimited Consulting Services, 2001); Saxton, Marsha. *The Impact of Violence on People with Disabilities.* (World Institute on Disability, 2007).

Factors Contributing to Violence against People with Disabilities

- Myths and stereotypes about disability that relegate persons with disabilities to powerless positions and the perception of being an "easy target" for perpetrators
- Power imbalances between persons with disabilities and their caregivers
- Isolation in homes or institutions away from public scrutiny
- Lack of education and training to help identify and address violence, especially for women and girls with disabilities
- Lack of training for family members, caregivers, and health professionals on appropriate care for people with disabilities
- Armed conflict and certain environmental hazards such as landmines
- Poverty
- Cultural practices, such as female genital mutilation.

Subjecting people with disabilities to harmful forms of treatment in the name of "fixing" or "curing" their disability has a long history. In many early cultures, disease was thought to be caused by an invasion of evil spirits, which healers attempted to exorcise with a variety of dangerous and potentially harmful techniques. The practices of displaying and photographing children with visible disabilities in hospital amphitheaters or subjecting people with disabilities to display in circuses with forced-labor conditions are degrading, as well as psychologically harmful. Many of these practices occur in a hospital or health-care setting and often against the most vulnerable populations of people with disabilities, such as people with psycho-social disabilities. Related practices occur in countries with under-developed health care systems.

The treatment of psycho-social illnesses especially illustrates such abusive practices that may amount to torture or cruel, inhuman, or degrading treatment or punishment. In many cultures persons with psycho-social illness are considered to be possessed by demons that must be driven out, often by violent means such as physical abuse, or even drilling into the skull to "release the demon." In the European middle ages, a standard "cure" for "madness" was isolation in darkness or public whipping. In the 18th century "enlightenment," people with psycho-social illness were often confined to public "madhouses" such as the infamous Bedlam Hospital in London, to which citizens could purchase tickets for the amusement of looking at the inmates.[2]

Such treatment of people with psycho-social disabilities is not confined to the past. Disability organizations have documented contemporary examples of such practices, which constitute some of the most extreme forms of torture and cruel, inhuman, and degrading treatment against people with disabilities. This includes the long-term use of restraints, especially under painful conditions; involuntary use of electroshock therapy (ECT) without anesthesia; and detention in dangerous facilities without any protection from violence or access to medical care for victims of violence. The use of brain-damaging surgeries without consent, such as lobotomy (brain surgery designed to numb the emotions), is still practiced, often performed on women deemed to be "too emotional." The use of harmful medications designed to "subdue" people with

2 Harris, James C. *Intellectual Disability: Understanding its Causes, Classification, Evaluation and Treatment* (Oxford: 2005), pp. 14-16; Albrecht, Gary L. et al., eds., *Handbook of Disability Studies* (Sage Publications: 2001), pp. 15-18.

psycho-social disabilities is another example of coercive treatments imposed on people that violate human rights. Mental Disability Rights International (MDRI) has exposed instances of abuse where a particular psychiatric "treatment" is in fact being used as a punishment and has argued persuasively that such conduct violates the torture prohibition, as in the case of using unmodified ECT without anesthesia.[3]

Physical and mental abuses and gross neglect endangering the lives of people with disabilities housed in institutional facilities are widespread. Reports issued by MDRI on conditions for people with mental disabilities warehoused in dismal and dangerous institutions detail unhygienic conditions of detention, excessive use of physical restraints, lack of adequate food, water, clothing and medical care, and other life-threatening conditions. MDRI has also documented instances of complete sensory deprivation in barren, long-term isolation cells in institutions.[4] These conditions are examples of violations that may fall under torture or cruel, inhuman, or degrading treatment or punishment, depending on the circumstances.

Addressing Human Rights Abuse in Institutional Settings

- In 2007, a Czech regional court upheld the human rights of a woman who had been detained in a psychiatric hospital against her will and forced to accept psychiatric medication without her consent. She had been institutionalized simply on the basis of an initiative by her landlord who attempted to have her unlawfully evicted. The court ruled that the detention violated her human rights.
- In 2006, the Inter-American Court on Human Rights held that Brazil violated the Inter-American Convention on Human Rights in its first case concerning a person with a psycho-social disability. The case concerned the death of a man in a private psychiatric clinic who was subjected to beatings by clinic personnel and who died three days after his admission. The Inter-American Court held that Brazil violated his right to life and the right to be free from cruel, inhuman, and degrading treatment.
- In 2001, the European Court of Human Rights held that detaining a person with a psycho-social disability in the psychiatric wing of a prison in a very small, hot cell with one other person and inadequate ventilation violated the prohibition against degrading treatment under Article 3 of the European Convention on Human Rights.
- In 1999, the US Supreme Court ruled that requiring people with disabilities to live in institutions in order to access services constitutes illegal discrimination under the Americans with Disabilities Act. The *Olmstead* decision requires public entities to provide services and conduct activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.

3 "Behind Closed Doors: Human Rights Abuses in the Psychiatraic Facilities,Orphanages, and Rehabilita tion Centers of Turkey." *Mental Disability Rights International (MDRI)*. 2005. http://www.mdri.org/projects/turkey

4 "Ruined Lives: Segregated from Society in Argentina's Psychiatric Asylums." 2007. *Mental Disability Rights International (MDRI) and the Center for Legal and Social Studies (CELS).* http://www.mdri.org/projects/americas/Argentina/MDRI.ARG.ENG.NEW.pdf

Medical and scientific experimentation without free and **informed consent** is a human rights violation to which people with disabilities continue to be subjected. Some of the worst and best-known examples of such abuse occurred during the Holocaust when people with disabilities were subjected to horrific medical experiments. At the Nuremberg Trials, Nazi doctors were ultimately tried and convicted of war crimes and crimes against humanity for their participation in such experiments. The prohibition of medical and scientific experimentation without informed consent is highly relevant in the context of certain diseases that cause disabling conditions and for which medical science offers no cure, but are the subject of medical research and experimentation. A situation often faced by persons with psycho-social disabilities is the provision of an untested regimen of various drugs or therapies that in their combination are unproven – such a practice must surely constitute "experimentation" as opposed to "treatment" and would therefore violate human rights law unless free and full informed consent is given.

People with disabilities are vulnerable to other forms of violence, abuse, and exploitation. Children with disabilities, particularly those living in large institutions, are exposed to many forms of violence which cause serious risks to their physical and mental integrity. Sexual abuse and exploitation is likewise a violation that people with disabilities – men and women, girls and boys – experience. Persons with disabilities living in institutions may be particularly vulnerable to such abuse and groups such as Mental Disability Rights International (MDRI) has documented sexual violence in such contexts.[5] Economic exploitation, in which children and adults with disabilities are frequently subjected to forced-labor, working for little or no pay in often dangerous working conditions, also presents serious threats to the health and physical, mental, and social development of people with disabilities. Cultural practices, such as female genital mutilation and early marriage, impact women and girls with disabilities and may also result in physical and psycho-social disability.

EXERCISE 6.1: The Effects of Violence on Persons with Disabilities

Objective: To understand the effects of violence on different populations of people with disabilities.
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Introduce:
Explain that people with disabilities are not at risk of violence and abuse because of their disabilities, but because of the actions of abusing individuals in society. Violence and abuse may affect different populations of persons with disabilities differently. These differences must be taken into consideration when designing violence and abuse prevention programs.

2. Brainstorm:
Divide participants into small groups and ask them to:

- list different populations of people with disabilities (e.g., women, children and teenagers, men, elders, refugees, internally displaced persons) and kinds of disability (e.g., visual, mobility, hearing, psycho-social); and
- provide examples of how violence and abuse may impact different populations.

Note to Facilitator: Save this list for use in Exercise 6.3.

5 "Not on the Agenda: Human Rights of People with Mental Disabilities in Kosovo." 2002. *Mental Disability Rights International (MDRI)*. http://www.mdri.org/pdf/KosovoReport.pdf

3. Report:
Ask a spokesperson from each group to report their findings. List these on a chart like that below. When the first two columns are complete, ask participants to identify challenges to addressing violence and abuse against each different group. Write the responses in the third column.

4. Analyze:
Ask participants to consider the following based on their initial discussion:

- What actions could be taken to address violence and abuse prevention?
- Who must be involved in order for prevention to be effective?

Group of Disabled People	Kinds of Violence	Challenges to Addressing this Violence

Source: Adapted from Marsha Saxton, *The Impact of Violence on People with Disabilities*, World Institute on Disability: http://www.wid.org

WHAT DOES HUMAN RIGHTS LAW SAY ABOUT FREEDOM FROM TORTURE AND OTHER FORMS OF VIOLENCE?

The prohibition against torture is a core principle in human rights law; the right to be free from torture may not be suspended or limited under any circumstances. Reflected in the **Universal Declaration of Human Rights** (UDHR)[6] and the **International Covenant on Civil and Political Rights** (ICCPR),[7] the right to be free from torture and cruel, inhuman, or degrading treatment or punishment also finds expression in many other international documents, including a specialized treaty on the subject, the **Convention against Torture** (CAT).[8] Specialized international human rights conventions have also sought to address forms of violence beyond torture and cruel, inhuman, and degrading treatment or punishment. For example, the **Convention on the Rights of the Child** (CRC)[9] protects the right of the child to be free from torture and also specifically protects the right of the child to be free from "all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse" and further recognize State obligations regarding sexual exploitation and abuse, economic exploitation, and promoting recovery of child victims.

Defining various categories of violence and abuse can be challenging and the lines between different forms of conduct are often not easily drawn. CAT provides detailed standards for the effective prohibition against torture and other ill-treatment, including guarantees of survivor assistance and legal redress for those who have experienced torture or other forms of prohibited treatment or punishment. Article 1 of CAT defines torture as "any act committed by a public official or other person acting in an official capacity or at the instigation of or with the consent of such a person – by which severe physical or mental pain or suffering is intentionally inflicted on a person for a specific purpose, such as extortion of information or confession,

6 See http://www.unhchr.ch/udhr/lang/eng.htm
7 See http://www.ohchr.org/english/law/ccpr/htm
8 See http://www.unhchr.ch/html/menu3/b/h_cat39.htm
9 See http://www.ohchr.org/english/law/crc.htm

punishment, intimidation or discrimination." Actions that do not meet this definition in all its elements may fall under the category of cruel, inhuman or degrading treatment or punishment, depending on the type of conduct in question. Human rights tribunals have not offered clear standards by which to evaluate when conduct is torture, or when it falls under another prohibited category.

The **Convention on the Rights of Persons with Disabilities** (CRPD) addresses violence and abuse in two specific provisions: Articles 15 (Freedom from torture or cruel, inhuman, or degrading treatment or punishment) and 16 (Freedom from exploitation, violence, and abuse) which recognize:

- The right of people with disabilities to be free from torture, as well as cruel, inhuman, or degrading treatment or punishment;
- The right of people with disabilities to be free from medical or scientific experimentation unless they have provided informed consent;
- The right of people with disabilities to be free from all forms of exploitation and abuse;
- The obligation of of States to take measures to prevent people with disabilities from being subjected to torture and other types of prohibited abuse;
- The obligation of States to take measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence, and abuse, including gender-related abuse;
- The obligation of States to take measures to prevent all forms of exploitation, violence and abuse. Such preventive measures must ensure, among other things, the availability of appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers. Examples include information and education on how to avoid, recognize, and report instances of exploitation, violence, and abuse;
- The obligation of States to ensure that protection services are age-, gender- and disability-sensitive;
- The obligation of States to ensure the effective monitoring of all facilities and programs designed to serve persons with disabilities;
- The obligation of States to take measures to promote the physical, cognitive and psychological recovery, rehabilitation, and social reintegration of persons with disabilities who become victims of any form of exploitation, violence, or abuse in an environment that respects the rights and dignity of victims, their age, and gender;
- The obligation of States to adopt laws and policies to ensure that exploitation, violence, and abuse against persons with disabilities are identified, investigated, and, where appropriate, prosecuted.

In sum, the right to be free from torture or other forms of abuse requires States to *respect, protect,* and *fulfill* these rights for people with disabilities. The obligation to "respect" means, among other things, that States must refrain from using torture in questioning prisoners with disabilities and refrain from subjecting people with disabilities in prison or otherwise detained or living in institutional settings from any form of abuse. States must also prohibit the subjection of people with disabilities to medical or scientific experimentation unless they are in a position to provide full and informed consent without any coercion or undue influence whatsoever. The obligation to "protect" means that States must protect people with disabilities against abuses by State and non-State actors, including inhuman or degrading conditions in both public and private institutional settings. The obligation to "fulfill" means that States must take active measures to ensure protection, such as training police officers in acceptable methods

of obtaining information and in how to accommodate prisoners with disabilities or monitoring facilities where people with disabilities receive services. Teacher training is required to ensure that children with disabilities are not subjected to forms of punishment that constitute violence and that they are protected against bullying and abuse by classmates.

EXERCISE 6.2: What Rights to Freedom from Torture and Other Forms of Abuse does the CRPD Affirm?

Objective: To review and understand CRPD Articles 15 and 16
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Review:
Assign different parts of Articles 15 and 16 to small groups of participants (You may wish to divide Article 16 into four parts). Ask them to work together to paraphrase their section in common language and give some examples of how that right could be enjoyed and make a difference for people with disabilities.

2. Paraphrase/Give examples:
Read each section of Articles 15 and 16 aloud and ask the assigned group to give its paraphrase. Discuss the meaning of the section until everyone can agree on a paraphrase. Write the final paraphrase of Articles 15 and 16 on chart paper and post. After each section ask for examples of how that right could be enjoyed and make a difference for people with disabilities.

3. Discuss:
- How can Articles 15 and 16 of the CRPD be used to set national disability rights agendas and formulate platforms of action for submission to political parties or government decision-makers?
- How can these provisions be used to monitor conditions in prisons or institutions or other settings where people with disabilities may be vulnerable to violence and abuse?
- How can these provisions be used to help advocate for violence prevention programs?

PHYSICAL AND MENTAL INTEGRITY IN PRISON SETTINGS

Human rights law guarantees the right of all people deprived of their liberty to be treated with humanity and with respect for their inherent dignity. Article 10 of the **International Covenant on Civil and Political Rights** (ICCPR) states that: “All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person.”[10] The **UN Human Rights Committee**, which monitors implementation of the ICCPR, has stressed in **General Comment** 21 that prisoners should not be “subjected to any hardship or constraint other than that resulting from the deprivation of their liberty.”[11] Little attention has been paid by the human rights community to the right of prisoners with disabilities. Accommodations must be provided for persons with disabilities while in prison to ensure respect for their human rights and dignity.

10 See http://www.ohchr/org/english/law/ccpr.htm
11 See http://www1.umn.edu/humanrts/gencomm/hrcomm21.htm

The prohibition against torture and abusive treatment applies to prison authorities and requires protection from violence by other prisoners. It also requires protection from prison conditions that amount to cruel, inhuman, or degrading treatment or punishment. International human rights instruments developed within the United Nations provide guidance as to how governments may comply with their international legal obligations in relation to prisoner rights. In some instances, specific guidance on the rights of prisoners with disabilities and detained persons with disabilities is also indicated. These documents include the **United Nations Standard Minimum Rules for the Treatment of Prisoners** (Standard Minimum Rules)[12] adopted by the Economic and Social Council in 1957; the **Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment**,[13] adopted by the General Assembly in 1988; and the **Basic Principles for the Treatment of Prisoners**,[14] adopted by the General Assembly in 1990. While these instruments are not treaties, they provide authoritative guidance on the interpretation of binding human rights law.

It should also be noted that a separate but related body of law applies during times of armed conflict and is intended to provide protection to civilians. This body of law, referred to as **International Humanitarian Law**, specifies the rights of civilians and those who are not combatants. These laws are set forth in the Fourth Geneva Convention Relative to the Protection of Civilian Persons in Time of War.[15]

Human rights advocates have been successful in exposing and in many instances correcting human rights violations in prisons. Human Rights Watch has documented serious abuses against prisoners with psycho-social disabilities in US prisons.[16] More recently, advocates have focused more specifically on accommodating the needs of prisoners with disabilities and some prison authorities have responded with their own initiatives. For example, the Northern Ireland Prison Service, in addition to appointing a human rights advisor, has adopted a disability action plan and has taken action to improve cell accessibility, modify educational programs to accommodate prisoners with intellectual and learning disabilities, and addressed communication needs of deaf and hard of hearing prisoners.[17]

EXERCISE 6.3: Understanding the Rights of People with Disabilities in Prison or Detention

Objective: To understand the particular needs of disabled people in prision or detention
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk
Optional: Copies of list generated in Exercise 6.1.

1. Introduce:
Explain that disabled prisoners, like all persons with disabilities, require accommodation for their disability. Review case summaries from European Court of Human Rights involving prisoners with disabilities to provide some context. (See text box on next page). Reintroduce the list of disability populations created in Exercise 6.1 or create a new list of different groups of people

12 See http://www.unhchr.ch/html/menu3/b/h_comp34.htm
13 See http://www.unhchr.ch/html/menu3/b/h_comp36.htm
14 See http://www.unhchr.ch/html/menu3/b/h_comp35.htm
15 See http://www.unhchr.ch/html/menu3/b/92.htm
16 "Ill Equipped: U.S. Prisons and Offenders with Mental Illness." 2003. *Human Rights Watch.* http://www.hrw.org/reports/2003/usa1003
17 "Northern Ireland Prison Service Disability Action Plan: July 2007-March 2010." *Northern Ireland Office*. http://www.nio.gov.uk/nio_disability_action_plan_july_2007_-_march_2010.pdf

with disabilities (e.g., women, children and teenagers, men, elders, refugees) and kinds of disability (e.g., visual, mobility, hearing, psycho-social).

2. Discuss:
Divide participants into small groups and ask each to use the list as a guide to –

- Provide examples of how prison conditions and treatment in detention may affect a person with a disability and present risks of violence/abuse;
- Identify challenges to addressing the rights of persons with disabilities in prison or held in detention;

3. Analyze:
Ask participants to consider the following based on their initial discussion:

- What actions could be taken to address the rights of persons with disabilities in prison or detention?
- Who must be involved in order for prevention to be effective?
- What advocacy initiative might help create change in this area?

European Court of Human Rights Finds United Kingdom Violated Disabled Prisoner's Rights

In *Keenan v. the United Kingdom* (2001) the European Court of Human Rights held, among other things, that the treatment of a prisoner with a psycho-social disability was inhuman and degrading treatment and punishment in violation of Article 3. The prisoner was found dead in his cell after he hung himself while in solitary confinement. The Court found deficiencies in his medical care and monitoring of his condition. The Court also found that his placement in segregation and the addition of 28 days to his sentence just nine days before his expected release may have threatened his physical and moral resistance, and in these circumstances was "not compatible with the standard of treatment required in respect of a mentally ill person."

In *Price v. United Kingdom* (2001), the European Court of Human Rights found that the United Kingdom violated the rights of a woman with a disability who had been held in detention. The applicant was a woman who was a wheelchair user and did not have the use of her limbs. She was sent to prison for one week and alleged that while in custody she was forced to sleep in her wheelchair, could not reach emergency buttons and light switches, and was unable to use the toilet. She was lifted onto a toilet by a female prison officer but was left there for over three hours until she agreed to allow a male nursing officer to assist her. The Court held that these conditions amounted to "degrading treatment contrary to Article 3."[18]

18 "European Court of Human Rights - mental disability cases." *Mental Disability Advocacy Center*. http://www.mdac.info/resources/echr_cases.htm

International Standards for Persons in Prison or Detention

Basic Principles for the Treatment of Prisoners

- Establishes prisoners' entitlement to a quality of health care comparable to that available in the outside community.

Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment

- Establishes the obligation of authorities to ensure prisoners are given medical screening upon admission and provided appropriate medical care and treatment as necessary and free of charge.

Standard Minimum Rules

- Provide that appropriate medical and mental health services are integral to a properly run prison and to the goal of rehabilitation: "The medical services…shall seek to detect and shall treat any…mental illnesses or defects which may hamper a prisoner's rehabilitation. All necessary…psychiatric services shall be provided to that end."
- Recognize the need to vary the housing, supervision, and care of offenders with mental disorders according to the degree of their disability. Prison mental health staff should provide for the psychiatric treatment of all other prisoners who need it.
- Recognize that prisons must have sufficient numbers of appropriately qualified competent health care staff to meet their human rights obligations. To the extent possible, prison staff should also include specialists in addition to psychiatrists, including psychologists, and social workers. Standards of care should not be lowered because those needing medical treatment are prisoners. "Health personnel, particularly physicians, charged with the medical care of prisoners and detainees have a duty to provide them with protection of their physical and mental health and treatment of disease of the same quality and standards as is afforded to those who are not imprisoned or detained."
- Stipulate that clinical medical decisions should be governed by medical criteria. International principles of medical ethics require prison medical staff to provide "the best possible health care for those who are incarcerated," and to make decisions regarding their care and treatment based on the prisoners' health needs, which should take priority over any non-medical matters.
- Recommend that proper psychiatric treatment in prison as in the community should be based on a treatment plan drawn up for each patient. The plan should consist of more than just medication. It should involve a wide range of rehabilitative and therapeutic activities, including access to occupational therapy, group therapy, individual psychotherapy, art, drama, music and sports;
- Recognize that patients should have regular access to suitably-equipped recreation rooms and have the possibility to take outdoor exercise on a daily basis; it is also desirable for them to be offered education and suitable work.[19]

19 "Ill Equipped: U.S. Prisons and Offenders with Mental Illness." 2003. *Human Rights Watch*. http://www.hrw.org/reports/2003/usa1003

SEXUAL VIOLENCE, EXPLOITATION, AND ABUSE

Studies indicate that sexual exploitation and abuse is a widespread phenomenon among persons with disabilities, particularly women and girls, although disabled men and boys also experience sexual violence, exploitation, and abuse. Studies indicate that nearly 50% of women with disabilities report some form of sexual abuse during their childhood and some 30% of disabled women report being subjected to sexual abuse in their adult lives.[20] Most instances of abuse go unreported and, therefore, remain unaddressed. Very often, abuse takes place in a private home dwelling or in an institution where it is sometimes imagined that people with disabilities will be free from abuse.

Sexual violence, exploitation and abuse have long-lasting harmful effects on persons with disabilities. Where such abuses occur in isolated settings, the chances of accessing the assistance needed for recovery may be slim. Moreover, such traumatic experiences may increase disability-related functional limitations or create secondary disabilities. Programs and services that do address sexual violence and abuse in the community, particularly those targeting women and girls, very often do not reach out to disabled persons. Disability advocates are working to address these gaps and to ensure that programs and services are inclusive and accommodating to all. Violence prevention advocacy is an important component of ensuring the right of persons with disabilities to be free from violence and to lead self-determined lives.

EXERCISE 6.4: Making a Commitment to Promote Freedom from Torture and other Forms of Violence and Abuse

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about the human right of people with disabilities to be free from torture and other forms of violence and abuse, the groups are 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 disability to be free from torture and other kinds of violence and abuse.

To plan 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.

USEFUL RESOURCES ON TORTURE AND OTHER FORMS OF ABUSE AGAINST PERSONS WITH DISABILITIES

- Human Rights Watch, *Ill Equipped: U.S. Prisons and Offenders with Mental Illness* (2003): http://www.hrw.org/reports/2003/usa1003
- Mental Disability Advocacy Center: http://www.mdac.info/index.html
- Mental Disability Rights International: http://www.mdri.org
- World Institute on Disability, *The Impact of Violence on People with Disabilities* (Marsha Saxton, 2006): http://www.wid.org

20 “The Impact of Violence on People with Disabilities.” 2006. *World Institute on Disability* (Marsha Saxton).

CHAPTER 7:
PRIVACY, INTEGRITY, HOME, AND THE FAMILY

UN Convention on the Rights of Persons with Disabilities

Article 17, Protecting the integrity of the person:
Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

Article 22, Respect for privacy:
1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.

2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

Article 23, Respect for home and the family:
1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:
   (a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
   (b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;
   (c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

OBJECTIVES

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

- Define the rights to respect for privacy, integrity, home and the family
- Explain the importance of these rights for people with disabilities
- Understand the interrelation between these rights and other human rights
- Identify ways in which these rights has been promoted or denied to people with disabilities
- Understand the provisions related to the rights to respect for privacy, integrity, home and the family in the UN **Convention on the Rights of Persons with Disabilities** (CRPD).

GETTING STARTED: THINKING ABOUT RESPECT FOR PRIVACY, INTEGRITY, HOME, AND THE FAMILY

Societies have long debated where divisions lie between the public sphere such as the political domain and community activities and the private sphere, such as a person's body, home, or family. They have likewise struggled to establish the degree to which the State and individuals should have control in these different spheres. This chapter addresses the private sphere, examining specifically the rights to respect for privacy, personal integrity, the home, and family.

Privacy and Respect for Personal Integrity

Today, the right to privacy includes a variety of elements, including:

- The right to privacy of information, meaning the right of individuals to decide for themselves what information about them should be communicated to others and who those others may be. This information includes thoughts, opinions, actions taken when a person should reasonably expect to be acting in private, and personal information such as that related to a person's health or finances;
- Related to privacy of information is privacy of communication, which refers to the security of people's private interactions with others, including letters, telephone conversations, private face-to-face conversations, e-mails, and other forms of communication. In other words, neither the State nor private actors have a right to read your correspondence or listen to your private discussions. Of course, there are some exceptions to this, such as when somebody is suspected of having committed a crime, but even then there are laws that govern these exceptions to ensure that such interference is both necessary and properly handled;
- The right to privacy applies to a person's personal environment, meaning primarily where he or she lives, such as their home and their family or others with whom they live. It can also apply to other personal spaces, such as a person's car or other personal property;
- Another aspect of the right to privacy is freedom from attacks on a person's honor or reputation. For example, unless it is true, people do not have the right to claim to others that you have engaged in some socially unacceptable or other behavior that might be damaging to your reputation;

Although they are separate rights that address distinct concepts, the right to personal integrity is connected to the right to privacy in that actions and circumstances that lead to the violation of

personal integrity are often preceded or joined by violations of the right to privacy. Essentially, the right to personal integrity may be described as the right to be treated in a human manner and in such a way that preserves a person's mental and physical "wholeness." In other words, we all have the right not to be physically or mentally harmed by the State or private actors.

Although people with disabilities have as much right to privacy and personal integrity as all others, they frequently experience violations of these rights. For example, many people with disabilities need an assistant or caregiver to help with personal care or to accomplish certain tasks. As a result caregivers often have easy access to a wide variety of personal information such as identification numbers and financial information. It may also be necessary for the caregiver to be in close physical contact with the person, such as when assisting someone to use the bathroom or take a bath. Although people with disabilities have the right to be treated by their caregivers in a manner that respects their privacy and personal integrity, and although many professional caregivers comply with a code of professional ethics, stories of violations are all too common. These can include misuse and manipulation of personal information, such as using financial information to steal money, as well as incidents of verbal, physical or mental abuse. Such actions not only violate the rights to respect for privacy and personal integrity, they also violate basic respect for the inherent human dignity of people with disabilities.

Among the many causes of violations of the rights to respect for privacy and personal integrity, a predominant cause is the attitudes and beliefs of other people, especially with regard to people with intellectual, learning, or psycho-social disabilities. The belief by some that such people with disabilities are "not capable" of taking care of their own private information may lead to people withholding that information or giving the information to people with whom the person with disabilities would not choose to share that information. Additionally, some people believe that it is permissible to violate the privacy, or physical or mental integrity of a person with disabilities, if they are not aware that it is happening. Furthermore, the belief that people with disabilities should confirm their thinking and/or behavior to what is considered by others as "normal," can lead to people with disabilities being forced or coerced into using medications or undergoing "treatments" that can cause both short and long-term mental and physical harm.

It is important to address such violations, not only so that people with disabilities can enjoy the rights to respect for privacy and personal integrity, but also because enjoyment of these rights can impact enjoyment of other human rights. For example, violations of the right to respect for personal integrity can, if left unchecked, progress into violations of the right to be free from torture, violence and abuse. Violations of the right to privacy may discourage people with disabilities from exercising their rights to freedom of expression and opinion, or to participate in political and public life. Similarly, violations of other rights may lead to violations of the rights to respect for privacy and personal integrity. For instance, lack of access to quality health care programs and services may expose people with disabilities to poor health-data management practices that violate the right to privacy, or to health care professionals that do not respect the right to personal integrity. Also, lack of access to justice may prevent people with disabilities from seeking a remedy for violations of privacy or personal integrity, resulting in such violations continuing.

Respect for the Home and Family

Other issues traditionally placed in the private sphere involve those relating to a person's home and family. Although there is no internationally agreed-upon definition of "family," the family has been considered the "natural and fundamental group unit of society," and as such is protected

by a number of different rights. Relevant rights in this area include–

- the right to marry on the basis of the full and free consent of both intended spouses, assuming partners are of "full age"
- the right to have equal rights with their spouses during their marriage, and during legal separation, or if the marriage is dissolved
- the right to "found a family," meaning the right of people to live together, to have children, and not to be subjected to discriminatory or compulsory State family planning policies
- the right to be reunited with their family if they are separated because of political, economic, or other reasons
- the right to have the family protected by society and the State.

As with the rights to respect for privacy and personal integrity, people with disabilities experience many violations of the right to respect for home and the family. For example, although all people of "full age" have the right to marry, many people with disabilities, especially people with intellectual or psycho-social disabilities, are denied this right by State legislation, policy, and/or practice. Where they do not wish to marry, people with disabilities are also often denied the equal opportunity to experience their sexuality and have sexual or other intimate relationships. Even when official State policies do not restrict such relationships, family members, health care professionals, or staff in institutional settings may act to prevent people with disabilities making and acting upon their own decisions with respect to intimate relationships.

Such violations often stem from assumptions and stereotypes that people with disabilities "cannot handle" their marriage or relationship responsibilities or that they could "get hurt." They also arise from the belief that people with disabilities should not have children because they may pass on their disability or be unable to care for their children. Such attitudes have also led to States sponsoring or endorsing practices to forcibly sterilize both adults and children with disabilities, counselling people with disabilities against having children, or denying women with disabilities access to adequate pre- and post-natal care.

Additionally, people with disabilities may find they are denied the opportunity to be adoptive parents, guardians, or trustees of children because of their disability. Where people with disabilities do have children, States or other family members often insist that the children be removed and cared for by others because of prevailing assumptions that being raised by parents with disabilities is "not in the best interests of the child." Even where children are not forcibly removed, many parents with disabilities do not have adequate access to the supports or assistance they may need to help them care for their child. Parents of children with disabilities often experience similar violations of their and their child's rights to remain together as a family as supports may not be available to them to assist them in their parenting or government officials may insist that the child would be "better off" elsewhere, typically in an institutional setting.

These and other violations of the right to respect for home and the family can lead to violations of other human rights. For example, preventing people with disabilities from living with their families constitutes a violation of the right to live independently and be included in the community, which recognizes that people with disabilities have the same choices as others regarding where and with whom they live. Similarly, forcible sterilization not only denies people with disabilities the right to have children, but is also a violation of the right to respect personal integrity and arguably constitutes a form of violence and abuse.

Violations of other rights also lead to violations of the right to respect for home and the family.

For example, lack of access to an adequate standard of living, health care, and rehabilitation services can lead to malnutrition or general ill-health and compromise the fertility of people with disabilities. Violation of the rights to equal recognition before the law and also freedom of expression and opinion may also deprive people with disabilities of the opportunity to make, communicate, and act upon their own decisions related to their personal relationships. Similarly, lack of accessible information may deny people with disabilities the opportunity to learn about sexual relations, family planning, availability of support services, or other information that they need to make informed personal decisions.

Together, the rights to respect for privacy and personal integrity and respect for home and the family address some of the issues of greatest importance to the equality and inherent dignity of people with disabilities. As noted by Eleanor Roosevelt, one of the drafters of the Universal Declaration of Human Rights, human rights begin "in small places, close to home," and "unless these rights have meaning there, they have little meaning anywhere."

EXERCISE 7.1: What does it Mean to Enjoy the Rights to Respect for Privacy, Integrity, Home, and the Family?

Objective: To understand what it means to enjoy the rights to respect for privacy, integrity, home, and the family
Time: 40 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Brainstorm/Discuss:
Divide participants into small groups and assign each one of these situations:

- Visiting the doctor;
- Telephoning, or writing a letter or e-mail to a friend;
- Visiting the bank;
- Meeting with your child's teacher to discuss the child's performance at school.

Ask each group to discuss the experience of people with disabilities in this situation:

- In which instances do people with disabilities need to enjoy privacy, personal integrity, and/or respect for home and family in order to participate fully? Make a list of life activities.
- What information might people with disabilities reasonably expect to be kept private?
- Would the personal integrity involve mental or physical integrity, or both?
- Who might be responsible for respecting the rights in the different examples?

2. Report:
Ask a spokesperson from each group to summarize their discussions.

- What similarities do you observe in experiences in these different settings?
- Are there other situations in everyday life when similar issues occur?
- What can people with disabilities do in these situations to protect their privacy and integrity?

3. Discuss:

- What changes can be made to protect the privacy and integrity of people with disabilities?

The Ethics of Personal Assistance

Those providing caregiver services to people with disabilities need to do so in a manner that respects the human rights of the people they are assisting. Although there is no internationally-accepted code of conduct for professional caregivers, the following is one example of a code for personal assistants that emphasizes respect for the rights of consumers, produced by the University of Missouri-Columbia School of Health Professions:

- Respect an employer's/consumer's rights regardless of race, religion, sexual preference, or other beliefs.
- Acknowledge that the employer/consumer is in charge of the working relationship and that the employer/consumer has the right to make the final decision concerning his/her assistance.
- Refrain from any act of abuse, neglect, or exploitation.
- Do not put personal preferences before the employer's/consumer's choice.
- Safeguard the employer's or consumer's right to privacy.
- Act to safeguard the consumer and the public when home-based assistance, health care and safety are affected by the incompetent, unethical, or illegal practice of any person.
- Assume responsibility and accountability for individual judgments and actions.
- Maintain competency levels in regard to home-based assistance.
- Exercise informed judgment and use individual competence and qualifications as criteria for seeking consultation, accepting responsibilities, and delegating activities to others.
- Make an effort to establish and maintain conditions of employment that promote high quality assistance.
- Make an effort to protect the public from misinformation and misrepresentation, and maintain integrity of home-based assistance.[1]

EXERCISE 7.2: Understanding Barriers to Respect for Privacy, Integrity, Home, and the Family

Objective: To identify barriers to enjoyment of the rights to respect for privacy, personal integrity, the home, and family faced by people with disabilities
Time: 40 minutes
Materials: List of life activities generated in Exercise 1

1. Analyze:
Using the list of life activities used in Exercise 1 and the responses that were given in the discussion, ask each participant (or pair of participants) to choose one activity and to evaluate the barriers a person with disabilities might face in enjoying the rights to respect for privacy, personal integrity, the home, and family whilst participating in that activity.

2. Role Play:
Ask each participant or pair to report on their analysis and to role play at least one fictional example of the barriers a disabled person might face in enjoying the rights to respect for

1 "Enhancing Independence: An Assistant's Guide to Personal Assistance Services." 1995. *Missouri Model Spinal Cord Injury System (MOMSCIS), School of Health Professions, University of Missouri-Columbia*. http://www.umshp.org/hp/resources/sci/atmanual/atman2.shtml

privacy, personal integrity, the home, and family while participating in that particular life activity. Variation: Role play both best- and worst-case versions of confronting these barriers, illustrating ways that such barriers might be addressed.

3. Discuss:

- What are the consequences when people with disabilities do not enjoy respect for their privacy, personal integrity, home and family? To the person with disability? To society as a whole?
- Which barriers have the greatest effect on people with disabilities?
- What can be done to eliminate these most significant barriers?

Ensuring Privacy and Personal Integrity of Travelers with Disabilities

Although security restrictions and checkpoints have been a part of air travel for many years, their use and rigor has increased in recent years, largely in response to terrorism and other related concerns. The result is that security checks at airports are often more invasive than they used to be, with many airports around the world requiring travelers to undress to some degree, and/or submit to searches of their luggage. In the U.S., this led to concerns from the disability community that the rights to privacy and personal integrity of travelers with disabilities were being violated, either as a result of the security measures themselves, or as a consequence of security staff being unaware of the specific needs of travelers with disabilities.

To address these concerns, the National Council on Disability, the Federal Aviation Administration, the Transport Security Administration (TSA) and the disability community worked together to develop guidelines and training programs that would address the rights of travelers with disabilities, as well as security considerations. The trainings are intended to raise awareness of security staff of the rights and needs of travelers with disabilities, as well as ensure that they know what the guidelines are and how to implement them. To ensure that travelers with disabilities are aware of their rights, the TSA has provided information on its website, so that travelers can prepare themselves before they travel. Should travelers feel that their rights have been violated, they can contact the TSA's Office of Civil Rights. The following are excerpts of some of the rights and responsibilities addressed in the guidelines:

- If a personal search is required, you may choose to remain in the public area or go to a private area for your screening. If you refuse either option you will not be able to fly.
- You should be offered a private screening before the beginning of a pat-down inspection if the pat-down will require the lifting of clothing and/or display of a covered medical device.
- You may request a private area for your personal search at any time during the screening process.
- Your companion, assistant, or family member may accompany you and assist you during a private or public screening. After providing this assistance, the companion, assistant, or family member will need to be rescreened.
- You may request a pat-down inspection in lieu of going through the metal detector or being handwanded. You do not need to disclose why you would like this option.
- If you have a disability, condition, or implant, that you would like to remain private and confidential, ask the Security Officer to please be discreet when assisting you through the screening process.[2]

2 "Tips for the Screening Process: Travelers with disabilities and medical conditions." *Transportation Security Administration*. http://www.tsa.gov/travelers/airtravel/specialneeds/editorial_1567.shtm

WHAT DOES HUMAN RIGHTS LAW SAY ABOUT RESPECT FOR PRIVACY, INTEGRITY, HOME AND THE FAMILY?

Article 12 of the **Universal Declaration of Human Rights** (UDHR) addresses the right to privacy, setting forth the protections against interference and attacks upon honor or reputation. Issues related to the right to marry and found a family, as well as protection of the family by society and the State, are addressed in Article 16. Similar provisions appear in Articles 17 and 23 of the **International Covenant on Civil and Political Rights** (ICCPR),[3] as well as Articles 14 and 44 of the **International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families** (ICRMW).[4] Although the **International Covenant on Economic, Social and Cultural Rights** (ICESCR)[5] does not address issues of privacy or integrity (which are civil and political rights), Article 10 does address the need for the State to provide protection and assistance to the family as the "natural and fundamental group unit of society." Similarly, the **Convention on the Elimination of All Forms of Discrimination Against Women** (CEDAW)[6] does not address issues of privacy, but does address, in Article 16, the need for equality between men and women in marriage, including in decisions regarding the number and spacing of children.

Article 16 of the **Convention on the Rights of the Child** (CRC)[7] mirrors the previously referenced provisions in its treatment of the right of a child to be free of interference with his or her "privacy, family, home or correspondence," and to be free from "unlawful attacks on his or her honor or reputation." As one might expect, the CRC contains numerous references to the family, though Article 9 is perhaps the most relevant, as it addresses the right of children not to be separated from their parents unless it is in the best interests of the child to do so. Also Article 23, which specifically addresses the rights of children with disabilities, references the need to provide appropriate assistance to the parents or other care-givers of children with disabilities.

None of these human rights instruments specifically reference "personal integrity," though they address the related concepts of "privacy," "security of the person" or "safety of the person," often in the context of deprivation of liberty, and of course, the fundamental concept of "inherent human dignity." However, the non-legally binding **UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** (Standard Rules)[8] does specifically address personal integrity, including in the context of family life. Rule 9 emphasizes the full participation of people with disabilities in family life, as well as the need to promote the right to personal integrity and "ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage, and parenthood." It also speaks to the need for education and awareness of how to prevent, recognize, and respond to situations of sexual and other forms of abuse. In addition, Rule 13 highlights the need to "protect individual privacy and personal integrity" when involved in the collection and dissemination of information and research.

The **Convention on the Rights of Persons with Disabilities** (CRPD) draws from the full

3 See http://www.unhchr.ch/html/menu3/b/a_ccpr.htm
4 See http://www.ohchr.org/english/la
5 See http://www.unhchr.ch/html/menu3/b/a_cescr.htmw/cmw.htm
6 See http://www.un.org/womenwatch/daw/cedaw/
7 See http://www.unicef.org/crc/
8 See http://www.un.org/esa/socdev/enable/dissre00.htm

range of approaches taken in prior human rights instruments and places the issues in the context of disability. Article 17 (Protecting the integrity of persons) clearly indicates that people with disabilities have the right to have their physical and mental integrity respected on an equal basis with others. This language closely mirrors that found in some regional human rights instruments, such as Article 5(1) of the **Inter-American Convention on Human Rights**,[9] which appears in that convention's section on "right to humane treatment."

Issues of privacy in the CRPD are dealt with almost exclusively in Article 22 (Respect for Privacy), which protects people with disabilities from "arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication," as well as from unlawful attacks on "honor or reputation." The Article does not, for example, prevent the police from carrying out a valid search of a disabled person's belongings, but it would prevent other types of searches or surveillance that are arbitrary or unlawful. In order to emphasize the importance of the right even in places such as institutions, where people with disabilities have historically experienced many violations of privacy, Article 22 expressly states that these protections extend regardless of "place of residence or living arrangements."

Also noteworthy is the Article's reference to "other types of communication," which was intended by drafters to update the more traditional reference to "correspondence." Some drafters felt that "correspondence" was too strongly connected to letters, and that there was a need to ensure that e-mail, text messaging, and other more modern and future forms of communication would be covered by the Convention. Lastly, Article 22 emphasizes the right of people with disabilities to have their personal, health, and rehabilitation information protected on an equal basis with others. This concept is reflected again in Article 31(1)(a) (Statistics and data collection), which requires States to "ensure confidentiality and respect for the privacy of persons with disabilities" when collecting and maintaining statistics and data.

The right to respect for home and the family is addressed at some length in Article 23 of the CRPD. Because of the historic discrimination against people with disabilities in the areas of marriage, family, parenthood, and relationships, Article 23 addresses each of these in some detail. Specifically:

- **Article 23(1)(a)** protects the right of people with disabilities to marry with the free and full consent of each person, and to found a family.
- **Article 23(1)(b)** protects the rights of people with disabilities to make their own decisions regarding when and how many children to have. It also ensures access to "age appropriate" information and "reproductive and family planning education," so that people with disabilities can make informed decisions in these matters.
- **Article 23(1)(c)** addresses the right of people with disabilities, including children, to "retain their fertility on an equal basis with others." This provision not only protects against forced sterilization of children and adults with disabilities, but also implicates the right of people with disabilities to have access to health care, nutrition, and other factors that are pre-conditions to retaining fertility.
- **Article 23(2)** ensures that people with disabilities have the right to be guardians, trustees, adoptive parents, or the like, wherever such rights also exist for other people. In other words, people with disabilities should not be prevented from being guardians, trustees, or adoptive parents because they are people with disabilities. Furthermore, States must provide "appropriate assistance" to parents with disabilities, should they need such assistance to perform their child-rearing responsibilities.

9 See http://www1.umn.edu/humanrts/oasinstr/zoas3con.htm

- **Article 23(3)** addresses some of the rights of children with disabilities, specifically the rights not to be concealed, abandoned, neglected, or segregated. It also requires States to provide information, services and support to children with disabilities and their families.
- **Article 23(4)** requires that children should not be separated from their parents unless it is in the "best interests of the child" and the decision has been made by "competent authorities" and "in accordance with applicable law and procedures." Furthermore, Article 23(4) does not permit a child to be separated from their parents on the basis of disability, regardless of whether it is the child and/or one or both of the parents who are disabled.
- **Article 23(5)** addresses the situation of children with disabilities who may not be in a position to be cared for by their immediate family. The State should "undertake every effort to provide alternative care within the wider family," and if that is not possible, then "within the community in a family setting." This is to prevent the practice, common in many countries, of automatically sending children with disabilities to live in institutional settings when they cannot be cared for by their immediate family.

Taken as a whole, States' obligations with regard to the right to respect for privacy, integrity, the home, and family, include:

1. The Obligation to *respect* the right by refraining from engaging in any act, custom or practice that creates barriers to enjoyment of the right (e.g., prohibiting people with disabilities from marrying or being parents);
2. The Obligation to *protect* the right by ensuring that non-State or private actors do not violate these rights (e.g., by monitoring and regulating health care and rehabilitation providers to make sure that private information of people with disabilities remains private);
3. The Obligation to *fulfill* means that States must take proactive action to ensure enjoyment of the right by people with disabilities (e.g., through providing support to families of parents and or children with disabilities, so that they can remain together).

In short, international human rights law strongly supports the rights of people with disabilities to respect for privacy, integrity, the home and family, so that they may fully enjoy these rights on an equal basis with others.

EXERCISE 7.3: Understanding Respect for Privacy, Integrity, Home, and the Family

Objective: To review and understand the provisions on rights to respect for privacy, integrity, home and the family in the CRPD
Time: 45 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Review:
Divide the participants into small groups. Ask each group to work together to discuss one of the sections of Articles 17, 22, and 23. Specifically, what does each section require be achieved? Who is responsible? What challenges might there be to implementation and how can these be overcome?

2. Discuss:
Have the groups report on the outcomes of their discussions.

3. Give examples:
Ask for examples of how each of the provisions of Articles 17, 22, and 23 could be applied to the real life examples discussed in Exercises 7.1 and 7.2.

4. Discuss:
How can Articles 17, 22, and 23 of the CRPD be used to set national disability rights agendas and formulate platforms of action for submission to political parties or government decision-makers? What would it mean in your country?

Personal Integrity for Children with Disabilities

The following data, provided by UNICEF on its website, strongly suggests that many children with disabilities around the world experience significant challenges to the enjoyment of their full physical and mental integrity, in addition to other human rights, both inside and outside the home:

- Women and girls with disabilities are particularly vulnerable to abuse. A small 2004 survey in Orissa, India, found that virtually all of the women and girls with disabilities were beaten at home, 25 percent of women with intellectual disabilities had been raped, and 6 percent of disabled women had been forcibly sterilized.
- According to UNICEF, 30 percent of street youths have disabilities.
- The United Kingdom's Department for International Development reports that mortality for children with disabilities may be as high as 80 percent in countries where under-five mortality as a whole has decreased below 20 percent, adding that in some cases it seems as if children are being "weeded out".
- Persons with disabilities are more likely to be victims of violence or rape, according to a 2004 British study, and less likely to obtain police intervention, legal protection, or preventive care.
- Research indicates that violence against children with disabilities occurs at annual rates at least 1.7 times greater than for their peers without disabilities.[10]

10 "Be in the Know Fact Sheet on children with disabilities." *UNICEF: Voices of Youth*. http://www.unicef.org/explore_3893.html

EXERCISE 7.4: Making a Commitment to Promote Respect for Privacy, Integrity, Home, and the Family

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about the right to respect for privacy, integrity, home and the family, 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 right to respect for privacy, integrity, home and the family to ensure their full enjoyment of all human rights.

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.

USEFUL RESOURCES ON RESPECT FOR PRIVACY, INTEGRITY, HOME, AND THE FAMILY

- General Comment No. 5 of the Committee on Economic, Social and Cultural Rights: http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/4b0c449a9ab4ff72c12563ed0054f17d?Opendocument
- General Comment No. 16 of the Human Rights Committee: http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/23378a8724595410c12563ed004aeecd?Opendocument
- General Comment No. 19 of the Human Rights Committee: http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/6f97648603f69bcdc12563ed004c3881?Opendocument

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**
• 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	• 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_cescr.htm
7 See http://www.umn.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 user***s 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 psycho-social 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 out grow 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.

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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 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 Symposia 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

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. *Independent 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

CHAPTER 10: THE RIGHT TO WORK

UN Convention on the Rights of Persons with Disabilities

Article 27: Work and employment

1. States Parties recognize the right of persons with disabilities to work on an equal basis with others; this includes the right to the opportunity to gain a livig by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, *inter alia*:

(a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;
(b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;
(c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;
(d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services, and vocational and continuing training;
(e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;
(f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;
(g) Employ persons with disabilities in the public sector;
(h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;
(i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;
(j) Promote the acquisition by persons with disabilities of work experience in the open labour market;
(k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

OBJECTIVES

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

- Define the right to work
- Explain the importance of the right to work for people with disabilities
- Understand the interrelation between the right to work and other human rights
- Identify ways in which the rights of people with disabilities to work have been promoted or denied
- Understand the provisions on work and employment in the UN **Convention on the Rights of Persons with Disabilities** (CRPD).

GETTING STARTED: THINKING ABOUT WORK AND EMPLOYMENT

The phrase “right to work” can be misleading. Just as the “right to health” cannot guarantee that a person will be healthy, the right to work cannot guarantee all people of working age a job. No government can realistically guarantee such a right. Instead, the “right to work” encompasses the right of all people to the *opportunity* to earn a living by freely choosing or accepting work, and to undertake that work in safe and favourable working conditions. The right to work also includes the right to form and join trade unions, through which people can protect their interests and advocate for safe and favourable working conditions.

Unfortunately, people with disabilities have frequently been denied the right to work. Attitudes and assumptions about the capabilities of people with disabilities often lead employers to the false assumption that a person’s disability makes him or her less capable, and so disqualifies him or her from being able to perform work-related tasks. This misconception causes people with disabilities not to be hired, or to be hired only for jobs that do not utilize their knowledge and skills. Similar attitudes lead employers to believe that some employees with disabilities, especially those with psycho-social disabilities, may be “dangerous” to themselves or others in the workplace or that customers will be offended or feel uncomfortable by the presence of persons with disabilities. Employers also often assume that the costs of implementing disability accommodations (such as accessibility features or flexible working schedules) are prohibitively expensive. Some employers use this rationale to pay their employees with disabilities a lower salary than that received by others doing comparable work. In more extreme cases, people with disabilities may find themselves forced into abusive, exploitative, slave-labour, or other unsafe working conditions, perhaps with no pay at all. Alternatively, people with disabilities are denied opportunities to work in mainstream settings, and may have to work in a segregated setting when they might not otherwise choose to do so.

Collectively these attitudes and assumptions result in many people with disabilities being denied the enjoyment of their right to work at any and all stages of the employment cycle, including initial hiring, continuing employment, and career advancement. Furthermore, the subtle and insidious nature of discrimination on the basis of disability in workplace settings can make it extremely difficult for people with disabilities to challenge the violation of their rights. For example, many employers will not openly state that a person’s disability is the reason they have failed to hire a person or have terminated a person’s employment. They might, for example, say that they preferred other applicants. Gathering the evidence needed to challenge such discrimination may prove almost impossible.

Violations of other human rights can create additional barriers to people with disabilities being able to fully enjoy their right to work. For example:

- The lack of accessible transportation may deprive people with disabilities of their ability to access places of employment;
- The lack of access to education and to access vocational and other training opportunities may leave people with disabilities unable to meet specific job qualifications, and may also restrict their earnings potential;
- The lack of opportunity to live independently and in the community may force people with disabilities to live in segregated institutional settings, where access to meaningful work opportunities may be non-existent or greatly restricted;
- The lack of access to health care services may leave people with disabilities in poor health and as a result unable to work; and
- The lack of access to information may make it difficult for people with disabilities to become aware of job postings and other information about potential employment.

Violations of the right to work may also lead to violations of the enjoyment of other human rights by people with disabilities. For example, a disabled person who is unable to work and earn a fair wage may be unable to attain an adequate standard of living. This circumstance, in turn, may force that person to become dependent upon others, restricting choices and curtailing the ability to live independently in the community. In many cases, people with disabilities who are unable to financially support themselves can become trapped in a cycle of poverty, and unable to meet even their most basic needs for food, water, clothing, and shelter, or indeed raise a family as they would wish. In some countries employment provides a means of accessing the health insurance needed to obtain health care services. Where people with disabilities are unable to obtain employment in such countries, their access to health care services may also be restricted.

Perhaps the most far-reaching impact of the denial of the right to work is on a person's sense of dignity and self-worth. In many societies, the ability to work is commonly viewed as one of the most important ways in which people can make their individual contributions to society, and those perceived as unable or unwilling to work may be viewed as less valuable members of that society, especially when their inability to earn a living causes them to become reliant on the support of the government or others. Thus, full enjoyment of the right to work can be of critical importance in the full inclusion of people with disabilities as equal members of the societies in which they live, as well as in the self-image and sense of self-worth that people with disabilities have of themselves.

The Right to Work for People with Disabilities and the International Labour Organisation

The International Labour Organisation (ILO) is the global body mandated to oversee the development and monitoring of international labour standards that promote enjoyment of decent work. Founded in 1919, it became the first specialized agency of the United Nations in 1946. The ILO is unique amongst UN agencies for its use of a "tripartite" system that brings together representatives of governments, employers, and workers to develop jointly policies and programmes.

Although the ILO works to promote decent work for all people, it also pays specific attention to the enjoyment of the right to work by specific groups of people, such as young persons, women, indigenous peoples, and people with disabilities. In addition to its adoption of Convention 159 (concerning Vocational Rehabilitation and Employment (Disabled Persons)) and its "Vocational Rehabilitation and Employment (Disabled Persons) Recommendation (No. 168)," the ILO also operates the "ILO Disability Programme":

The ILO Disability Programme promotes decent work for women and men with disabilities and facilitates means to overcome the obstacles preventing people with disabilities from full participation in the labour markets. Working from the Infocus Programme on Skills, Knowledge and Employability, the programme involves the following main activities:

- Improving knowledge on disability-related matters concerning training and employment;
- Advocacy, guidance and policy advice to governments, workers and employers' organizations on training and organizations of/for people with disabilities;
- Technical advisory services and cooperation activities.[1]

EXERCISE 10.1: What Does it Mean to Enjoy the Right to Work?

Objective: To understand what it means to enjoy the right to work
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Define:
Divide participants into small groups and ask each group to come up with their own definition of "the right to work."

2. Report/Discuss:
Ask a spokesperson from each group to give their definition. Record these and discuss the differences and similarities of these definitions. Help the group recognize where their definitions may differ from that used in this chapter.

1 See http://www.ilo.org/public/english/employment/skills/disability/iloprog.htm

3. Discuss:

- Do you know people with disabilities in your community who work? Where do they work and what kinds of jobs do they do?
- Do the people with disabilities in your community who work seem to enjoy the right to work according to your definition?
- Do you think that most people with disabilities in your community enjoy the right to work? Who in particular do you think *does* enjoy the right to work? Who does not?
- What can be done to ensure that all people with disabilities in the community can fully enjoy the right to work?
- What can be done to ensure that all people with disabilities in the community can fully enjoy the right to work?

Examples of Barriers to the Right to Work

- Physical barriers to places of work – in other words, the workplaces themselves are not physically accessible;
- Lack of accessible transportation to places of work;
- Legislation, regulations, policies, or practices that prohibit people with disabilities from working in particular jobs or that do not protect people experiencing disability-based discrimination in employment settings;
- Lack of accessible information about available employment opportunities;
- Lack of accommodations to facilitate communication in employment settings by people with disabilities, especially blind, deaf, deafblind, people with intellectual disabilities, and people with learning disabilities;
- Attitudes about the ability of people with disabilities to work and be qualified and contributing employees.

EXERCISE 10.2: Understanding Barriers to Enjoyment of the Right to Work

Objective: To explore barriers to the right to work
Time: 45 minutes
Materials: None

1. Introduction:
Ask for people to give examples of barriers that prevent some people with disabilities in the community from enjoying the right to work. List these.

Ask if some particular groups of people with disabilities are especially prevented from enjoying the right to work.

2. Discuss:
Divide participants into small groups of two or three. Ask each to make up a short fictional but typical biography of a person with disabilities in this community, describing how he or she was denied the right to work.

3. Report:
Ask each group to present its "biography."

4. Analyze/Discuss
Discuss with the group what it would take for each of these fictional people to achieve the right to work.

- Consider the various supports and accommodations referenced in Article 27.
- What could be done to obtain these supports and accommodations?

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

The right to work is addressed in a variety of human rights law instruments. For example, the **Universal Declaration of Human Rights** (UDHR) discusses the right to work in Article 23, addressing such issues as freedom of choice in employment, fair pay, equal pay for equal work, and the right to form and join trade unions. The **International Covenant on Civil and Political Rights** (ICCPR) also contains provisions relevant to the right to work in Article 8, which focuses on the right of everyone not to be held in slavery or servitude, as well as to be free from forced or compulsory labor except in certain limited circumstances.

The **International Covenant on Economic, Social and Cultural Rights** (ICESCR) elaborates further on the right to work, with three articles addressing related issues, including:

- **Article 6 –** affirming the right to work and calling on governments to achieve its realization through polices and practices that safeguard "fundamental political and economic freedoms to the individual";
- **Article 7 –** addressing the right of everyone to "just and favourable conditions of work," including safe and healthy working conditions, fair wages, equal opportunity for promotion subject to seniority and competence, and rest and leisure time;
- **Article 8 –** addressing the right of everyone to form and join trade unions, and the rights of trade unions to function freely subject only to those restrictions necessary in a democratic society to preserve public order or protect the rights and freedoms of others.[2]

General Comment No. 5 of the **Committee on Economic, Social and Cultural Rights** (the treaty body responsible for monitoring implementation of the ICESCR) addresses some of the barriers faced by people with disabilities in fully enjoying the right to work under the ICESCR, such as the pervasiveness of disability-based discrimination in the employment field, the limited and often substandard employment options available to people with disabilities, and the barriers to work resulting from lack of enjoyment of other human rights, such as access to transportation to get to work. It also notes the need for governments to ensure that people with disabilities can fully enjoy their trade union-related rights, and to regularly consult with organizations of persons with disabilities on employment and other matters.[3]

Article 32 of the **Convention on the Rights of the Child** (CRC) recognizes the right of all children to be free from economic exploitation and any work that might interfere with their education, or that would be harmful to their "health or physical, mental, spiritual, moral or social development." In addition, it requires States to establish a minimum age (or minimum ages) for employment, to regulate the hours and conditions of employment, and to ensure the use of penalties or other sanctions in order to enforce Article 32.[4]

2 See http://www.unhchr.ch/html/menu3/b/a_cescr.htm
3 See http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En
4 See http://www.unhchr.ch/html/menu3/b/k2crc.htm

The 1993 **UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** (Standard Rules) addresses a number of issues that can impact the ability of people with disabilities to enjoy the right to work, including:

- Awareness-raising of the rights, needs, potential and contributions of people with disabilities in society (Rule 1);
- Rehabilitation (Rule 3);
- Support services to promote independence and facilitate the exercise of rights by people with disabilities (Rule 4);
- Physical, informational and communication accessibility (Rule 5);
- Education (Rule 6);
- Employment (Rule 7);
- Personnel training (Rule 19).[5]

The **Convention on the Rights of Persons with Disabilities** (CRPD) expands upon the issues addressed in earlier human rights documents and helps to clarify how States can respect, protect and fulfill the right to work. Because of the **interrelated**, **interdependent** and **indivisible** nature of human rights, many articles in the CRPD can be considered relevant to the enjoyment of this right. However, Article 27 specifically focuses on the right to work.

Quite a lengthy article, Article 27 contains two subsections. The first and longest of these expressly recognizes the right of persons with disabilities to work on an equal basis with others, including the right to the opportunity to gain a living by work freely chosen or accepted. It further states that the right to work should be enjoyed in a "labour market and work environment that is open, inclusive and accessible to persons with disabilities." Article 27(1) then goes on to address some of the specific steps that States should take in promoting the realization of the right to work by people with disabilities, including:

- Prohibiting discrimination on the basis of disability regarding all areas and forms of employment;
- Protecting the right to just and favourable conditions of work, including through equal pay for equal work, safe and healthy working conditions, protection from harassment, and resolution of complaints;
- Ensuring that people with disabilities can exercise their labour and trade union rights on an equal basis with others;
- Enabling access to general technical and vocational guidance programmes and other placement and training services;
- Promoting employment opportunities and career advancement for people with disabilities and providing assistance in finding, obtaining, maintaining and returning to employment;
- Promoting opportunities for self-employment, entrepreneurship, developing cooperatives and business start-up;
- Employing people with disabilities in the public sector;
- Promoting employment in the private sector through affirmative action, incentives and other appropriate policies and measures;
- Ensuring provision of reasonable accommodation in the workplace;
- Promoting work experience for people with disabilities in the open labour market; and
- Promoting vocational and professional rehabilitation, job retention and return-to-work programmes.

5 See http://www.un.org/ecosocdev/geninfo/dpi1647e.htm

Although much shorter, Article 27(2) is an important provision addressing the issue of exploitative labor. It requires States to ensure that people with disabilities are not held in slavery or servitude and are protected on an equal basis with others from forced or compulsory labour.

States must *respect* the right work by ensuring that State actors such as government officials do not interfere with the exercise and enjoyment of the right by people with disabilities. States must also *protect* the right by ensuring that non-State actors, such as businesses and trade unions, do not interfere with the exercise and enjoyment of the right. Furthermore, States have an obligation to *fulfill* the right by taking action (such as the steps outlined in Article 27(1)) to ensure that people with disabilities are able to exercise the right. In short, international human rights law strongly supports the right of people with disabilities to work, not only as a right in itself, but so that people with disabilities may better enjoy their other human rights and fully assume their responsibilities as members of society and contribute to that society.

EXERCISE 10.3: Understanding the Right to Work

Objective: To review and understand the right to work affirmed by the CRPD
Time: 45 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Review:
Divide the participants into small groups. Ask each group to work together to paraphrase Article 27 in common language and give some examples of how that right could be enjoyed and make a difference for people with disabilities in their community.

Note to Facilitator: Given the length of Article 27, you may want to ask different groups to address different sections.

2. Paraphrase:
Read Article 27 aloud. Pause at each comma or natural section to ask different groups for their paraphrase. Discuss the meaning of the section until everyone can agree on a paraphrase. Write the final paraphrase of Article 27 on chart paper.

3. Give examples:
Ask for examples of how the right to work could be enjoyed and make a difference for people with disabilities.

4. Discuss:
How can Article 27 of the CRPD be used to set national disability rights agendas and formulate platforms of action for submission to political parties or government decision-makers? What does it mean to people with disabilities in your country?

AWARENESS-RAISING IN EMPLOYMENT SETTINGS

In order for employers to uphold their obligations to current and potential employees with disabilities, and in order for people with disabilities to advocate for full enjoyment of their rights, both employers and people with disabilities need to be aware of their obligations and rights. Many employers in both the public and private sectors are increasingly adopting disability policies that outline their responsibilities and the rights of people with disabilities. Sometimes

employers adopt such policies of their own accord, and sometimes they do so in response to national legislation and the encouragement of disabled people's organizations. Such policies help to remind those in decision-making roles of the responsibilities they have towards employees and customers with disabilities. They can also help to empower people with disabilities to claim their rights and challenge violations of their rights.

However, policies alone are typically not enough to ensure awareness or guarantee that people with disabilities fully enjoy their rights. It is not enough for an employer to *have* a policy, but rather steps also need to be taken to ensure that all affected by the policy are aware of its content and understand what they need to do to put the policy into action. Training may be needed to help people understand their rights and responsibilities under the policy, and further supports may be needed to give effect to a policy. In addition, mechanisms need to be in place to address violations of the policy effectively, and people wishing to challenge violations need to understand how to use those mechanisms and feel safe in doing so. If employees worry that they may lose their job or be punished in some way for drawing attention to a violation, then arguably even a well-written policy is ineffective.

- Can you think of any employers that have policies addressing the inclusion of employees with disabilities?
- Were these policies developed with the input of people with disabilities and/or their representative organizations?
- How could these policies or the actions taken to effectively implement them be improved?
- How could you or your organization advocate for or assist in the adoption of such policies?

Volkswagen's Corporate Commitment to People with Disabilities

As part of the 2003 European Year of People with Disabilities, and building upon earlier company initiatives, international car manufacturer Volkswagen signed an agreement pledging to better integrate staff with disabilities into the mainstream work process through education, training and internal communications. As part of the 2003 celebrations, Volkswagen also released a brochure entitled "Away From Paternalism Toward Enablement," in which it outlined a variety of steps it is taking to promote disability issues, including:

- Working to ensure that its products are accessible to people with disabilities;
- Prohibiting disability-based discrimination in the work environment;
- Utilizing principles of universal design to promote a healthy and safe work environment, to integrate employees with disabilities, and to re-integrate employees who may have become disabled during the time they have been employed with the company;
- Utilizing reasonable accommodation where universal design features do not adequately accommodate employees with disabilities; and
- Forming "integration teams" of different management departments and representatives of people with disabilities, in order to work cohesively towards the gradual implementation of disability policies throughout all company departments and manufacturing plants.

EXERCISE 10.4: Making a Commitment to Promote the Right to Work

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about the human right to work of people with disabilities, 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 work. For example how can participants better help employers to understand that employing people with disabilities is not only legally required, but a desirable thing for employers because of the contributions that people with disabilities can make to the work and workplace?

To plan 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.

USEFUL RESOURCES ON THE RIGHT TO WORK

- Americans with Disabilities Act Guide for Small Businesses: http://www.ada.gov/smbustxt.htm
- General Comment No. 5 of Committee on Economic, Social and Cultural Rights: http://www.unhchr.ch/tbs/doc.nsf/(Symbol)4b0c449a9ab4ff72c12563ed0054f17d?Opendocument
- 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
- ILO Skills and Employability Department – Disability and Work cross-cutting theme: http://www.ilo.org/public/english/employment/skills/disability/index.htm

CHAPTER 11: LIVING INDEPENDENTLY AND WITH DIGNITY IN THE COMMUNITY

UN Convention on the Rights of Persons with Disabilities

Article 19, Living independently and being included in the community:

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 28, Adequate standard of living and social protection:

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.
2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:
   (a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;
   (b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;
   (c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counseling, financial assistance and respite care;
   (d) To ensure access by persons with disabilities to public housing programmes;
   (e) To ensure equal access by persons with disabilities to retirement benefits and programmes.

Article 12, Equal recognition before the law:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

OBJECTIVES

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

- Define the right to live independently and with dignity in the community
- Explain the importance of living independently and with dignity in the community for people with disabilities
- Understand the interrelation between living independently and with dignity in the community and other human rights
- Identify ways in which the rights of people with disabilities to live independently and with dignity in the community have been promoted or denied
- Understand the provisions on living independently and with dignity in the community in the UN **Convention on the Rights of Persons with Disabilities** (CRPD).

GETTING STARTED: THINKING ABOUT LIVING INDEPENDENTLY AND WITH DIGNITY IN THE COMMUNITY

Very few people in the world live completely by themselves without any contact with other people! All of us rely to some extent on other people, to provide us with advice, friendship, goods, services, and a variety of other kinds of support. What then does “living independently” mean if not living solely by yourself? In essence, the right to live independently means the right to choose how you live, where you live, with whom you live, and to what degree you wish to interact with your community. It also means having access to any support you might need to realize those choices and to achieve an adequate standard of living.

A critical component of the right to live independently in a manner that respects inherent human dignity is the opportunity to make one’s own decisions and to have those decisions be respected and acted upon. Many people with disabilities have been denied this right, even with respect to the most basic of decisions, such as what to wear or eat or drink. In some cases, national legislation has expressly barred people with disabilities (especially people with intellectual or psycho-social disabilities) from making their own decisions by depriving them of the **legal capacity** needed to do so. In other instances, people have ignored the decisions of family members or friends with disabilities because they do not believe the person has the capacity to make “sensible” decisions.

Information and communication barriers can also negatively impact the ability of people with disabilities to make decisions. For example, the lack of accessible information can deprive people with disabilities of the information they need to reach a decision. The lack of communication accommodations (e.g., computer-aided real-time transcription or CART) or sign language interpreters) may make it difficult for people with disabilities to express themselves and make their opinions and decisions understood.

Violations of other human rights can create barriers to the ability of people with disabilities to live independently and with dignity in the community. For example:

- Disability-based discrimination in employment settings may deprive people with disabilities of the means to earn an income to support themselves;
- The lack of accessible transportation not only deprives people with disabilities of the right to liberty of movement, but also harms their ability to access work, education, healthcare, and shops, as well as to interact fully with the community;
- Services such as medical care or rehabilitation that are available to others locally in a general hospital or on an outpatient basis may only be available to persons with disabilities in an institutional setting;
- The lack of an adequate standard of living may force people with disabilities to live in a segregated institutional setting or with family members merely for survival reasons, such as access to food and shelter;
- The lack of accessible housing may greatly reduce the choices available to people with disabilities who want to live in a particular community;
- Negative and discriminatory attitudes towards people with disabilities may make persons with disabilities feel uncomfortable or unsafe among other community members and in turn encourage them to avoid such interactions. Such attitudes may even encourage family members to hide their family members with disabilities from the community.

Violations of the right to live independently in the community also frequently lead to violations of other human rights. For example, forcing people with disabilities to live in segregated settings deprives them of the opportunity to participate fully in the social, cultural, and political life of their community. Children with disabilities who must live apart from their families are deprived of the opportunity to grow up in a family setting, and often are denied quality inclusive education. Institutional settings can often expose people with disabilities to a higher risk of violence, sexual abuse and even death, especially women and girls with disabilities and people with intellectual disabilities. Segregated settings may also deprive people with disabilities of the opportunity to exercise their right to marry and have a family of their own. These examples illustrate that human rights are **indivisible**, **interdependent**, and **interconnected**. Above all, violation of the right to live independently in the community disrespects the basic dignity of people with disabilities that is inherent in all human beings.

EXERCISE 11.1: What Does it Mean to Live Independently and with Dignity in the Community?

Objective: To understand what it means to live independently and with dignity
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Brainstorm/Discuss:
Brainstorm, listing responses:

- What does “living independently” mean to you? To your community?
- Where and how do most people with disabilities in your communities live?
- Who in your community is typically placed in an institution? What kinds of disabilities do they typically have?
- Do you know people with disabilities who live independently according to your definition?

The Ten Principles of "Independent Living"

In some countries "independent living centers" provide supports, services and other assistance to empower people with disabilities to exercise their right to live independently and with dignity in their communities. Many of these centers subscribe to common principles that reflect the "philosophy of independent living." These principles are:

1. Human rights: equal rights and opportunities for all; no segregation by disability type or stereotype.
2. Consumerism: a person ("consumer" or "customer") who is using or buying a service or product decides what is best for him- or herself.
3. De-institutionalization: no person should be institutionalized (formally by a building, program, or family) on the basis of disability.
4. De-medicalization: people with disabilities are not "sick," as prescribed by the assumptions of the medical model and do not necessarily require help from certified medical professionals for daily living.
5. Self-help: people learn and grow from discussing their needs, concerns, and issues with people who have had similar experiences. "Professionals" are not the source of the help provided.
6. Advocacy: systemic, systematic, long-term, and community-wide change activities are needed to ensure that people with disabilities benefit from all that society has to offer.
7. Barrier removal: in order for human rights, consumerism, de-institutionalization, de-medicalization, and self-help to occur, architectural, communication and attitudinal barriers must be removed.
8. Consumer control: the organizations best suited to support and assist individuals with disabilities are governed, managed, staffed and operated by people with disabilities.
9. Peer role models: leadership for living independently and disability rights is vested in individuals with disabilities, not parents, service providers, or other representatives.
10. Cross-disability: activities designed to achieve the first five principles must be cross-disability in approach, meaning that they work to be done must be carried out by people with different types of disabilities for the benefit of all persons with disabilities.[1]

1 Adapted from "The Independent Living Philosophy: Ten Principles." *Rockland Independent Living Center*. http://www.rilc.org/principles.htm

2. Brainstorm/Discuss:
Emphasize that all human beings have a right to live in dignity and equality. Brainstorm, listing responses:

- What does "living with dignity" mean to you?
- Do you think people with disabilities would give the same definition as people who do not currently have a disability?
- Do you think most people with disabilities in your community live in dignity? Who in particular do you think *does* live in dignity? Who does not?

3. Discuss:
What can be done to ensure that all people with disabilities in the community can live in dignity? Can live independently?

Examples of Barriers to Living Independently and with Dignity in the Community

- Physical barriers to places of work, shops, health care facilities, and public buildings.
- Lack of accessible transportation to places of work, shops, health care facilities and public buildings.
- Legislation, regulations, policies, or practices that force people with disabilities to live in segregated and institutional settings against their will.
- Lack of accessible information about services to support living independently and what the rights and responsibilities of persons with disabilities are with respect to accessing those services and supports.
- Lack of accommodations to facilitate communication by people with disabilities, especially blind, deaf, deafblind, people with intellectual disabilities, and people with learning disabilities.
- Attitudes about the ability of people with disabilities to live where and with whom they choose and to make decisions for themselves.

EXERCISE 11.2: Understanding Barriers to Enjoyment of the Right to Live Independently and with Dignity in the Community

Objective: To understand barriers to living independently and with dignity
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Introduce:
Ask for people to give examples of barriers that prevent some people with disabilities in the community from living independently and with dignity. List these.

- Are some groups of people with disabilities especially prevented from living independently and with dignity? Why?

2. Discuss:
Divide participants into small groups of two or three. Ask each to make up a short fictional but typical biography of a person with disabilities in this community, describing how he or she was denied the right to live independently or with dignity.
Alternative: Present these "biographies" as role plays.

3. Report/Analyze:
Ask each group to present its "biography." After each, discuss what specific human rights were violated in this fictional person's story. List these.

4. Analyze/Discuss
Discuss with the group what it would take for each of these fictional people to achieve the right to live independently and with dignity. You might frame this as how to reverse the negative biographies and violations reported in Step 3.

- Consider the various supports guaranteed in Articles 12, 19, and 28.
- What could be done to obtain these supports?
- Would it help to advocate for these supports in terms of human rights?

WHAT DOES HUMAN RIGHTS LAW SAY ABOUT LIVING INDEPENDENTLY AND WITH DIGNITY IN THE COMMUNITY?

A number of human rights law instruments are relevant to the right to live independently and with dignity in the community. For example, the **Universal Declaration of Human Rights** (UDHR) discusses the right to an adequate standard of living (Article 25), and the right to recognition before the law (Article 6), which is relevant to the ability to make one's own decisions.[2] The **International Covenant on Civil and Political Rights** (ICCPR)[3] also contains provisions relevant to decision-making, such as Article 16, which recognizes everyone as equal before the law, and Article 17, which recognizes the right of everyone to freedom of expression. General Comment No. 5 of the **Committee on Economic, Social and Cultural Rights,** which monitors implementation of the **International Covenant on Economic, Social and Cultural Rights** (ICESCR),[4] states that governments must adopt policies "to enable persons with disabilities to live an integrated, self-determined and independent life," and that "[d]isability policies should ensure the access of [persons with disabilities] to all community services."[5] The ICESCR itself also contains provisions in Article 11 that relate to the right of everyone to an adequate standard of living, "including adequate food, clothing and housing, and to the continuous improvement of living conditions."

The **Convention on the Rights of the Child** (CRC) emphasizes throughout its provisions the need to support the ability of children to live with their families (where it is in the best interests of the child to do so), and the right of children with disabilities to "participate in the community" (Article 23). The Committee on the Rights of the Child has further encouraged States to –

> *…make every effort to provide assistance for children with disabilities and support services for their families, to the maximum extent possible on an out-patient or*

2 See http://www.unhchr.ch/udhr/
3 See http://www.ohchr.org/english/law/ccpr.htm
4 See http://www.unhchr.ch/html/menu3/b/a_cescr.htm
5 See http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/CESCR%20General%20comment%205.En?Opendocument

community basis, thereby avoiding removal of children with disabilities from their families for placement in institutions.[6]

The 1993 **UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** (Standard Rules) addresses a number of issues directly relevant to the right of people with disabilities to live independently in the community, including:

- Awareness-raising of the rights, needs, potential and contributions of people with disabilities in society (Rule 1);
- Medical care and rehabilitation services available in the local community (Rules 2 and 3);
- Support services to promote independence and facilitate the exercise of rights by people with disabilities (Rule 4);
- Physical, informational and communication accessibility (Rule 5).
- Personnel training (Rule 19).[7]

The Convention on the Rights of Persons with Disabilities (CRPD) expands upon the issues addressed in earlier human rights documents and helps to clarify how States can respect, protect, and fulfill the right to live independently in the community. Because of the **interrelated**, **interdependent,** and **indivisible** nature of human rights, there are many articles in the CRPD relevant to the enjoyment of this right. However, Articles 19, 28, and 12 are especially important to issues of living independently and with dignity in the community.

Article 19 of the CRPD explicitly addresses the right of people with disabilities to live independently and be included in the community. Specifically, Article 19 emphasizes the right of persons with disabilities to "have choices equal to others," including the opportunity to choose where and with whom they live, and to not be forced to live in a particular living arrangement. Article 19 also requires States to ensure that people with disabilities have access to the kinds of supports and services they may need to enable them to live independently and avoid segregation and isolation from the community. Such supports might include personal assistance and/or other in-home or community services. Article 19 also requires that community services and facilities that are available to the wider population are also available on an equal basis to people with disabilities and that those services and facilities are also responsive to the needs of people with disabilities.

Article 28 of the CRPD addresses the right to an adequate standard of living and social protection. Article 28 recognizes the right of people with disabilities to have an adequate standard of living, "including adequate food, clothing and housing, and to the continuous improvement of living conditions," and to be able to enjoy this right without discrimination on the basis of disability. States must also ensure that people with disabilities enjoy social protection without discrimination on the basis of disability. For example, people with disabilities (particularly women and girls with disabilities and older persons with disabilities) need to be assured equal access to clean water, social protection and poverty reduction programs, public housing, and retirement benefits and programs.

States' obligations with regard to the right to live independently and with dignity in the community include:

1. Obligation to *respect* the right by ensuring that State actors such as government officials do not interfere with the exercise and enjoyment of the right by people with disabilities;
2. Obligation to *protect* the right by ensuring that non-State actors such as businesses and

6 See http://www.unhcr.ch/html/menu2/6/crc/doc/days/violence.pdf
7 See http://www.un.org/esa/socdev/enable/dissre00.htm

families do not interfere with the exercise and enjoyment of the right;
3. Obligation to *fulfill* the right by taking action to ensure that people with disabilities are able to exercise the right.

In short, international human rights law strongly supports the right of people with disabilities to live independently and with dignity in the community, not only as a right in itself, but also so that people with disabilities may better enjoy their other human rights and fully assume their responsibilities as members of society.

Article 12 of the CRPD addresses the right to equal recognition before the law, and confirms that people with disabilities "enjoy legal capacity on an equal basis with others in all aspects of life." Historically many people with disabilities have been subjected to laws and practices that deprived them of their legal capacity and, consequently of their autonomy and freedom to choose how and where to live their lives.

Of particular concern is the fact that people with disabilities are often subjected to the substituted decision-making of other people. Even when substitute decision-makers act in good faith and with good intentions, such practices still deny people with disabilities the right to make their own decisions. Article 12 seeks to correct this approach, by recognizing the legal capacity of persons with disabilities and providing measures to support their right to *exercise* their legal capacity. Some people with disabilities require no support in making decisions, and others may need a lot of support. Regardless of the level of support needed, States must ensure that this support is not abusive and does not infringe the person's human rights.

Lastly, States must ensure the equal right of people with disabilities to "own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit," as well as not be arbitrarily deprived of their property. These measures are important because living independently in the community can be difficult to achieve without the ability to access and control financial and property resources.

EXERCISE 11.3: Understanding the Right to Live Independently and with Dignity in the Community

Objective: To review and understand the right to live independently and with dignity affirmed by the CRPD
Time: 45 minutes
Materials: Chart paper and markers or blackboard and chalk; handouts

1. Paraphrase and Discuss:
Divide participants into three groups and assign each one of the CRPD articles: 12, 19, and 28. Because of its length, you may want to divide Article 19 among three groups, with items 4 and 5 being considered by separate groups. Give each group copies of its respective article and the additional questions about the article.

Assignment:
a. Paraphrase all parts of the article into everyday language. Write your paraphrase on chart paper.
b. Answer the following questions about your article:

Article 12

- What do you think is meant in Part 1 by "recognition everywhere as persons before the law"?
- What do you think is meant in Part 2 by "enjoy legal capacity"?
- What kind of support do you think is intended in Part 3 by "support they may require in exercising their legal capacity"?
- What are some examples of "the exercise of legal capacity" mentioned in Part 4?

Article 19

- What do you think is meant by "independent living"? Give some examples.
- What do you think is meant by "full inclusion and participation in the community"?

Article 28

- What do you think is meant in Part 1 by "adequate standard of living"?
- What do you think is meant in Part 1 by "continuous improvement of living conditions"?
- What do you think is meant in Part 2 by "social protection"?
- What "services, devices and other assistance" do you think are meant in Part 2(a)?

2. Report:
Ask each group to post their paraphrase and read it aloud with the whole group, pausing at each phrase to ask if participants have questions or alternative language. Ask them to explain their answers to the questions that come with each article. Try to arrive at a clean and clearly understandable version of each article.

3. Give examples:
Ask for examples of how these rights could be enjoyed and make a difference for people with disabilities.

4. Discuss:
How can these articles be used to set national disability rights agendas and formulate platforms of action for submission to political parties of government decision-makers?

EXERCISE 11.4: Making a Commitment to Promote Living Independently and with Dignity in the Community

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about the human right of people with disabilities to live independently and with dignity in the community, 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 exercise their right to live independently and with dignity in the community.

To plan 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.

Supported Decision-making for People with Disabilities

Increasingly, people around the world are moving away from *substituted* decision-making models, where other people make decisions on behalf of people with disabilities, to *supported* decision-making where people with disabilities themselves make their own decisions, utilizing the support of others if and when they request it. This approach attempts to respect the inherent dignity of people with disabilities and avoid paternalism. Though potentially useful for anyone requiring help to make decisions, it is particularly relevant for people with psycho-social or intellectual disabilities, who historically have been forced to comply with substituted decision-making.

Though there are as yet no internationally agreed upon standards or guidelines regarding supported decision-making, the following may be helpful for those interested in ensuring that supported decision-making activities respect the rights of people with disabilities:

- People with disabilities have the right to be respected for their inherent decision-making abilities;
- People with disabilities have the right to develop authentic decision-making voices;
- People with disabilities have the right to receive support where they request it;
- People with disabilities have the right to genuine choices and options and to make decisions based on those options;
- People with disabilities have the right to be able to make mistakes.

Can you think of other helpful standards or guidelines for meaningful supported decision-making activities?[8]

USEFUL RESOURCES ON LIVING INDEPENDENTLY AND WITH DIGNITY IN THE COMMUNITY

- Access Living center for independent living: http://www.accessliving.org
- Canadian Association of Independent Living Centers (CAILC): http://www.cailc.ca
- Committee on the Rights of the Child, Report on the twenty-fifth session, Sept./Oct. 2000, CRC/C/100, paras. 688.17, 20-22, 24-25: http://www.unhcr.org/home/RSDCOI/3f4782b74.pdf
- Disability Rights and Independent Living Movement in the United States. University of California: http://bancroft.berkeley.edu/collections/drilm
- *The Independent Living Philosophy: Ten Principles*. Rockland Independent Living Center: http://www.rilc.org/principles.htm
- *Supported Decision-making*, Planned Lifetime Advocacy Network: http://www.plan.ca/Programs_Decisions.php

8 Adapted from “Supported Decision-making.” *Planned Lifetime Advocacy Network*. http://www.plan.ca/Programs_Decisions.php

CHAPTER 12: ACCESS TO JUSTICE

UN Convention on the Rights of Persons with Disabilities

Article 13, Access to Justice:

1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

OBJECTIVES

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

- Define the right to access to justice
- Explain the importance of equal access to justice for people with disabilities
- Understand the interrelation between access to justice and other human rights
- Identify ways in which the rights of people with disabilities to access justice have been promoted or denied
- Understand the provisions on access to justice in the UN **Convention on the Rights of Persons with Disabilities** (CRPD).

GETTING STARTED: THINKING ABOUT ACCESS TO JUSTICE

"Access to justice" is a broad concept, encompassing people's effective access to the systems, procedures, information, and locations used in the administration of justice. People who feel wronged or mistreated in some way usually turn to their country's justice system. In addition, people may be called upon to participate in the justice system, for example, as witnesses or as jurors in a trial. Unfortunately people with disabilities have often been denied fair and equal treatment before courts, tribunals, and other bodies that make up the justice system in their country because they have faced barriers to their access. Such barriers not only limit the ability of people with disabilities to use the justice system, but also limit their contributions to the administration of justice.

The ability to access justice is of critical importance in the enjoyment of all other human rights. For example, a person with a disability who feels that she or he has been denied the right to work may wish to turn to the justice system to seek a remedy. However, if the justice system fails to accommodate their physical, communication, or other disability-related needs, and/or expressly discriminates against her or him, then clearly denial of access to the justice system also results in denial of protection of the right to work. Similarly, a person with a disability who

has been the victim of a crime may wish to report the crime to the police and press charges against the offender. However, if he or she is denied physical access to the police station, clear communication with the police, or access to information that is understandable, then that person may not be able fully to exercise her or his rights as a victim. These examples demonstrate that human rights are **indivisible**, **interdependent**, and **interconnected**.

The enjoyment of other human rights can also positively or negatively impact the ability of people with disabilities to enjoy access to justice. For example, the accessibility of transportation may determine whether or not a person with a disability is able to travel to a police station, courthouse, or other place where justice is administered. Similarly, a person with a disability who has had access to a quality education will be better able to understand and use the justice system, but if she or he has been denied the right to education, then participation in the justice system may be difficult or impossible.

To be fully included in society, people with disabilities need access to justice. As long as they face barriers to their participation in the justice system, they will be unable to assume their full responsibilities as members of society or their rights. For this reason it is important that barriers be removed so that people with disabilities can enjoy the equal opportunity to perform their duties as witnesses, jurors, lawyers, judges, arbitrators, and other participants in the administration of justice.

EXERCISE 12.1: Turning to the Justice System

Objective: To recognize the complexity of the justice system and how people use it
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Brainstorm:
Ask participants to name some typical reasons that people in their community turn to the justice system. List as many of these as you can on a chart like that below. Include issues related to property, family matters, violent crimes, or instances where one person has hurt another but it is not considered a crime (e.g., making false spoken or written statements about a person). For each reason given, ask what institutions people turn to for justice in each situation (e.g., police, council of elders, religious authorities, magistrates, courts). List these on the chart.

2. List:
Ask what are the various roles individuals play in these institutions of the justice system mentioned in Step 1 (e.g., victim, perpetrator, witness, police, elder, lawyer, judge, specialized expert, juror, prison official) and list these on the chart.

- Do people with disabilities usually play any of these roles in your community? Check those that apply.

3. Discuss:
Consider those roles that people with disabilities do *not* play:

- What happens when people with disabilities are excluded from these roles and thus from full participation in the justice system? To the person with disabilities? To the justice system?
- Why do you think people with disabilities are excluded from these roles?

- What can be done to increase the participation of people with disabilities in the justice system?

Reason for Turning to the Justice System	Institution Turned To	Roles in This Institution

Examples of Barriers to Access to Justice

- Physical barriers to police stations, courthouses, jails, prisons, and other public buildings;
- Lack of accessible transportation to police stations, courthouses, and other public buildings;
- Legislation, regulations, policies, or practices expressly barring people with disabilities from being witnesses, jurors, judges, or lawyers;
- Lack of accessible information about how the justice system works and what a disabled person's rights and responsibilities are within the justice system;
- Lack of accommodations to facilitate communication by people with disabilities, especially blind, deaf and deafblind people, people with intellectual disabilities, and people with learning disabilities;
- Attitudes about the ability of people with disabilities to participate meaningfully in the administration of justice, for example the belief that people with psycho-social disabilities cannot be reliable witnesses;
- Lack of training for police and other officials to understand the specific needs of people with disabilities in accessing justice and how to provide necessary accommodations.

EXERCISE 12.2: Barriers to the Justice System

Objective: To identify barriers to participation in the justice system faced by people with disabilities
Time: 30 minutes
Materials: List of roles generated in Exercise 12.1

1. Analyze:
Using the list of people and institutions involved when people turn to the justice system generated in Exercise 12.1, ask each participant (or pair of participants) to choose one role and to evaluate the barriers a person with a disability might face in fulfilling this role.

2. Role Play:
Ask each participant or pair to report on their analysis and to role play at least one of the barriers a person with a disability would face in fulfilling this role.

3. Discuss:

- What are the consequences when people with disabilities are excluded from full participation in the justice system? To the person with a disability? To the justice system? To society as a whole?
- Which barriers have the greatest effect on people with disabilities? On the justice system? On society as a whole?
- What can be done to eliminate these most significant barriers to full participation? List these and save the list for reuse in Exercise 12.3.

Support Services for Victims with Disabilities

In the absence of formal support services for people with disabilities who are the victims of crime, some advocacy groups are working to provide in-person support services. These services include such activities as:

- Accompanying the victim to the police station.
- Talking with the police to help them understand the nature of the victim's disability.
- Making suggestions for modifications that could be made to the usual procedures in order to help the investigation.
- If desired by the victim, being present with him or her during police questioning.
- Accompanying the victim to the courthouse prior to any official meetings there, in order to prepare them for the courtroom environment.
- Helping the victim understand what procedures will occur and easing their concerns about these procedures.
- Accompanying the victim during court proceedings, in order to help calm and support them if requested by the victim.
- Where appropriate, and with the victim's permission, asking the court to make modifications to the testimony procedures. For example, moving proceedings to the judge's chambers or other environment less intimidating than the courtroom, or bringing in an expert to help court officials understand the victim's disability and its possible impact on the testimony.[1]

WHAT DOES HUMAN RIGHTS LAW SAY ABOUT ACCESS TO JUSTICE?

The right to access to justice has its foundation in provisions in international law that address the equality of people before the law, their right to equal protection under the law, and their right to be treated fairly by a tribunal or court. These rights are addressed in Articles 6 through 11 in the **Universal Declaration of Human Rights** (UDHR)[2] and are addressed in more detail in Articles 14 – 16 of the **International Covenant on Civil and Political Rights** (ICCPR).[3]

1 *Israeli Human Rights Center for People with Disabilities*. http://www.bizchut.org.il/eng
2 See http://www.un.org/Overview/rights.html
3 See http://www.unhchr.ch/html/menu3/b/a_opt.htm

Other treaties address the need to ensure that specific groups are able to enjoy these rights on an equal basis with others. The **International Convention on the Elimination of All Forms of Racial Discrimination** (CERD)[4] and the **Convention on the Elimination of All Forms of Discrimination Against Women** (CEDAW)[5] are particularly relevant for people with disabilities who may be subject to multiple discrimination, such as women with disabilities and ethnic minorities with disabilities. For example, Article 5(a) of CERD requires that States "eliminate racial discrimination in all its forms," and guarantee the right of everyone "to equal treatment before the tribunals and all other organs administering justice." Article 15 of CEDAW addresses these issues as they relate to women, and requires that States treat women "equally in all stages of procedure in courts and tribunals."

Although the 1993 **UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** (Standard Rules) does not expressly address the issue of access to justice, it does address a number of issues that can impact the enjoyment of access to justice by people with disabilities:

- Awareness-raising of the rights, needs, potential and contributions of people with disabilities in society (Rule 1)
- Support services to promote independence and facilitate the exercise of rights by people with disabilities (Rule 4)
- Physical, informational and communication accessibility (Rule 5)
- Education (Rule 6)
- Personnel training (Rule 19).[6]

The Convention on the Rights of Persons with Disabilities (CRPD) expands upon the issues addressed in earlier human rights documents and helps to clarify how States can *respect*, *protect*, and *fulfill* the enjoyment of access to justice by people with disabilities. CRPD Article 13 guarantees the right of people with disabilities:

- to effective access to justice on an equal basis with others;
- to effective access to justice at all phases of the administration of justice, including at preliminary stages, such as initial investigations;
- to be both direct and indirect participants, including being witnesses;
- to receive procedural and age-appropriate accommodations to facilitate their access to justice.

Article 13 also requires States to provide training to those working in the administration of justice in order to help ensure effective access to justice by people with disabilities.

States must *respect* the right to access to justice by ensuring that State actors (e.g., police, judges, prison staff) do not interfere with the exercise and enjoyment of access to justice by people with disabilities. States must also *protect* the right by ensuring that non-State actors (e.g., private attorneys, families) do not interfere with the exercise and enjoyment of the right. Furthermore, States have an obligation to *fulfill* the right, by taking action to ensure that people with disabilities are able to exercise the right. The provision of disability-related training to those working in the administration of justice, is just one example of the type of action required of States by Article 13 to *fulfill* the right to access to justice.

4 See http://www.unhchr.ch/html/menu3/b/9.htm
5 See http://www.unhchr.ch/html/menu3/b/e1cedaw.htm
6 See http://www.un.org/esa/socdev/enable/dissre00.htm

International human rights law strongly supports the right of people with disabilities to have meaningful and effective access to justice in all its phases, not only as a right in itself, but also so that people with disabilities may better enjoy their other human rights and fully assume their responsibilities as members of society.

EXERCISE 12.3: What Rights to Access to Justice Does the CRPD Affirm?

Objective: To review and understand the right to access to justice affirmed by the CRPD
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Review:
Divide the participants into small groups. Ask each group to work together to paraphrase Article 13 in common language and give some examples of how that right could be enjoyed and make a difference for people with disabilities in their community.

2. Paraphrase:
Read Article 13 aloud. Pause at each natural section to ask different groups for their paraphrase. Discuss the meaning of the section until everyone can agree on a paraphrase. Write the final paraphrase of Article 13 on chart paper.

3. Give examples:

Ask for examples of how that right could be enjoyed and make a difference for people with disabilities.

4. Discuss:

- How can Article 13 of the CRPD be used to set national disability rights agendas and formulate platforms of action for submission to political parties or government decision-makers?
- How can it be used to engage in dialogues with court administrators and ministries of justice?

EXERCISE 12.4: Making a Commitment to Promote Access to Justice

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about the human right of people with disabilities to access justice, 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 access to justice.

To plan 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.

Access to Justice in Action: South African Equality Court Supports Access for People with Disabilities

Esthe Muller is a South African lawyer and also a wheelchair user. When she and other people with disabilities were unable to access her local courthouse because of the presence of steps, she brought a case in 2003 under the "Promotion of Equality and Prevention of Unfair Discrimination Act" of 2000. Her case was supported by the South African Human Rights Commission and was brought against the Justice Department and the Department of Public Works.

Because of the inaccessibility of the courthouses, Ms. Muller had to be carried up the stairs to enter the courthouse. On another occasion the court had to postpone her cases because she could not get into the room. "It's embarrassing for my client to have his lawyer carried into court. It's also embarrassing for me," she said.

In September 2004 the South African Equality Court reached a final settlement in the case. The two government departments admitted that they had failed to provide proper wheelchair access. They also admitted that their failure was a form of unfair discrimination against Ms. Muller and other people with similar accessibility needs, and they apologized for this. The departments committed to a plan to ensure that all court buildings throughout the country will be made accessible within three years. At least one courtroom and one toilet in each building will have to be accessible to people with disabilities. The plan requires specific actions to be taken by specific dates, and the departments will report on their progress to the Equality Court. In the meantime, inaccessible courthouses will need to find other ways to make sure that people with disabilities can access their facilities. For example, some have constructed "makeshift" courtrooms, and in other instances judges and magistrates have moved their proceedings to more accessible spaces.[7]

USEFUL RESOURCES ON ACCESS TO JUSTICE

- Advocacy Incorporated: http://www.advocacyinc.org/index.cfm
- Reach Canada Equality and Justice for People with Disabilities: http://www.reach.ca/

7 "Equality Court Victory for People with Disabilities." 24 Feb. 2004. *South African Human Rights Commission*. http://www.sahrc.org.za/sahrc_cms/publish/article_150.shtml; Reynolds, Dave. "Government sets date for all courts to be accessible." 15 September 2005. *Inclusion Daily Express*. http://www.inclusiondaily.com/archives/04/09/15/091504sacourtaccess.htm

CHAPTER 13: THE RIGHT TO EDUCATION

UN Convention on the Rights of Persons with Disabilities

Article 24, Right to Education:

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning directed to:
   a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
   b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
   c) Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:
   a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
   b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
   c) Reasonable accommodation of the individual's requirements is provided;
   d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
   e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:
   a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
   b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;
   c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

OBJECTIVES

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

- Define the right to education
- Explain the importance of education for people with disabilities
- Understand the interrelation between education and other human rights
- Identify how the rights of people with disabilities to education have been promoted or denied
- Understand the provisions on education in the UN **Convention on the Rights of Persons with Disabilities** (CRPD)
- Understand different perspectives on inclusive and special education
- Seek strategies to advance the right of people with disabilities to participate in education.

GETTING STARTED: THINKING ABOUT EDUCATION

People with disabilities are often denied their right to education. According to best estimates of international agencies, 90% of children with disabilities in developing countries do not attend school.[1] If they do, all children with disabilities face barriers such as inaccessible schools, untrained staff, and the assumption or stereotype that people with disabilities are unable to learn or do not need to learn. Every human being, including people with disabilities, should be able to enjoy their right to lifelong education. States are legally bound to provide people with disabilities the opportunity and support they need to access quality, lifelong education that will maximize the full development of their mental and physical abilities. This means that people with disabilities are entitled to an equal opportunity to participate in inclusive education settings - that is the general education system - along with all other people in the community in which they live.

Barriers to Education

- Attitudes of teachers, school administrators, families, and peers about the ability of persons with disabilities to learn and actively participate in schooling.
- Lack of accessible transportation to educational facilities.
- Physical barriers to educational facilities. Lack of ramps and accessible workspace.
- Lack of materials in accessible formats such as Braille, sign language or visual representations of verbal information.
- Lack of teacher training programs, resulting in a shortage of qualified teachers and support staff.

As affirmed in the **Convention on the Rights of the Child** (CRC),[2] the key goal of education is to prepare all students with the skills and abilities to become effective and contributing members of society. In order to achieve this goal, all students have the right to free primary

1 "Towards Inclusion: Education for Persons with Disabilities." Jul. 2005. *World Bank Institute: Development Outreach*. http://www1.worldbank.org/devoutreach/july05/textonly.asp?id=322

2 See http://www.unhchr.ch/html/menu3/b/k2crc.htm

education and access to secondary and lifelong learning opportunities. It is not enough for people with disabilities to be allowed to attend school; the content of the curriculum should be *accessible* for meaningful learning to occur. People with disabilities are entitled to **reasonable accommodation** in order to learn the curriculum, communicate effectively, and utilize the support services they need to develop life skills that enable independent living in the community.

The Right to Qualified Teachers

Realizing the right to quality education requires that States provide and train qualified teachers. Teachers should be knowledgeable in effective practices for instructing people with disabilities including:

- Methods to communicate in different ways (e.g., Braille, Sign Language, Augmentative and Alternative Communication)
- Individualization of instruction to meet the needs of various disabilities, such as psycho-social disabilities, intellectual disabilities, visual impairments, deafness, and multiple disabilities
- Skills for promoting acceptance and awareness of disabilities with peers, teachers, families, and school administrators.

The right to education is interrelated and central to the enjoyment of all other human rights. Through education, people with disabilities learn the necessary skills to advocate for their rights and become responsible and contributing members of society. Although the understanding of "contributing members of society" depends on varying cultural norms, family values, and personal choice, the concept can be loosely defined as having the skills and abilities for **independent living** and community inclusion, gainful employment, participation in political and public life, the right to home and family, and the ability to effectively navigate the judicial system, which are all aspects of everyone's basic human rights.

The CRPD provides the framework for guaranteeing access to quality education that builds the capacity and skills of people with disabilities. For education to be truly successful, society, including teachers, administrators, parents, and peers, needs to provide people with disabilities the *opportunity* and *respect* to use their knowledge and skills to lead independent and self-directed lives.

EXERCISE 13.1: What Rights to Education Does the Convention on the Rights of People with Disabilities Affirm?

Objective: To review and understand the right to education affirmed by the CRPD
Time: 30 minutes
Materials:
- Copies of CRPD Article 24
- Chart paper and markers or blackboard and chalk

1. Review:
Divide the participants into small groups. Give each group a copy of Article 24 and ask them to work together to paraphrase it in common language. Since the article is long, you may wish to assign different parts to different groups.

2. Paraphrase:
Read Article 24 aloud. Pause at each comma or natural section to ask different groups for their paraphrase. Discuss the meaning of the section until everyone can agree on a paraphrase. Write the final paraphrase of Article 24 on chart paper.

3. Give examples:
Encourage participants to draw from their past experiences and give some examples of how that right could be enjoyed and make a difference for people with disabilities in their community.

4. Discuss:
How can Article 24 of the CRPD be used to set national disability rights agendas and formulate platforms of action for submission to political parties or government decision-makers?

WHAT DOES HUMAN RIGHTS LAW SAY ABOUT EDUCATION?

The right to education has its foundation in provisions of international law. The **Universal Declaration of Human Rights** (UDHR) Article 26, the **Convention on the Rights of the Child** (CRC) Articles 28 and 29, and the 1993 **UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** (Standard Rules) Rule 6, address the right to education.

These treaties affirm that everyone has a right to an equal and accessible education. CRC Article 28 encourages the development of general and vocational education, as well as educational guidance that is available and accessible to every child. It also states that measures should be taken to encourage regular attendance at schools and that discipline should be administered in a manner consistent with the child's human dignity. Article 29 of the CRC states that education of the child shall be directed to the development of a child's personality, talents, and mental and physical abilities to their fullest potential.

The Standard Rules address the right to education in Rule 6 (Education),[3] which states that general education authorities are responsible for the education of people with disabilities in integrated settings and affirms that people with disabilities be considered when planning national education, curriculum, and school organization. Rule 6 encourages the active involvement of parent groups and organizations in the education process and recommends particular attention to very young children with disabilities, adults with disabilities, and populations at risk for double discrimination such as, women and ethnic minorities. Rule 6 states that educational provisions must be made to accommodate people with disabilities in integrated regular school settings and that clearly stated policies should promote acceptance of the terms of Rule 6 at the school and community level. The development of quality materials, flexible for addition and adaptation, and ongoing teacher training are encouraged. Most importantly, the Standard Rules point out that integrated education and community-based programs are often the most cost-effective way to educate people with disabilities.

The CRPD expands upon the issues addressed in earlier human rights documents, ensuring qualified teachers, reasonable accommodation and entitling people with disabilities the right to **inclusive education**, not just **integrated education** (see box on next page)**.** The essence of CRPD Article 24 on Education is framed around the philosophy of full inclusion and the provision of tools that best support full inclusion. It stipulates that education should be

3 See http://www.un.org/esa/socdev/enable/dissre00.htm

Education in Action: Shudarson Subedi's Story

Shudarson Subedi has a disability. He founded Nepal Disabled Human Rights Center (DHRC-Nepal) in 2000 to pressure the government to enforce existing laws related to persons with disabilities. His precedent gives persons with disabilities the courage to fight for their rights to inclusive education, access to health care, and fair and equal employment opportunities. In one exciting victory, he fought all the way to the Supreme Court of Nepal to *guarantee free and equal education for persons with disabilities*. At the same time, Shudarson has made a concerted effort to draw attention to this victory through the media, so that all persons with disabilities may take advantage of this right. More than 2000 students with disabilities from all over Nepal who had previously been denied acceptance in schools have received free education after the Court ruling. He also sent letters to the Ministry of Education, who then circulated them to the district and regional education officers, putting everyone on notice that persons with disabilities were not to be denied their right to education.

Shudarson knows that disseminating information is the best way to ensure that rights are enforced; too many people with disabilities do not realize that they are legally entitled to have access to equal education and employment opportunities despite their disabilities, and too many government officials and employers don't realize that they have a legal obligation to accommodate persons with disabilities. Shudarson initiated a weekly radio program in 2002, broadcasting stories produced by disabled journalists on topics of interest to listerners with disabilities. Listeners are encouraged to form "Radio listener clubs," which serve as citizen watchdog groups for the rights of persons with disabilities. There are now more than 170 self-motivated radio listeners clubs throughout Nepal. Shudarson has also founded *Disability Voice,* a monthly journal dedicated to the concerns, issues, and rights of disabled people.

Shudarson supports local cross-disability networks and self-help groups, which help individuals with disabilities and their families, integrate into the wider community. He has initiated an umbrella organisation, "Rights-Based Advocacy Network, Forum for the Rights of People with Disability," bringing together over sixty national and community-based advocacy organizations. Shudarson has also built a Resource and Learning Center to train people in areas of work, such as journalism and law. The Center provides the necessary resources for persons with disabilities who want to have their rights enforced. Among the services offered, DHRC-Nepal publishes legal aid manuals, compiles state laws and policies for people with disabilities, and provides free consultations with specialized staff trained on the subtle nuances of disability and civil rights law.[4]

provided in the general education system by quality teachers who implement quality instruction reasonably accommodated to meet the needs of diverse students. The goal of the education article is to promote equal opportunities to lifelong learning to enable people with disabilities to participate actively and effectively as contributing members in society.

International human rights law strongly supports the right of people with disabilities to have access to meaningful and effective lifelong educational opportunities. This support is not only seen as a right in itself, but also as a means to ensure that people with disabilities may

4 Source: http://www.ashoka.org/node/3651

better enjoy their other human rights and fully assume their responsibilities as members of an inclusive society.

EXERCISE 13.2: Experiencing Education

Objective: To share personal stories of the education system and evaluate suggestions and ideas for how it ought to be.
Time: 45 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Introduce:
Explain that this exercise invites everyone to remember and analyze their own educational experience. Remind participants of the terms “inclusive,” “integrated,” or “segregated” education (See text box “Inclusive versus Integrated Education**”** above) and encourage them to use these to describe the education that they received.

Divide participants into groups of 2-3 to discuss the following:

- Were you taught in an inclusive, integrated, or segregated setting?
- Describe the best parts of your educational experience. What made it so good?
- Describe the worst parts of your educational experience. What made it so bad?
- Did your worst experiences violate the right to education?

To the Facilitator: Because the definitions and questions are fairly complicated, you may want to give each group a copy of the text box and a list of the questions.

2. Report:
Ask a spokesperson from each group to summarize their discussion:

- What kinds of educational environment did people experience (e.g., inclusive, integrated, or segregated)?
- What factors created good or bad educational experiences? List these.

3. List:
Ask group members to list some reasonable accommodations that they had in their educational experiences or what reasonable accommodations may have enhanced their educational experiences (e.g., different types of communication systems such as Braille or Visual Supports, support services and therapies, peer mentors). List these in two columns.

4. Discuss:

- Does the current education system support people with disabilities and provide reasonable accommodations? Should it?
- Consider the roles that people with disabilities currently play in the education system: what happens when people with disabilities are excluded from these roles or excluded entirely from the education system?
- Now consider what changes or improvements you would make to prevent others from experiencing the same barriers to education.

Inclusive versus Integrated Education

What is "inclusion"?

The term "inclusion" has had a number of meanings, often relating to children with disabilities or disaffected children. Historically, it has often been used to mean either the moving of children with disabilities into the mainstream settings, or reducing the exclusion of other pupils from school.

Inclusion of disabled children

Historically, "integration" was the term used in the 1980s, but this came to be seen as involving the "placing" of disabled children in a mainstream setting, without providing the support they required and "allowing" them to be there as long as they were able to fit into the existing systems and cultures. The term "assimilation" has a similar meaning in relation to race equality. It is now acknowledged that ***the inclusion of disabled children involves going much further, and involves changing the policies, practices and attitudes within the school***.

"Once the disabled child is in a mainstream setting, there should be an expectation that the school will change as a response to the contribution and participation of the child."
Joe Whittaker "Inclusive Education versus Integrated Education"

It has been recognized that for inclusion to be successful, the child and their parents and caregivers must play a full part in the process.

Inclusion of *all* pupils

More recently, inclusion has been seen as a process that is relevant to all children in a school, but particularly focusing on those groups who have historically been marginalized or have underachieved in our schools. It is also recognized to include the way the school involves all parents and caregivers, staff and governors in its practices and decision-making processes.

"Inclusion is integration on our own terms. You can do integration to us, but there can be no inclusion without us playing a full part in the process."
Alliance for Inclusive Education - a partnership between adults with disabilities and the parents of children with disabilities

"Inclusion is seen to involve the identification and minimizing of barriers to learning and participation and the maximizing of resources to support learning and participation."
Booth and Ainscow, 2000

Source: Bristol Children & Young People's Services http://www.bristol-cyps.org.uk/services/eit/definitions.html

EXERCISE 13.3: Identifying the Causes of Discrimination in Education

1. Brainstorm:
Ask participants what they consider to be the principal problems of discrimination or barriers to accessing quality education. List these.

- Solicit input from other people who notice the problem and are affected by it.
- Note: A record should be kept of the session to be studied subsequently for evaluation.

2. Analyze:
Divide participants into small groups and ask each to choose a problem from the list to analyze. Explain that their task is to break the problem down into manageable parts. Give these instructions and introduce the fish-bone diagram, explaining that it pushes you to consider all possible causes of the problem. Illustrate how to use the diagram using a simple problem.

Step 1: Identify the problem. Write down the problem you face in detail.
Step 2: What are the major factors involved? Draw lines of the spine of each factor and label it. These may involve people, systems, equipment, external forces, etc.
Step 3: Identify possible causes for each factor you consider in Step 2. Show these as smaller lines coming off the "bones" of the fish. For a large or complex problem, it may be best to break it down into sub-causes. Show these as lines coming off each cause line.
Step 4: Analyze your diagram. Depending on the complexity and importance of the problem, you can investigate or create plans for taking action to address the problem.

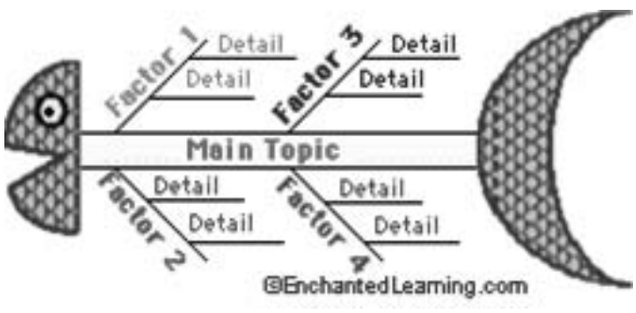
Alternative: Create an outline with the problem as the heading and factors and sub-causes as sub-headings.

3. Report/Discuss:
Ask a spokesperson from each group to summarize their analysis. Mount each diagram at the front of the room.

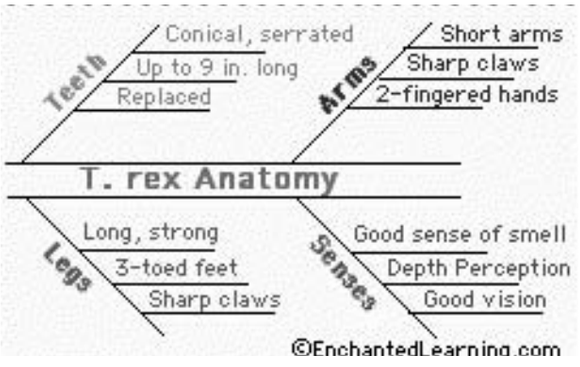
4. Summarize:
Ask participants to draw some general conclusions from these analyses, asking questions like these:

a. Did you observe any similarities in these analyses?
b. Were similar causes and sub-causes identified?
c. Why do you think these causes were identified in so many different problems?
d. What can be done to address some of these principal causes?

Sample Fish Diagram



Analyzing Tyrannosaurus rex Anatomy



EXERCISE 13.4: Speaking Up for Education

Objective: To examine discrimination in education systems and consider how to take action against it
Time: 60 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Introduce:
Reintroduce the list of discrimination or barriers in accessing quality education used in Exercise 13.2. Observe that while that exercise looked at the causes of these problems, this one seeks to articulate them and look for solutions.

2. Plan:
Divide participants into small groups of 3-6 people, if possible mixing people with differing abilities. Ask each group to choose a problem from the list that they would like to focus on. Give these instructions:

- Plan a five-minute presentation to a mock "Board of Education" that includes teachers, administrators, and parents;
- Ask groups to choose a spokesperson for the presentation and someone to serve on the "board of education";
- Were the responses of the "Board" typical of opinion in your community?
- While the groups plan presentations, each member of the "Board of Education" meets to decide on their roles. These roles should reflect the attitudes, both positive and negative, found in the community. Roles might include teacher, parent, peer, administrator, religious or community leader, or government official;
- Presentations should:
  - Describe the discrimination, including whom it affects and some of its causes;
  - Relate the discrimination to a human right in the CRPD;
  - Describe the discrimination's affect on the lives of people with disabilities;
  - Describe how addressing the problem can improve the lives of persons with disabilities;
  - Propose next steps or specific actions that can be taken to address the problem.

3. Role Play/Discuss:
Have the spokesperson from each group make a presentation to the "Board." Encourage members of the "Board" to respond according to their role.

4. Discuss/Draw Conclusions:
Debrief each presentation by asking for questions, comments, objections, or suggestions from the larger group. Ask questions like these:

- How did the spokesperson feel when presenting the problem?
- How did the "Board" react? What attitudes and barriers were represented?
- Were the responses of the "Board" typical of opinion in your community?
- Were the problems human rights issues?
- Was the tactic for addressing the problem feasible in your education system? Why or why not?
- What would be the next step be in real life for addressing this problem?

From Basic Education to Quality Education

Compasito, the Council of Europe manual on human rights education for children, states that free access to basic education is no longer considered sufficient to guarantee the right to education. Three other requirements should be met:

1. Equal opportunity: The state should guarantee not only equal access but also equal opportunities for success. This means that some children may need extra help and special conditions. Deaf children, for example, have a right to reasonable accommodations to help them learn, such as sign language, hearing aids, and interpreters whenever needed. Similar adjustments should be made for other children with special needs so that they can be included in the same schools with other children with equal opportunity to succeed.

   Equality in opportunities for success in education also requires attention to other aspects, like use of a child's mother tongue, homework conditions and access to books or help in any learning difficulty. Learning in one's mother tongue not only favors school success, but also constitutes a cultural right. School failure is no solution for learning difficulties. These must be met by well-trained teachers capable of differentiating learning styles and with non-teaching staff like social assistants, mediators or psychologists.

2. Quality education: The state should guarantee equal access to quality education. Too often a two-tier system exists, with one kind of schooling for the elite and another for the poor. A basic education that is common to all up to a certain age and that promotes the knowledge and skills needed for the future should be guaranteed.

3. Education for full development of the human personality: The scope of education to which all human beings are entitled is not limited to literacy and mathematics. The UDHR explicitly states that education should aim at "the full development of human personality, the respect of human rights and understanding and peace among the nations of the world". The CRC elaborate further on the kind of education to which every child is entitled:

The right to education is therefore also the right to an education for human rights.[5]

5 Source: *Compasito – a manual on human rights education for children* (Council of Europe, 2007).

EXERCISE 13.5: Making a Commitment

Objective: To emphasize and examine that human rights involve both rights and responsibilities.
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Action:

- Ask if after learning about the human right of people with disabilities to education, the group members are 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 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 right to education for people with disabilities;
- Record the commitments on chart or board to distribute a summary of actions to all participants after the training.

To plan 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.

USEFUL RESOURCES ON EDUCATION

The following groups also provide services to assist people with disabilities in accessing their right to education:

- **Bristol Children and Young People’s Services:** http://www.bristol-cyps.org.uk/
- **CAST Universal Design for Learning**: http://www.cast.org/index.html
- **Centre for Studies on Inclusive Education:** http://inclusion.uwe.ac.uk/csie/index.htm
- **Inclusion International:** http://www.inclusion-international.org/en/ii_priority_areas/ie/index.html
- **Inclusive Education. UNESCO:** www.unesco.org/education/inclusive/

CHAPTER 14: THE RIGHT TO SPORT AND CULTURE

UN Convention on the Rights of Persons with Disabilities

Article 30, Participation in cultural life, recreation, leisure and sport:

1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:
   a. Enjoy access to cultural materials in accessible formats;
   b. Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;
   c. Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.

2. States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.

3. States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials.

4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

5. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures:
   a. To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;
   b. To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;
   c. To ensure that persons with disabilities have access to sporting, recreational and tourism venues;
   d. To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;
   e. To ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.

OBJECTIVES

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

- Define the right of people with disabilities to participate in cultural life, recreation, leisure, and sport
- Explain the importance of participation in culture and sport for people with disabilities
- Understand the interrelation between participation in cultural life, recreation, leisure, and sport and other human rights
- Identify ways in which the rights of people with disabilities to participate in cultural life, recreation, leisure, and sport have been promoted or denied
- Understand the provisions on cultural life, recreation, leisure and sport in the UN **Convention on the Rights of Persons with Disabilities** (CRPD).

GETTING STARTED: THINKING ABOUT PARTICIPATION IN CULTURAL LIFE, RECREATION, LEISURE, AND SPORT

Participation in cultural life, recreation, leisure, and sport are all essential components of being a part of one's community. Unfortunately, people with disabilities have often been denied the right to participate in the wide array of cultural, recreational, sporting and leisure opportunities that the rest of society takes for granted. And all too often, children with disabilities are denied their right to play.

Discrimination in the area of cultural life is a global phenomenon that takes on many forms. Cultural venues are all too often inaccessible to persons with disabilities, denying them their right to participate in cultural life as direct participants and as spectators. Even the most basic activities that should be readily open to all people in a community are often unavailable to disabled community members. For example, people who use wheelchairs are sometimes denied entry to movie theaters on the basis that their wheelchairs present a fire hazard for other participants. Tourism facilities around the world are full of barriers that restrict movement or prevent access altogether. Hotels have few, if any, accessible rooms and do not provide accessible signage to persons with visual impairments. Tour buses are rarely able to accommodate wheelchair users. Restaurants have been known to refuse to serve persons with intellectual disabilities and throughout the world are notoriously inaccessible to persons with physical disabilities. Television programming and other technology allowing people to access culture and sport is not made accessible for deaf persons.

Around the world, people with disabilities experience discrimination and exclusion from active participation in sport, recreation, and leisure activities. Social and communication barriers prevent disabled persons from participating as athletes and as spectators because of attitudes and lack of access to information about sporting opportunities. Physical barriers prevent disabled persons from accessing sporting faculties and venues. Legal and policy barriers may also lead to exclusion. For example, many universities and schools do not have policies of inclusion for allowing students with disabilities to participate in sport, and coaches have no idea how to adapt sport for athletes with disabilities.

Children with disabilities often face numerous barriers in accessing their rights to sport, recreation and play. Save the Children has documented the particular challenges that children with disabilities face in this regard. At the same time, many disability organizations have successfully worked to open up opportunities for disabled children through the development of adaptive physical education programming in schools or community-based efforts to build accessible playgrounds.

Disabled peoples organizations worldwide are working to promote their meaningful participation in cultural life, sport, recreation, and leisure activities, which directly affects their enjoyment of all other human rights. For example, being denied the right to participate in sport in your school may directly impact the right to health. The right to participate in cultural activities is closely related to the right to access information; if information on cultural events is not provided in accessible formats, then one is effectively denied participation in that event. Increasingly, sport and cultural programming is seen as an important tool for peace building, social mobilization, and the support of public health initiatives, such as HIV/AIDS education or polio immunization campaigns. The exclusion of disabled persons from such activities impacts their rights to social and political participation, as well as health and education. These examples demonstrate how human rights are **indivisible**, **interdependent**, and **interconnected**.

Examples of Barriers to Cultural Life, Sport and Recreation for Disabled Persons

- Attitudes about the ability of people with disabilities to participate meaningfully in cultural life, sport, and recreation both as participants and as spectators.
- Physical barriers to museums, theaters, music halls, spectator sporting venues, parks, sporting centers, and other cultural and recreational buildings and facilities.
- Lack of accessible transportation to cultural sites and sporting events.
- Lack of accessible information about cultural events and sporting opportunities, including events for persons with disabilities.
- Lack of accommodations to facilitate communication by people with disabilities.
- Lack of knowledge and understanding about sign language as a distinct language/linguistic identity for many deaf and deafblind people.
- Lack of training for those involved in the organization of recreational, tourism, leisure, and sporting activities, as well as cultural activities, to understand the specific needs of people with disabilities and how to provide necessary accommodations.
- Lack of knowledge and experience about how to include children with disabilities in sport and recreation and how to develop adaptive physical education in schools and design accessible playgrounds and equipment.

EXERCISE 14.1: Barriers to Participation in Cultural Life, Recreation, Sport, and Leisure

Objective: To identify barriers to participation in cultural life, recreation, sport, and leisure faced by people with disabilities
Time: 60 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Analyze:
Ask each participant (or pair of participants) to select a specific area covered by Article 30 (e.g., particular types of cultural activities, language/linguistic identity, sport, recreation, leisure, play) and to evaluate the barriers a disabled person might face in achieving full participation in the selected context. Encourage participants to think of a scenario in which their issue is reflected, perhaps drawing from their personal experience.

2. Role Play:
Ask each participant or pair to report on their analysis and to role play at least one of the barriers a disabled person would face in fulfilling this role.

3. Discuss:
What are the consequences when people with disabilities are excluded from full participation in cultural life, recreation, sport, leisure and related areas? What are the consequences for the community? For the person with a disability? For society as a whole?

- Which barriers have the greatest effect on people with disabilities? On the community? On society as a whole?
- What can be done to eliminate these most significant barriers to full participation? List these.

4. Develop:
As a whole group, develop a fact sheet or checklist for inclusion on one or more topics. For example, the group may wish to draft a list of the benefits of inclusion for a specific issue area (e.g., inclusion in sport, inclusion in tourism) that includes concrete solutions on how to accommodate people with disabilities in a specific area. Another option is to draft a list of tips for including and accommodating people with disabilities in culture or sport. These tools may then be used in disability rights advocacy and awareness-raising on a particular topic. Encourage participants to distribute their list to their target audience (e.g., local community, sport center, or tourism authority).

WHAT DOES HUMAN RIGHTS LAW SAY ABOUT PARTICIPATION IN CULTURAL LIFE, RECREATION, LEISURE AND SPORT?

The rights to participate in cultural life, recreation, leisure and sport are reflected in a number of international human rights law instruments, including, for example, the **Universal Declaration of Human Rights** (UDHR) and the **International Covenant on Economic, Social and Cultural Rights** (ICESCR).[1] Specialized conventions also reflect these rights, including the **Convention on the Elimination of All Forms of Discrimination against Women** (CEDAW) which affirms the right of women to participate in recreational activities, sports and all aspects

1 See http://www.unhchr.ch/html/menu3/b/a_cescr.htm

of cultural life.[2] The **Convention on the Rights of the Child** (CRC) recognizes the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child, and to participate freely in cultural life and the arts.[3]

While reflected in various human rights instruments, these rights are not as well-developed as other human rights and are often forgotten. The right of persons with disabilities to participate in a wide array of cultural, recreational, sporting, and leisure activities is recognized as central to full inclusion for disabled people and is therefore defined in some detail in Article 30 of the CRPD. For this reason the CRPD is an important development in human rights law on participation in culture, sport, recreation and related activities.

Article 30 of the CRPD recognizes:

- The duty of States to take measures to support access to places where cultural performances or services take place. This includes, for example, theatres, museums, cinemas, libraries and tourism services. It also includes, as far as possible, access to monuments and sites of national cultural importance.

- The right of people with disabilities to develop and practice their creative, artistic, and intellectual potential for both individual and societal benefit. This recognizes that people with disabilities are full participants in the cultural life of their communities as, for example, artists, musicians, scholars and actors.

- The duty of States to ensure that laws protecting intellectual property rights do not present unreasonable or discriminatory barriers in access to cultural materials by persons with disabilities. This would cover, for example, translating books and other material into Braille, providing audio cassettes or providing sign language or forms of accessible technology for artistic performances.

- The right of disabled persons to equal recognition and support of their cultural and linguistic identity. This includes, for example, the right to use sign languages and recognition and support of Deaf culture. The CRPD therefore recognizes that people who are part of Deaf culture use sign language as their primary language and see themselves not as disabled, but as members of a cultural or language minority.

- The duty of States to promote the inclusion of persons with disabilities in mainstream sporting activities. This approach favors an inclusive approach to programming, where people with disabilities have equal access to sport and recreational facilities (such as equal access to swimming pools and adaptive playgrounds) and have opportunities for participation in both disability-specific sport and recreation (such as wheelchair basketball) and mainstream sport programming.

- The rights of persons with disabilities to organize, develop, and participate in sport and recreation with other persons with disabilities, including activities organized specifically for persons with disabilities. This covers both mainstream as well as disability-specific sport.

2 See http://www.un.org/womenwatch/daw/cedaw
3 See http://www.unhchr.ch/html/menu3/b/k2crc.htm

- The duty of States to take measures to ensure that persons with disabilities are included as recipients of services and programming by those who organize recreational, tourism, leisure, and sporting activities.

- The right of persons with disabilities to access and to use sporting, recreational and tourism facilities. This would include sport arenas, community pools, museums, cinemas, hotels, and other facilities.

- The right of children with disabilities to play and to participate in recreation, leisure and sporting activities in the school system. This also includes access to playgrounds in the community and adaptive physical education in schools.

In summary, States have the obligation to ***respect, protect and fulfill*** the rights of people with disabilities to participate in cultural life, recreation, leisure, sport, and play. In meeting their obligation to *respect* the rights of people with disabilities. States must refrain from limiting or interfering with the access of people with disabilities to exercise their rights to access sporting and recreational venues, use their own language, such as sign language, and otherwise participate in cultural activities. States must also refrain from enforcing discriminatory practices as State policy and must not impose discriminatory practices relating to cultural life, such as restricting or limiting the use of sign language. Obligations to *protect* include, among other things, the duties of States to adopt all appropriate legislative, administrative, and other measures to facilitate the enjoyment of cultural, recreation, sporting, and leisure rights. Examples include providing sign language interpretation for a cultural event or building public sporting arenas without physical barriers. Finally, the obligation to *fulfill* requires States to, among other things, undertake measures to fully implement rights. States Parties to CRPD must, for example, ensure the appropriate training of those involved in the organization of recreation, tourism, leisure, and sporting opportunities.

Disability and the Arts: Principles for Inclusion

- Every young person with a disability deserves access to high quality arts learning experiences;
- All art educators should be prepared to include students with disabilities in their instruction;
- All children, youth, and adults with disabilities should have complete access to cultural facilities and activities;
- All individuals with disabilities who aspire to careers in the arts should have the opportunity to develop appropriate skills.[4]

4 "Access and Opportunities: A Guide to Disability Awareness." *VSA Arts*. http://www.vsarts.org

EXERCISE 14.2: What Rights to Participate in Cultural Life, Recreation, Sport, and Leisure Does the Convention on the Rights of Persons with Disabilities Affirm?

Objective: To review and understand the right to participate in cultural life, recreation, leisure and sport in the CRPD
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Review:
Divide the participants into small groups. Ask each group to work together to paraphrase Article 30 in common language and give some examples of how the rights in the provision could be enjoyed and make a difference for people with disabilities in their community. Since Article 30 is rather long, you may want to divide different parts among the groups.

2. Paraphrase:
Read Article 30 aloud. Pause at each comma or paragraph to ask different groups for their paraphrase. Discuss the meaning of the section until everyone can agree on a paraphrase. Write the final paraphrase of Article 30 on chart paper.

3. Give examples:
Ask for examples of how that right could be enjoyed and make a difference for people with disabilities.

4. Discuss:
How can Article 30 of the CRPD be used to set national disability rights agendas and formulate platforms of action for submission to political parties or government decision-makers? What organizations at the community, national and international levels might support these rights (Consider both governmental as well as non-governmental bodies).

THE RIGHTS TO CULTURAL AND LINGUISTIC IDENTITY

All people have the right to participate in the cultural life of their community without facing harassment or coercion. Thus, people with disabilities should not, as they often are, be restricted from the practice of their own culture, nor should they be prohibited from participating in the cultural life of their community. International human rights law recognizes the rights of linguistic minorities to use and develop their own languages and cultures, and also to access language education so that they may attain fluency in additional “official” or “national” languages.

The **Universal Declaration of Human Rights** (UDHR)[5] recognizes the right to be free from discrimination on the basis of one’s language (Article 2) and other international instruments affirm this right, including the **Declaration on the Rights of Persons Belonging to National, or Ethnic, Religious and Linguistic Minorities**.[6] Such protections are of great relevance to those people with disabilities who utilize sign language, Braille, or other modes and means of communication.

5 See http://www.unhchr.ch/udhr/lang/eng.htm
6 See http://www.unhchr.ch/html/menu3/b/d_minori.htm

The inclusion in CRPD of language specifically recognizing the right of people with disabilities to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture, is an important development in human rights law. Deaf advocates at the UN Disability Convention negotiations worked hard to ensure such recognition and emphasized to governments that members of deaf culture use the term “Deaf” (often in print the term is capitalized when used as a cultural marker of identity) as a way of describing their cultural identity and affiliation much more than as a term that expresses their hearing status. The right of persons with disabilities to use sign language and to affiliate with a particular cultural identity is therefore a major advance. It is also a clear recognition of the discrimination that many people with disabilities have experienced in using sign language and other modes and means of communication in their communities.

EXERCISE 14.3: What are the Cultural Rituals in Your Community?

Objective: To consider the cultural rituals within the family or community and barriers that people with disabilities face in accessing their right to participate in culture
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Brainstorm/Discuss/Report:
Ask participants to brainstorm in small groups:

- What are the rituals in your culture that mark the important events in a person’s life (e.g.,birth, coming of age, marriage, death) or the seasons of the year (e.g., religious holidays, national holidays)? List these.
- What is the value and importance of these rituals to the individual? To the family? To the community or society as a whole?

2. Analyze:
Ask each group to report back on their findings and combine the lists.
Discuss among the whole group:

- Are people with disabilities welcome or permitted to participate in these rituals? If not, why not?
- How does exclusion impact people with disabilities personally?
- How does exclusion impact their ability to participate as full members in society?

3. Strategize:
Ask the group to consider ways of addressing discrimination in relation to participation in these cultural rituals.

- How might these barriers be challenged: (i) within the family; (ii) within the community?

SPORT AS A HUMAN RIGHT

The 1982 **World Programme of Action Concerning Disabled Persons**[7] stressed that governments should encourage sport activities of disabled persons by providing facilities and organizations. The 1993 **Standard Rules on Equalization of Opportunities for Persons with Disabilities**[8] provide detailed guidance on making sport and recreation accessible to people with disabilities. Rule 11 emphasizes that States should take measures to make sport facilities accessible and that sports organizations should be encouraged to develop opportunities for participation by persons with disabilities in sports activities, both through accessibility measures that open up opportunities for participation and, where appropriate, through developing disability-specific programming. Rule 11 also promotes the concept of people with disabilities participating in national and international events. Rule 11 stresses that persons with disabilities participating in sports activities should have access to instruction and training of the same quality as other participants. Most important, Rule 11 underscores the importance of consultations with disabled peoples organizations by organizers of sports and recreation in the development of their services.

Building upon these earlier efforts, the **CRPD** supports the right of people with disabilities to participate in both mainstream and disability-specific sporting activities. Inclusion recognizes the role of mainstream sports organizations and institutions in delivering disability sport programs and services to persons with disabilities and in providing accommodations to make programs and services accessible. *Disability sport* refers to sport organized specifically for persons with disabilities to provide equitable and fair categories, based on disability and ability, in order to even the playing field. Disability sport may therefore be regarded as a category of sport, such as women's sport.

For many years disability advocates have been promoting the participation of people with disabilities in sport and recreational activities. The Paralympics are an example of disability sport at the highest levels of sporting competition. Other international disability-specific initiatives include the Deaf Games, organized by the International Committee of Sports for the Deaf, and the Special Olympics, a worldwide movement to provide competitive sport and recreational opportunities for people with intellectual disabilities. However, there are numerous examples of community-based sporting opportunities, often organized by disabled peoples organizations, to promote inclusion in mainstream sport or to promote disability-specific programming. A recent report issued by the UN **Special Rapporteur** on Disabilities noted that in many countries around the world, athletes with disabilities are a great source of national pride and that opportunities for persons with disabilities to participate in sport at the community level were on the rise.[9] An interesting example of effective advocacy to promote disability inclusion in sport is the initiative sponsored by the Australian Sports Commission (See text box on following page).

7 See http://www.un.org/esa/socdev/enable/diswpa00.htm
8 See http://www.un.org/esa/socdev/enable/dissre00.htm
9 UN Special Rapporteur on Disabilities, Global Survey on Government Action on the Implementation of the Standard Rules (Doha: 2006).

Disability Sport in Australia: Project CONNECT

Project CONNECT is a national initiative of the Australian Sports Commission and a transition program designed to provide national sporting associations with assistance in meeting the needs of people with disabilities. The program addresses sport for people with disabilities at all levels, from grassroots to elite competition. It aims to create athletic opportunities for people with disabilities and to break down barriers within disability and non-disability sport structures. The program forms partnerships at national, state, and local levels to address the full range of issues that impact participation of people with disabilities in sport. A core part of the initiative is the development and implementation of Disability Action Plans for participating national sport organizations, which forms the basis of the range of support services provided through Project Connect:

- Disability Action Plan negotiated between Project CONNECT and national sporting organizations
- Strategies in Plans outline agreed outcomes, time frames, and evaluation methods
- Funding assistance is provided to the national sporting organization for realization of the strategies
- Disability Action Plans must ensure that strategies to develop the sport by the national sport organization will create opportunities at all levels. Disability Action Plan is registered with the Australian Human Rights and Equal Opportunity Commission.

The Disability Standards for Sport, endorsed by the Australian Sports Commission, provide a framework for assessing outcomes:

- **Development:** Sports organizations must develop their sport in a manner that attracts and retains peoples with disabilities in a variety of roles within sport (e.g., as volunteer, spectator, administrator, player, coach and/or official);
- **Participation:** Sports organizations must ensure that people with disabilities are provided with opportunities to participate in disability and non-disability specific sport;
- **Competition:** Sports organizations must ensure that competition opportunities exist for athletes with disabilities in disability and non-disability specific sport.

Project CONNECT has brought about the filing of Disability Action Plans by a wide variety of national sport organizations covering the following sports: athletics, basketball, swimming, tennis, tenpin bowling, yachting, baseball, softball, surfing, table tennis, cricket, golf, bowls, and riding.[10]

10 *Australian Sport Commission, Disability Sport Unit, Project CONNECT*. http://www.ausport.gov.au/connect/index.asp

EXERCISE 14.4: What is an Athlete?

Objective: To consider the attributes of athletes and the barriers that athletes with disabilities face in accessing their right to participate in sport
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Brainstorm/Discuss:
Ask participants to brainstorm

- What are the general attributes of an athlete?
- What words or phrases come to mind in thinking about an athlete?

Next, ask participants to think about an athlete with a disability. Record responses on chart paper.

- What do you think about when you think about an athlete with a disability?
- What words come to mind?

2. Analyze:

- How are the responses different?
- How are they the same?
- Does anything about these two lists surprise you?

3. Discuss:

- Are there athletes with disabilities in your community?
- If so, what kinds of sports do they engage in?
- If not, why not?
- What organizations at the community, national, and international levels might support the rights of athletes with disabilities? (Consider both governmental as well as non-governmental bodies).

Variation: This exercise may be easily adapted to address artists, musicians and other participants in cultural life, sport and recreation.

Source: Adapted from material by Eli Wolff, Northeastern Center for Sport and Society.

Case Law: Addressing Discrimination in Professional Golf

In 2001, the United States Supreme Court reached a decision in *P.G.A. Tour v. Martin*, a case involving Casey Martin, a professional golfer with a disability who had requested accommodation in the form of permission to ride a golf cart in tournaments of the Professional Golfer's Association (PGA). Martin's disability was due to a disease affecting the blood flow in one of his legs which caused extreme pain and fatigue, which was made worse by walking. The Supreme Court ruled that the PGA Tour is a place of public accommodation under the Americans with Disabilities Act. Accordingly, the PGA, as an operator of golf courses, must not discriminate against any player in the full and equal enjoyment of the goods, services, facilities, advantages or accommodations of those courses. Since the PGA Tour is a place of public accommodation, the Court decided that the PGA had to accommodate Martin unless to do so would fundamentally alter the nature of the event. The Court held that providing Martin with a golf cart would not fundamentally alter the nature of the event because the fundamental nature of golf is shot making.[11]

TOURISM

Tourism is the largest industry in the world. In the United States alone some 42 million travelers with disabilities take 31.7 million trips per year. They spend $13.6 billion annually, including $3.3 billion on airfare, $4.2 billion on hotel accommodations, and $2.7 billion on food and beverage.[12] Responsible tourism development and tourism that respects the human rights of persons with disabilities must consider inclusion in planning, designing, and implementing tourism projects. Most important, disabled peoples organizations must participate in such processes and need to engage in accessible tourism advocacy. The CRPD, which is the only major international human rights treaty to explicitly mention tourism, requires States to ensure that persons with disabilities have access to tourism and tourist services.

11 P.G.A. Tour, Inc. v. Martin, S32 U.S. 661, 121 S. Ct 1879 (2001)

12 Rains, Scott Paul. "The Global Reach of Accessible Tourism." 16 May 2005. *suite101.com.* http://www.suite101.com/article.cfm/travel_with_disabilities/115976/3

Barriers Faced by Tourists with Disabilities

- Inaccessible airport transfer and ill-trained airport staff.
- Lack of accessible transport.
- Inaccessible hotel rooms.
- Professional staff not trained to inform and advise about accessibility issues.
- Lack of information about a specific attraction's accessibility (e.g., museums, castles, exhibitions).
- Non-adapted toilets in restaurants and public places.
- Inaccessible restaurants and tourist attractions.
- Inaccessible streets (e.g., no curb cuts, cars blocking wheelchair access lanes).
- Lack of disability equipment rental (wheelchairs, bath chairs, toilet raisers, electric scooters).

EXERCISE 14.5: Speaking Up for Accessible Tourism

Objective: To examine discrimination in tourism and tourism development and to consider how to take action against it
Time: 60 minutes
Materials: Chart paper and markers or blackboard and chalk

1. List:
Ask participants what they consider are the main problems of discrimination or barriers in tourism for persons with disabilities. List these.

2. Plan:
Divide participants into small groups. Ask each group to choose a problem from the list that they would like to focus on. Give these instructions:

a. Plan a five-minute presentation to a mock “Tourism Development Board” that includes officials, representatives of the tourist industry, and members of the public;
b. Choose a spokesperson for your presentation and someone to serve on the “Tourism Development Board.”;
c. While the groups plan presentations, each member of the “Tourism Development Board” meets to decide on their roles. (These roles should reflect the attitudes, both positive and negative, found in the community);
d. Presentations should:
   - Describe the discrimination, including whom it affects and, if possible, its cause(s);
   - Relate the discrimination to a human right in the CRPD;
   - Describe the effects of discrimination on the lives of people with disabilities;
   - Describe how addressing the problem can improve the lives of persons with disabilities, and of people generally;
   - Propose next steps or specific actions that can be taken to address the problem.

3. Role Play/Discuss:
Have the spokesperson from each group make a presentation to the “Tourism Development Board”. Encourage members of the “Board” to respond. Debrief each presentation by asking for questions, comments, objections, or suggestions from the larger group.

4. Conclude:
Debrief the exercise by asking questions like these:

- How did the spokesperson feel when presenting the problem?
- How did the “Board” react? What attitudes and barriers were represented?
- Were the problems human rights issues?
- Was the tactic for addressing the problem feasible in your community? Why or why not?
- What would be the next step be in real-life for addressing this problem?

DISABILITY ADVOCACY AND TOURISM

There is a large and growing movement within disability activism to promote accessible tourism. Many innovative and successful strategies have resulted in opening tourism to persons with disabilities:

- In Perth, Western Australia, a program called "Beyond Accessibility" requires the hotels to use from 10% to 15% of the profit they earn from the conventions brought to them by the Convention Bureau to enhance hotel accessibility.
- In Australia's state of Tasmania, a tourism group purchased several properties throughout the seven tourist regions of the island. Each location is fully wheelchair accessible. A bus with a lift for wheelchair is made available to tourists for travel throughout the region and, as a result, the entire island is open to travelers with disabilities.
- In the Canary Islands, disability advocates have improved access to services for Canary Island residents with disabilities by consulting with the tourism industry, developing an accessibility directory for Tenerife and a sophisticated online resource offering tourism information for travelers with disabilities.
- Architects and their students from the Rhode Island School of Design are combining environmentally sensitive, "green" construction methods and building materials with accessibility concepts to develop an accessible eco-lodge in the US Virgin Islands. The resort, known as Concordia Estates, allows people with disabilities close access to unspoiled nature. Tourist hotels in Hawaii have also shown some initiative, not only in providing guests with comfortable accessible rooms, but also in advising them on accessible places for food and entertainment and arranging for the rental of specialized beach wheelchairs to make the beach truly accessible for all.[13]
- In Costa Rica, disabled advocates worked with government officials to develop an accessibility protocol to enhance access to the wonders of the rainforest. (See text box)

What is clear is that without the initiative of disability advocates, the goal of tourism for all will not be realized.

13 Rains, Scott Paul. “The Global Reach of Accessible Tourism.” 16 May 2005. *suite101.com.* http://www.suite101.com/article.cfm/travel_with_disabilities/115976/3

Access to National Parks in Costa Rica

In Costa Rica, a successful example of inclusive planning for national parks development resulted in the design and implementation of an *Accessibility Protocol for Persons with Disabilities in Protected Wildlife Areas,* based on extensive research and participation by the disability community. Disability groups, in partnership with the responsible ministry, worked to identify barriers to access in protected areas, trained park personnel on access issues, and drafted and implemented an accessibility plan. The project was overseen by the Ministry of the Environment and Energy, which established an Institutional Commission on Disability and an internal disability policy, as called for in domestic disability legislation.[14]

EXERCISE 14.5: Making a Commitment to Promote Participation in Cultural Life, Recreation, Sport, and Leisure for People with Disabilities

- Emphasize that human rights involve both rights and responsibilities;
- Ask if after learning about the human right of people with disabilities to participate in cultural life, recreation, sport and leisure, 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 that she or he is willing and able to take in the next month to promote the human right of people with disabilities to participate in cultural life, recreation, sport and leisure.

To plan 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.

USEFUL RESOURCES ON PARTICIPATION IN CULTURAL LIFE, LEISURE AND SPORT

- Adaptive Sports Foundation: http://www.adaptivesportsfoundation.org
- Center for the Study of Sport in Society at Northeastern University, Disability in Sport Program: http://www.sportinsociety.org/vpd/dis.php
- International Committee of Sports for the Deaf: http://www.deaflympics.com
- International Paralympic Committee: http://www.paralympic.org
- John F. Kennedy Center for the Performing Arts: http://www.kennedy-center.org
- National Arts and Disability Center: http://www.nadc.ucla.edu
- Society for Disability Arts and Culture: http://www.s4dac.org
- Special Olympics: http://www.speicalolympics.org
- United States Association of Blind Athletes: http://www.usaba.org
- VSA Arts: http://www.vsarts.org

14 Source: Gatjens, Luis Fernando Astorga. “Costa Rica Designs and Tests First Accessibility Protocol in Protected Wildlife Areas.” 2003. *Disability World.* http://www.disabilityworld.org/01-03_03/access/costarica.shtml

CHAPTER 15: THE HUMAN RIGHTS OF CHILDREN WITH DISABILITIES

UN Convention on the Rights of Persons with Disabilities

Preamble:

Recognizing that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child.

Article 3, General Principles:

Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Article 4, General Obligations:

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

Article 7, Children with Disabilities:

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

OBJECTIVES

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

- Understand discrimination against children with disabilities as a human rights issue
- Understand the interrelation and interdependence of the rights of children with disabilities and other human rights
- Identify ways in which the rights of children with disabilities have been promoted or denied
- Explain the importance of allowing children with disabilities a voice regarding issues that involve them
- Understand and apply the provisions on the human rights of children with disabilities in the UN ***Convention on the Rights of Persons with Disabilities*** (CRPD)
- Highlight possible strategies to advance the rights of children with disabilities.

GETTING STARTED: THINKING ABOUT THE HUMAN RIGHTS OF CHILDREN WITH DISABILITIES

Children as a whole are marginalized; however, some groups of children, such as children with disabilities, girl children, and children from ethnic minorities face even greater discrimination. Children with disabilities are uniquely at greater risk for discrimination due to the fact that 1) they have a disability and 2) they are children and therefore more vulnerable to marginalization, exploitation, and abuse. Unless these groups are specifically mentioned in human rights treaties, they may be deprived of the protections and guarantees of the general children's human rights agenda, including the **Convention on the Rights of Persons with Disabilities** (CRPD). For this reason children with disabilities are mentioned in a separate article in the CRPD. For them, as for all children, the assurance of their human rights, especially to health, survival, and an adequate standard of living, is critical.

> There are an estimated 150 million children with disabilities in the world. More than 80 percent of them live in developing countries with little or no access to services, such as education.[1]

Many different experiences shape a childhood, including a child's personal characteristics, gender, class, ethnicity, culture, religion, (dis)ability, socio-economic situation, location, family situation, environment, education, work, and sexual orientation. These experiences need to be taken into account when guaranteeing the human rights and fundamental freedoms of children with disabilities.

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1 *Committee on the Rights of the Child, General Comment No. 9: The Rights of Children with Disabilities*. 29 Sep. 2006. UN doc. CRC/C/GC/9 http://www.ohchr.org/english/bodies/crc/docs/co/CRC.C.GC.9.doc

Barriers to Children with Disabilities

Before Birth
- Poor maternal health and nutrition
- Poverty
- Inadequate prenatal care
- Prenatal screening and termination of pregnancy

At Birth
- Euthanization
- Denial of appropriate medical treatment
- Risk of rejection by parents
- Institutional placement

After Birth
- Institutional placement
- Isolation in the home and isolation from the community
- Denial of the right to education and many other human rights
- Risk of continual medical treatments, some painful and unnecessary
- Denial of the right to participate in decisions that effect their lives

EXERCISE 15.1: What Rights of Children with Disabilities Does the CRPD Affirm?

Objective: To review and understand the rights of children with disabilities affirmed by the CRPD
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Review:
Divide the participants into small groups. Ask each group to work together to paraphrase the paragraph in the CRPD Preamble, Articles 3, 4, and 7 in common language and give some examples of how that right could be enjoyed and make a difference for children with disabilities in their community.

2. Paraphrase:
Read the CRPD sections above aloud, pausing at each comma or paragraph to ask different groups for their paraphrase. Discuss the meaning of each section until everyone can agree on a paraphrase. Write the final paraphrase on chart paper.

3. Give examples:
Ask for examples of how these rights could be enjoyed and make a difference for children with disabilities.

4. Discuss:
How can these articles of the CRPD be used to create social change or impact national policy or local/community decision-making?

Realizing a Child's Rights and Freedoms

A child's enjoyment of his or her rights and freedoms depends on many interrelated factors. The following factors may influence the extent to which a child with a disability is excluded within their particular culture and context:

- **Prejudice and ignorance:** negative attitudes and false beliefs are by far the main barriers in all cultures and contexts;
- **Gender:** female children with impairments are more likely not to survive, to be abandoned, to be discriminated against, to be excluded from education, to be deemed un-marriageable and to be excluded from motherhood and general participation in their society;
- **Poverty:** where communities lack access to basic resources, families having members with disabilities are frequently the poorest and most marginalized. Even the very poorest families initially try to care for and protect their child, but they often become trapped in a cycle of poverty and exclusion due to negative beliefs and behaviors and a lack of information, knowledge, skills, and resources;
- **Crisis situations:** children in particularly difficult circumstances such as natural disasters, armed conflict, and refugee situations are particularly vulnerable to exclusion.

The CRPD and the **Convention on the Rights of the Child** (CRC) provides the legal framework for guaranteeing children access to their human rights, but many factors influence the extent to which children with impairments realize those rights:

- attitudes and behaviors of others towards them (e.g., parents, teachers, neighbors, other children)
- satisfaction of basic needs (e.g., survival, food, shelter, stimulation)
- international and national policies which include or exclude them
- accessibility of the physical environment (e.g., home, school, community)
- access to supports for their physical, social, mental, communication, and personal development (e.g., basic aids and equipment, assistance, health and education services, access to early childhood care and education).

Child-Centered Approach to Rights Programming

It is important to remember that children with disabilities, like all children, have the right to be active participants in decisions that affect them. Some key considerations for child-rights programming using a child-centered approach are:

- Consider children's **best interests**;
- **Listen** to children with disabilities;

- **Challenge your own** and others' **assumptions** about the needs and perspectives of children with disabilities;
  - Don't make assumptions about what children with disabilities can and cannot do;
  - Don't make assumptions about the needs and perspectives of children with disabilities (ask them!);
- **Value diversity**
  - Consider differences between disabilities and abilities;
  - Seek to develop the child's abilities and competencies;
- **Consider the child as a whole** and the whole range of his or her development and needs
- **Analyze** the situation of the child as a whole in its broader context of family and community;
- **See children with disabilities as "social actors"** who are involved in decision-making.

EXERCISE 15.2: Attitudes, Beliefs, and Views on Diverse Childhoods

Objective: To identify common attitudes, beliefs, and views on diverse childhoods
Time: 40 minutes
Materials: Handout; chart paper and markers, or blackboard and chalk

1. Reflect/Analyze:
Break into small groups and ask them to discuss the first and second column of Handout 15.2.

- What are 5 common negative beliefs and attitudes in your country about children with disabilities and their childhood?
- What are 5 common positive beliefs and attitudes in your country that support children with disabilities and their childhood?
- Ask groups to record their answers on chart paper in the same format as Handout 15.2.
- After brainstorming on the first and second column, ask groups to reflect on both columns and now discuss the third column;
- If you listen to children with disabilities, what are their concerns and opinions regarding opportunities and programs available to them (programs for all children and/or programs for children with disabilities)? How do positive and negative beliefs (Columns 1 & 2) impact their opportunities?
- Invite groups to post their charts on the wall. Have participants move around the room quietly reading the charts of groups and noting common ideas and differences.

2. Discuss:
Reconvene as a larger group to discuss reflections. After the reflections, summarize the session and review some of the key points from Handout 15.2:

- How do the differing abilities of children with disabilities impact these views (e.g., children with visual impairments, psycho-social disabilities, multiple disabilities)?
- How does age affect expectations (e.g., for toddlers, youth, young adults)?
- How does gender affect expectations for children with disabilities?
- How is this cycle of oppression/exclusion strengthened through individuals and society? How do cultural expectations influence children with disabilities?
- In challenging our assumptions about children with disabilities, how can we promote a child-centered approach (e.g., listening to children, allowing them to be active participants involved in decision-making)?
- How can this cycle can be broken through program interventions?

Handout 15.2

What are 5 common negative beliefs, attitudes, and views in your country about children with disabilities and their childhood?	What are 5 common positive beliefs, attitudes, and views in your country that are supportive of children with disabilities and their childhood?	When you listen to children with disabilities, what are their concerns and opinions regarding opportunities and programs available for them (programs for all children and/or programs for children with disabilities)? How do positive and negative beliefs (Columns 1 & 2) impact their opportunities?

WHAT DOES HUMAN RIGHTS LAW SAY ABOUT THE RIGHTS OF CHILDREN WITH DISABILITIES?

Children's rights have foundations in provisions of international law. The **Universal Declaration of Human Rights** (UDHR)[2] Article 25, the **Convention on the Rights of the Child** (CRC)[3] and the 1993 **UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** (Standard Rules)[4] address the rights of children with disabilities.

The 1948 Universal Declaration of Human Rights (UDHR) mentions children in Article 25 and 26. Article 26 states that motherhood and childhood are entitled to special care and assistance and that all children, regardless of whether they are born in or out of wedlock, shall enjoy the same social protection. Article 26 entitles everyone to equal access to education and allows parents the right to choose the kind of education given to their child.

The 1989 CRC, the most universally ratified of all human rights treaties (only the USA and Somalia are not States Parties), lays the foundation for and defines the many rights that

2 See http://www.unhchr.ch/udhr/lang/eng.htm
3 See http://www.ohchr.org/english/law/crc.htm
4 See http://www.ohchr.org/english/law/opportunities.htm

the CRPD affirms. The CRC provides an over-arching framework for children's rights and makes special mention of children with disabilities in Articles 2 and 23. It is important to remember, however, that every article in the CRC that refers to "the child" applies also to the child with disabilities. This inclusion marks an important shift in thinking towards a "rights-based approach," holding governments legally accountable for failing to meet the needs of all children. The CRC creates a new vision of children as bearers of rights and responsibilities appropriate to their age, rather than viewing them as the property of their parents or the helpless recipients of charity.

The CRC has special provisions for children with disabilities. Article 2.1 prohibits discrimination on various grounds, including disability, and Article 23 sets out the right to special care, education, and training. Children's rights cover four main aspects of a child's life that apply equally to children with disabilities: the right to survive, the right to develop, the right to be protected from harm, and the right to participate.

- **Survival rights:** the right to life and to have the most basic needs met (e.g., adequate standard of living, shelter, nutrition, medical treatment);
- **Development rights:** the rights enabling children to reach their fullest potential (e.g., education, play and leisure, cultural activities, access to information and freedom of thought, conscience and religion);
- **Participation rights:** rights that allow children and adolescents to take an active role in their communities (e.g., the freedom to express opinions, the freedom to have a say in matters affecting their own lives, the freedom to join associations). Respecting a child's opinion (Article 12) is especially important as it gives children the right to a voice in all matters concerning them (e.g., kinds of treatment for disabled children);
- **Protection rights:** rights that are essential for safeguarding children and adolescents from all forms of abuse, neglect and exploitation (e.g., special care for refugee children and protection against involvement in armed conflict, child labor, sexual exploitation, torture, and drug abuse).

The 1993 **UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** (Standard Rules) address the rights of children and their families in Rule 2 (medical care), Rule 6 (education), which includes very young children with disabilities, and Rule 9 (family life and personal integrity).

Rule 2 states that infants and children should especially have access to the same level of medical care that others have. Rule 9 states that persons with disabilities should be enabled to live with their families. States should encourage the inclusion in family counseling of appropriate modules regarding disability and its effects on family life. Respite-care and attendant-care services should be made available to families that include persons with disabilities. The Education Rule 6 states that general education authorities are responsible for the education of people with disabilities in integrated settings and encourages the active involvement of parent groups and organizations in the education process. Special attention is given to very young children with disabilities and populations at risk for double discrimination.

It is important to remember that all international treaties apply, protect, and enable *all***,** including infants, children, and youth with disabilities.

PARENTS AND FAMILIES OF CHILDREN WITH DISABILITIES

Regardless of ethnicity, economic status, or class, all parents are distressed when they learn that their child has a disability. The differences among them are very great, however, when you compare their beliefs and the resources and supports available to them. Traditionally, families, including grandparents and siblings, carry the responsibility for providing care to children with disabilities with little to no help from society. To effectively advocate for services, parents need to understand their rights and the rights of their child, as defined by CRC and CRPD.

Support for the Family

- **Raise Community Awareness:** Dispel myth and stigma associated with disability.
- **Provide Information and Resources:** Build the knowledge and skills of family members, peers, and the community.
- **Provide Access to Rehabilitation and Habilitation:** Provide access to adequate medical care and equipment, as well as to support and services for children with disabilities.

One Parent's Story

I am a parent of a disabled child. I am also a community worker with a good understanding of our early intervention program.

I felt great about this opportunity to increase awareness about disability (the START Program at the Sunshine Centre). I also wanted to help and support the parents of disabled children in this area. Often such parents do not trust people who have not had the same experiences. I know they can feel very isolated and ignored. I understand from my own experience that many of them do not get support from their families because there is no understanding of the needs of their disabled children.

Many fathers of the disabled children do not give their support. My husband had great difficulty in accepting that our son was disabled. I was not supposed to walk in the street with my child. His father could not believe that other people could see the beauty of this child. I struggled because he refused to give me any money for the special food our child needed.

I know how lonely and frightened these parents can feel. I worried about who would be responsible for our child if something happened to me. I even believed it would be the best thing if my child died before me.

I became a community worker because I saw how parents of disabled children really need support. I knew that with training, parents could help each other. They do not need people who feel ashamed of disabled children. They need to talk to someone who can understand that even though the child is disabled, he is still a human being. He does not have a disease that can affect other people.[5]

5 Lloyd, G. "An Integrated, Specialized Educational Service Responding to Local Need in Gauteng, South Africa." 2000. *International Special Education Congress*. http://www.isec2000.org.uk/abstracts/papers_l/lloyd_1.htm

As the example above demonstrates, raising community awareness and providing supports can enable a child with a disability to gain the skills necessary to participate in education, care for themselves, and contribute to society.

For more information on a child's right to education, see Part 2, Chapter 13, "The Right to Education," p. 165.

THE CHILD'S RIGHT TO PARTICIPATE

The child participation is key to enabling children's rights. Children have the right to express their views and be consulted in matters that may affect them. This should happen at levels of policy, community, family, and self. Once children or young adults have the skills to communicate their wants and needs, it is vital that they contribute to decisions made on their behalf.

A rights-based approach to participation means putting girls and boys from all backgrounds and disability types, including intellectual and psychosocial disabilities, at the center of human rights policy and programming. This approach also recognizes children with disabilities as right-holders and members of society and holds governments accountable for ensuring the rights of all their citizens, including children with disabilities.

How to Achieve Children's Participation

Social and Political Movements

- Children form their own movements and organizations to claim their rights with support from adults;
- Change the power relations between children and adults;
- Enable children to become democratic citizens.

Human Rights

- Promote children's civil rights (e.g., expression, thought, information, organization);
- Recognize children as rights holders.

Child Development

- Develop children's abilities, confidence, and independence;
- Develop children's ability to protect themselves;
- Improve children's locus of control, level of empowerment, and learning.

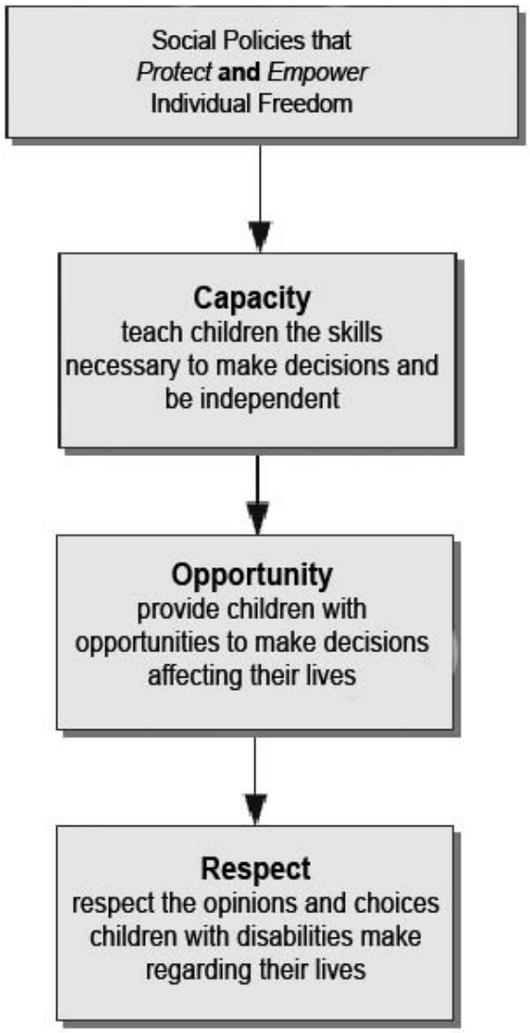
Development

- Understand children better;
- Develop better programs and policies for children.

According to Equal Opportunity Theory,[6] social policies can be put in place to empower and protect persons with disabilities. But until we teach children the skills (i.e., increase their capacity) to make decisions, provide them with opportunities to make decisions, and respect the choices they make, equality and inclusion, which are principal tenets of the CRPD, will not be

6 Mithaug, Dennis E. "Your right, my obligation?" *The Journal of the Association for Persons with Severe Handicaps, 23*(1), 41-43 Spr 1998.

achieved. It is not only a matter of making choices, but also of being empowered to act, subject to individual circumstances, toward pursuing one's own ends in life in the community.



Equal Opportunity Model
Mithaug (1998)

HUMAN RIGHTS LAW THAT GUARANTEES CHILDREN'S PARTICIPATION

Primary Article on Participation in the Convention on the Rights of the Child:

- **Article 12:** the general principle that children have the right to express their views freely in matters affecting them and that their views should be given due weight in accordance with their age and maturity.

The right to participation is also explicitly or implicitly expressed in many other CRC articles:

- **Article 5:** parental supervision of direction and guidance in accordance with respect for children's evolving capacity
- **Article 9:** non-separation of children from families without the right to make their views known

- **Article 13:** the right to freedom of expression
- **Article 14:** the right to freedom of conscience, thought and religion
- **Article 15:** the right to freedom of association
- **Article 16:** the right to privacy
- **Article 17:** the right to information
- **Article 29:** the right to education that promotes respect for human rights and democracy
- **Article 31:** the right to play.

Primary Article on Participation in the CRPD

Article 7: states parties should take all necessary measure to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children; the best interests of the child is the primary consideration; they have the right to express their views freely on all matters affecting them, given due weight to their age and maturity; and are to be provided with disability and age-appropriate assistance to realize their rights.

The right to participation is also expressed in many other the CRPD articles, which build upon the CRC:

- **Preamble:** children with disabilities should have the same human rights and fundamental freedoms as other children as included under the provisions of the CRC;
- **Article 3:** respect for evolving capacities of children with disabilities and their right to preserve their identities;
- **Article 4:** children with disabilities should be consulted with and involved in the development of legislation and policies to implement the CRPD.

EXERCISE 15.3: Describing Good Practices and Overcoming Resistance to Children's Participation

Objective: To describe good practices of child participation and identify common forms of adult resistance to child participation and strategies to overcome resistance
Time: 50 minutes
Materials: Handout; chart paper and markers, or blackboard and chalk

1. Small Group Work:

- Break participants into small groups and share experiences of working with children and young people with disabilities as partners in their programs/projects. Ask them to focus on those that have resulted in positive outcomes;
- Ask individuals to present some of their key examples. After each presentation, ask their reasons for selecting those particular examples;
- Using Handout 15.3, identify and record adult resistance to child participation and ways of overcoming adult resistance toward the participation of children with disabilities (e.g., in family, schools, communities, local government);
- Analyze the answers to identify the common resistance and strategies for overcoming resistance;
- Reflect on resistance and how it varies: for different types of disability, for girls or boys, for school-going or non-school-going children, and in rural and urban settings.

2. Discuss:

- Ask participants to share their outcomes.
- Encourage them to cite positive personal experiences as inputs into the process of overcoming resistance.

Handout 15.3: Adult resistance to child participation and overcoming resistance

	Adult's resistance to child participation	Overcoming adult resistance
Family		
School		
Community		
Workplace		
Local Governance		
Within own organization or NGO		
Add more…		

EXERCISE 15.4: Children with Disabilities as Partners in Programming

Objective: To identify good practices for enlisting the participation of children with disabilities in the program cycle or parts of the program cycle and to identify ways for strengthening children with disabilities participation in programs and projects
Time: 60 minutes
Materials: Handout, chart paper and markers or blackboard and chalk

1. List:
Ask participants to share good examples of working with children with disabilities as partners in programs and to identify the gaps in their interventions. List the gaps on chart paper or board.

2. Small Group Work:

- Break into smalls groups and discuss the following questions about their gaps:
  - Are children with disabilities (including children with intellectual disabilities) consulted and involved: are their views incorporated into stages of programming/the project cycle?
  - Is relevant and child/ability-friendly information provided?
  - Are the views of different groups of children (different disabilities/ages) taken into consideration?
  - Will the project empower children and/or adults to claim the rights of children (as in the CRC) and the rights of persons with disabilities (as in the CRPD)?
- While still in their groups, ask participants to focus their discussion on ways to strengthen the participation of children with disabilities in programs and projects. What are some key lessons:
  - on empowering children with disabilities?
  - on encouraging adults to realize the rights of children with disabilities?

3. Discussion:

- Bring all groups together to share ideas. Summarize by going through some of the program and project cycle and identifying a few key elements in similar and contrasting ways to strengthen the participation of children with disabilities. You may refer to the information below to better understand some positive outcomes of working with children and young people with disabilities.

POSITIVE OUTCOMES OF WORK WITH CHILDREN AND YOUNG PEOPLE WITH DISABILITIES

These examples point to key lessons on empowering both children and adults working together to realize child rights.

Recognition of Children as Social Actors

- Parents and community members develop respect for the views and rights of children with disabilities, thereby increasing their status and voices;
- Children with disabilities are recognized as social actors who make positive contributions to local communities and society;
- Children with disabilities bring about attitude changes amongst adults, thus challenging discrimination in the family, school, and community.

Children as Right Holders

- Children with disabilities are empowered to address violations of rights and claim their rights;
- Educational performance of children with disabilities is improved;
- Self-esteem, confidence, and resilience of children with disabilities are enhanced;
- Enthusiasm of children with disabilities to address issues for the benefit of their peers and community is developed;
- Communication, negotiation, and teamwork skills are increased;
- Values, skills, and knowledge of democratic functioning among children with disabilities are enhanced;
- Girls and boys with disabilities through knowledge of their own rights and recognition of the value of their participation are empowered.

Working with Children in Program Development

- Opportunities are created for children with disabilities to participate in planning, decision-making, reporting and legal amendments at different levels of their community and government;
- Children with disabilities are able to express their own perspectives, their understanding of issues, problems, analysis, solutions, and priorities, which often differ from those of adults.

Program Outcomes

- Reduction in discrimination against children with disabilities;
- Increased inclusion in the community and school;
- Persuading the local community to take action; improve attitudes and access to the home, community, and school;
- Children with disabilities are able to protect themselves from abuse.

Attitudes and Support of Adults

- Adults are more accepting of children's representation and views at the community and district level;
- Social changes can be seen in adults' and peers' attitudes and mindsets;
- Adults are being held more accountable to address child and disability rights violations and to provide accessible, quality services to all children;
- Increased commitment amongst adults to work with and for children with disabilities.[7]

Throughout this chapter you have *learned* how children have the right to participate fully and express their views in matters that affect them, as well as how adults can be resistant to their participation for many reasons. You have *discovered* that children's rights need to not only be protected, but promoted as well. And most importantly, that children can actively participate as partners in programming, leading to many positive outcomes, such as empowerment, social action and inclusion, and the reduction of discrimination. Because the rights of children with disabilities are *vulnerable* to abuse, it is the *responsibility of human rights law and society* to ensure these rights are upheld.

7 Adapted from O'Kane, Claire. "Children and Governance," (draft). *Save the Children's Training Manual Child Rights Programming*. http://seap.savethechildren.se/South_East_Asia/Misc/Puffs/Child-Rights-Programming-Training-Manual

EXERCISE 15.5: Making a Commitment

Objective: To emphasize and examine that the human rights of children with disabilities involve both rights and responsibilities
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Action:

- Ask if, after learning about the human rights of children with disabilities, the group members are 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 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 rights of children with disabilities.
- Record the commitments on chart or board to distribute a summary of actions to all participants after the training.

The rights of children with disabilities are the same as those of everyone else. Children with disabilities are entitled under the CRC and the CRPD to the same human rights and fundamental freedoms as all other children and as all other persons with disabilities. States Parties and organizations are obligated to involve children with disabilities and enable them to attain their rights and freedoms. The active involvement of children with disabilities in policy and programming is not only an obligation, but also a benefit both to the child and the whole community.

To plan 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.

USEFUL RESOURCES ON THE HUMAN RIGHTS OF CHILDREN WITH DISABILITIES

- Child Rights Information Network: http://www.crin.org/ and http://www.crin.org/themes/ViewTheme.asp?id=5
- Equal Opportunity Theory: Mithaug, D. E. (1998). Your right, my obligation? *The Journal of the Association for Persons with Severe Handicaps, 23*(1), 41-43
- International Save the Children Alliance: http://www.savethechildren.net/alliance/index.html
- Lessons for Including Children in Policymaking: http://www.savethechildren.net/alliance/resources/12lessons.pdf
- Mithaug, Dennis. E.,“Your right, my obligation?” *The Journal of the Association for Persons with Severe Handicaps, 23*(1), 41-43 Spr 1998
- Save the Children UK: http://www.eenet.org.uk/bibliog/scuk/scuk_home.shtml
- The Sunshine Centre Association (START Distance Project): http://www.sunshine.org.za
- Training Manual Child Rights Programming: http://seap.savethechildren.se/South_East_Asia/Misc/Puffs/Child-Rights-Programming-Training-Manual/
- UNICEF: http://www.unicef.org/crc

CHAPTER 16: THE RIGHT TO NON-DISCRIMINATION AND EQUALITY FOR WOMEN WITH DISABILITIES

UN Convention on the Rights of Persons with Disabilities

Preamble:

q. Recognizing that women and girls with disabilities are often at greater risk, both within and outside the home of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation,

s. Emphasizing the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities.

Article 3, General Principles:

The principles of the present Convention shall be…

g. Equality between men and women;

Article 6, Women with disabilities:

1. States Parties recognize that women and girls with disabilities are subject to multiple discriminations, and in this regard shall take measures to ensure the full and equal enjoyment by them of all their human rights and fundamental freedoms.

2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

Article 16, Freedom from exploitation, violence and abuse:

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, *inter alia*, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive...

5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

OBJECTIVES

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

- Explore the right to equality and freedom from sex discrimination for women and girls with disabilities
- Explain the importance of these concepts for women and girls with disabilities
- Understand the interrelation between non-discrimination and equality and other human rights
- Identify ways in which the rights of women with disabilities to freedom from sex discrimination have been promoted or denied
- Understand the provisions on gender equality and non-discrimination in the UN **Convention on the Rights of Persons with Disabilities** (CRPD).

> *"Discrimination starts at home, in the early years of the life of a disabled woman. This discrimination brings with it a reluctance on the part of families, or rather, decision-makers within the families, to make tangible and intangible resources available to disabled women, thus further undermining their life chances."*
>
> L. Abu-Habib[1]

GETTING STARTED: THINKING ABOUT EQUALITY AND NON-DISCRIMINATION

Throughout the world, women with disabilities are subject to two-tiered discrimination, based on their gender *and* disability. They are denied jobs, excluded from schools, are considered unworthy of marriage or partnership, and are even barred from certain religious practices. Women and girls with disabilities are often the last to receive the necessary support to enable them to overcome poverty and lead productive and fulfilling lives (e.g., education, employment, appropriate general health care services). They are at higher risk for abuse and violence, which can, in turn, aggravate existing disabilities or create secondary disabilities, such as psychosocial trauma.

The susceptibility of women with disabilities to discrimination is a global phenomenon, but how a society or culture understands and addresses this issue varies greatly. Women with disabilities in the developing world experience a triple bind:

- They are discriminated against because they are women;
- They are discriminated against because they have disabilities;
- They are discriminated against because they are from the developing world where they are more likely to be poor, where opportunities and accessibility for girls and women with disabilities are extremely restricted and where prejudice against this group is pervasive.

The rights of women and girls to non-discrimination and equality are interrelated with all other human rights issues. When treated in a discriminatory or unequal manner, women and girls cannot fully enjoy their other rights. For example, a disabled girl who receives an inferior education in relation to boys will be treated unequally throughout her work life. The lack

1 Abu-Habib, L. *Gender and Disability: Women's Experiences in the Middle East* (Oxfam, UK, 1997).

of access to general health care by women with disabilities, including reproductive health, impacts not only their right to health but also their right to information and potentially their rights in relation to family and parenthood. These examples demonstrate how human rights are **indivisible**, **interdependent**, and **interconnected**.

EXERCISE 16.1: The Far-Reaching Effects of Discrimination

Objective: To understand the multiple effects of discrimination experienced by women and girls with disabilities
Time: 60 minutes
Materials: Copies of an Effects Cascade, paper and markers
Optional**:** Paper cut into circles or paper plates and markers

1. Brainstorm:
Ask participants to brainstorm ways in which women or girls with disabilities experience discrimination or unequal treatment. List these, combining similar examples. Keep this list for use in Exercise 16.2.

2. Analyze:
Divide participants into pairs or small groups and ask each pair to choose one example of discrimination to analyze. Give these instructions and illustrate how to use the Effects Cascade:

- **Step 1:** Identify the problem. Write down the problem in the circle at the top of the cascade.
- **Step 2:** Think of three results of that problem in the lives of women and girls with disabilities and write these in the three circles below the big circle.
- **Step 3:** For each of the three results, think of two additional effects that may follow. If you identify more responses, add extra circles.

Example: If the problem is that women and girls with disabilities do not receive an equal education, three results might be:

- They cannot read or write;
- They cannot earn an adequate living;
- They are excluded from others in their age group.

From the effect “They cannot read or write,” three results might be:

- They cannot receive written information;
- They cannot read instructions on medications;
- They cannot communicate by letter or email.

Alternative: If time permits, use a positive cascade using what would result if the right were enjoyed (e.g., “Disabled women and girls receive an equal education”).

3. Report:
Ask each pair to present its Effects Cascade. At the end of each presentation, ask the whole group for additional ideas about other effects. Add these to the diagram. Keep all the diagrams mounted at the front of the room.

4. Discuss:
Emphasize that just as these effects of discrimination are far reaching, they also involve

violations of human rights that have multiple effects. Review each chart and ask participants to identify what human rights might be violated in each chart, besides the general rights to equality and freedom from discrimination.

Example: On the effects of "Women and girls with disabilities do not receive an equal education," you might write:

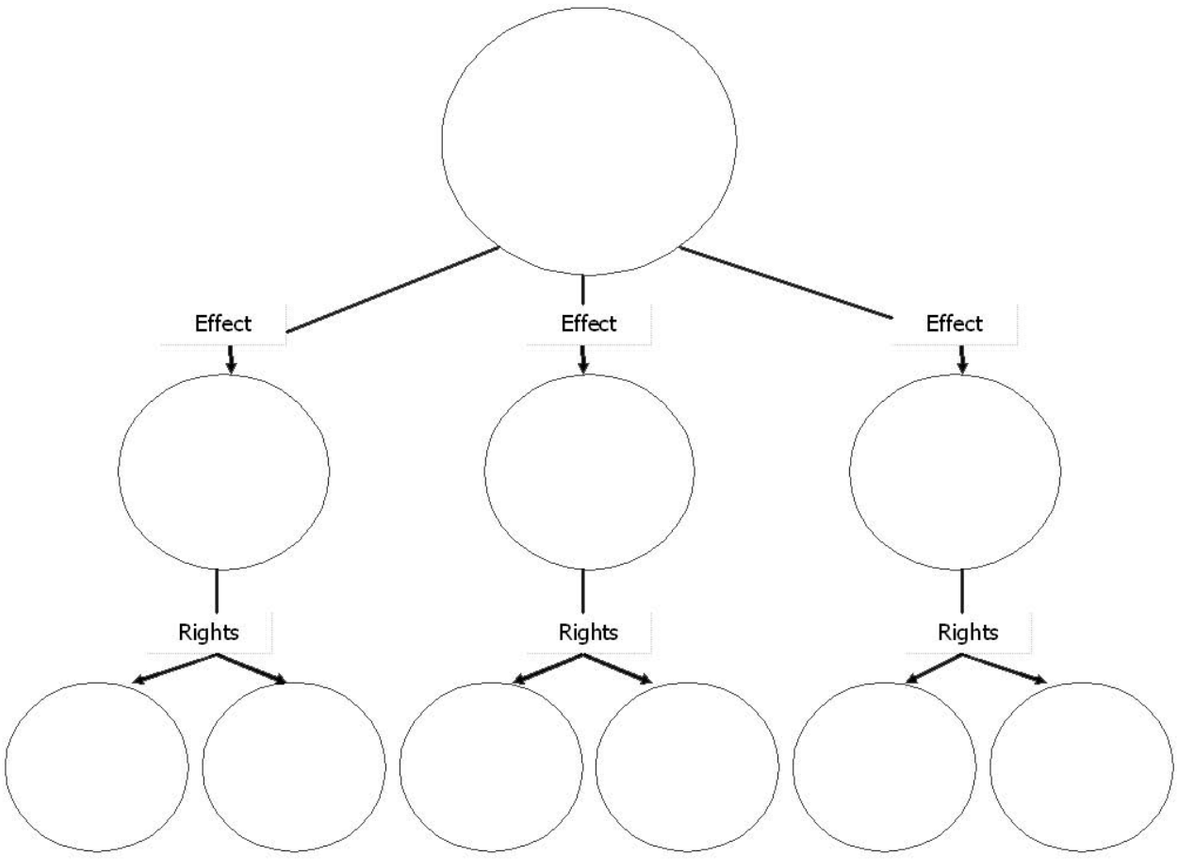
- "They cannot read or write" = Right to Education;
- "They cannot earn an adequate living" = Right to an Adequate Standard of Living;
- "They are excluded from others in their age group" = Right to Association and Right to Participate in the Community.

5. Conclude:

Conclude by emphasizing the inter-relatedness of rights. Illustrate how this works both positively as well as negatively. Take any one of the issues analyzed and do a positive Effects Cascade, showing how the realization of one right affirms other human rights.

Example: If "Women and girls with disabilities receive an equal education," the effects might be:

- "They can read and write" = Right to Education;
- "They can earn an adequate living" = Right to an Adequate Standard of Living;
- "They participate in their age group" = Right to Association and Right to Participate in the Community.



WHAT DOES INTERNATIONAL LAW HAVE TO SAY ABOUT THE RIGHTS OF WOMEN AND GIRLS WITH DISABILITIES?

International human rights law clearly establishes the right of all human beings to non-discrimination and equality. The **Universal Declaration of Human Rights** (UDHR) protects women and girls with disabilities against discrimination on account of their sex, as does the **International Covenant on Civil and Political Rights** (ICCPR).[2]

The most important specialized international human rights treaty addressing the rights of women is the **Convention on the Elimination of All Forms of Discrimination Against Women** (CEDAW).[3] While CEDAW does not specifically address the rights of women and girls with disabilities, it applies to all women and establishes important rights and obligations relating to non-discrimination in public and private spheres. The **CEDAW Committee**, the body that monitors implementation of CEDAW, issued a **General Comment** (General Recommendation No. 18 (Disabled women)[4] calling on States to include information on women and girls with disabilities in their reports to the Committee). The **Convention on the Rights of Persons with Disabilities** (CRPD) adopts a dual approach in addressing the rights of women and girls with disabilities. These may be characterized as a more general or "broad brush" approach and a more specific or "thin brush" approach.

General "Broad Brush" Approach to Gender Discrimination

The "broad brush" approach establishes general principles of equality and non-discrimination that apply to the whole of the CRPD. Equality and non-discrimination form the cornerstone upon which all human rights are constructed. At its core, recognition of human rights means accepting the notion that all human beings have equal worth and are entitled to respect for their human dignity. Thus, although the precise language differs, nearly every contemporary international human rights instrument contains a provision, usually placed at the beginning, stating that it should be applied on the basis of equality and without discrimination.

In Article 3(g), the CRPD provides that "equality between men and women" is a general principle underlying the entire treaty. This means that even if a certain provision is silent on the issue of gender equality, the principle of equality still informs the application of a treaty provision. In this way, gender equality applies across the entire CRPD.

States have both affirmative and negative duties to *respect, protect and fulfill* the provisions of the Convention. The State should always take care to *respect* women's equality in relation to men. For example, in addressing CRPD Article 13 on access to justice, the state must not do anything that favors men and further widens disparities in power between men and women in society. On the contrary, any solutions to problems identified by the Convention should *protect* the gains that women have already made in society and advance (or *fulfill*) their future goals for improving their position in society even further.

Article 6 of CRPD is somewhat unusual in that it explicitly recognizes that states have the duty to address the "multiple discriminations" facing women with disabilities. It declares that States Parties shall take all appropriate measures to ensure the full development, advancement, and empowerment of women for the purpose of guaranteeing them the exercise and enjoyment of their human rights.

2 See http://www.ohchr.org/english/law/ccpr.htm
3 See http://www.un.org/womenwatch/daw/cedaw/cedaw.htm
4 See http://www1.umn.edu/humanrts/gencomm/generl18.htm

Specific or "Thin Brush" Approach to Gender Discrimination

As a complement to a general "broad brush" equality/nondiscrimination provision, many international human rights instruments also feature very specific provisions focusing on specific issues of particular interest to certain affected populations. The CRPD adopts a "thin brush" approach with respect to exploitation, violence, and abuse.

In addressing violence, the CRPD directs the state to move far beyond the duty to *respect,* and gives specific instructions on how to *protect* and *fulfill.* Significantly, in so doing, the Convention breaks down the artificial divide between the public sphere and the private (family) sphere (sometimes referred to as the "public/private split") by recognizing specific state obligations in each sector.

In the public sector:

> States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

In the private sector:

> States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, *inter alia*, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse.

Further advancing the state's duty to protect and fulfill, with regard to violence and abuse, CRPD (art. 16, para 5) declares: "States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted."

EXERCISE 16.2 The Roots of Discrimination

Objective: To analyze causes of discrimination experienced by women and girls with disabilities
Time: 60 minutes
Materials: Copies of a Fishbone Diagram, paper and markers

1. Introduce:
Reintroduce the list of examples of discrimination used in Exercise 16.1. Explain that while the first exercise looked at the effects of discrimination, this one will analyze its causes.

2. Analyze:
Divide participants into pairs or groups and ask each to choose an example of discrimination to analyze. These may be the same groups and topics as Exercise 16.1, or both may be new. Give each pair copies of a fishbone diagram, chart paper and markers. Explain that their task

is to beak the problem down, into manageable parts. Give these instructions and introduce the fish-bone diagram, explaining that it pushes you to consider all possible causes of the problem. Illustrate how to use the diagram using a simple problem.

- **Step 1:** Identify the problem. Write down the problem in a single sentence or phrase.

- **Step 2:** What are the major factors involved? Draw lines of the spine of each factor and label it. These may involve many factions such as people, systems, equipment, external forces, attitudes, customs and cultural traditions.

- **Step 3:** Identify possible causes for each factor you consider in Step 2. Show these as smaller lines coming off the "bones" of the fish. For a large or complex problem, it may be best to break these "bones" down into sub-causes. Show these as lines coming off each cause line.

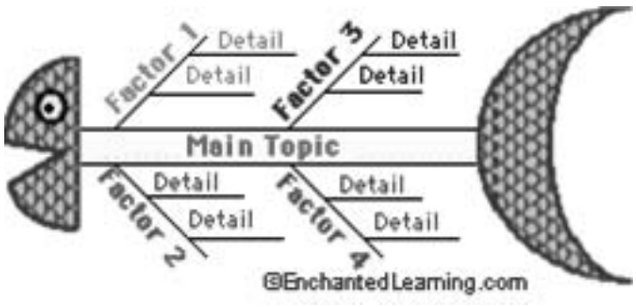
- **Step 4:** Analyze your diagram. Depending on the complexity and importance of the problem, what are some things you could do to address the problem.

Alternative: Create an outline with the problem as the heading and factors and sub-causes as sub-headings.

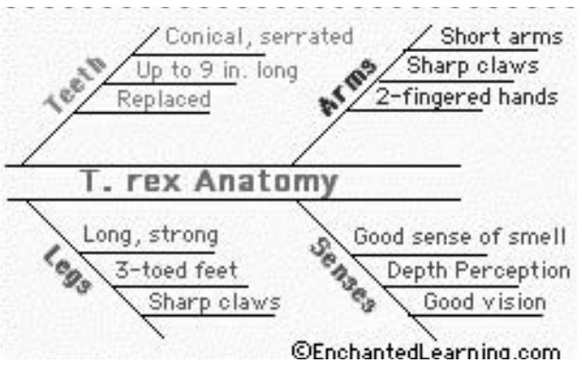
3. Report:
Ask each pair to present their diagram. At the end of each presentation, ask the whole group for additional ideas about other causes or how to address the problem.

4. Summarize:
Ask participants what common causes they observed in these different analyses. List these and discuss how these principal sources of discrimination might be addressed.

Sample Fish Diagram



Analyzing Tyrannosaurus rex Anatomy



EXERCISE 16.3: How Does the CRPD Affirm the Rights of Women and Girls to Non-discrimination and Sex Equality?

Objective: To review and understand the human rights of women and girls affirmed by the CRPD
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Review:
Divide the participants into small groups. Ask each group to work together to discuss the "broad brush" and "thin brush" approaches to nondiscrimination and sex equality undertaken by the CRPD.

2. Give examples:
Ask for examples of how the rights of women and girls with disabilities could be enjoyed and make a difference in their lives.

3. List:
List 3-5 examples vertically on a big piece of paper. Make three columns across the top labeled, "respect, protect, fulfill." Fill in the chart with examples.

4. Discuss:
How can the sex equality and nondiscrimination provisions of the CRPD be used to set national disability rights agendas and formulate platforms of action for submission to political parties or government decision-makers?

SPECIFIC FORMS OF SEX DISCRIMINATION AND INEQUALITY EXPERIENCED BY WOMEN AND GIRLS WITH DISABILITIES

Violence

Women with disabilities face high rates of violence, both at the hands of family members and of personal assistants. Caregivers can include attendants, interpreters, homemakers, drivers, doctors, nurses, teachers, social workers, psychiatrists, therapists, counselors, and workers in hospitals and other institutions. This large number of people and the intimate physical and emotional contact involved in the care they provide greatly increase the risk of abuse to persons with disabilities. Furthermore because they must often depend on caregivers, women with disabilities face even more difficulty than other women to pursue a remedy for abuse. Surveys conducted in Europe, North America, and Australia have shown that over half of all women with disabilities in those countries have experienced physical abuse, compared to one-third of women without disabilities. In the United States, research has shown children with disabilities to be almost twice as likely to experience sexual abuse as children without disabilities.

Forms of Violence Against Women and Girls with Disabilities

Violence against women with disabilities can take many forms, which can occur at the same time. It occurs not only as deliberate maltreatment and abuse, but also in the more passive form of neglect:

- **Neglect** - denial of food, lack of or inappropriate personal or medical care;
- **Physical abuse** - assault, rough or inappropriate handling, inappropriate personal or medical care, overuse of restraint, inappropriate behavior modification, overmedication, confinement;
- **Psychological abuse** - verbal abuse, intimidation, social isolation, emotional deprivation, denial of the right to make personal decisions, threat of having her children taken away;
- **Sexual abuse** - denial of a woman's sexuality, denial of sexual information/education (e.g., about birth control and childbirth), verbal harassment, unwanted sexual touching, assault, forced abortion or sterilization.[5]

Access to Rehabilitation Services

Rehabilitation services are not available to the vast majority of persons with disabilities who may benefit from them and services that do exist are very often inaccessible or unavailable to women and girls. In many war-affected countries, rehabilitation services are available only to men. In developing countries, women and girls with disabilities are far less likely to have access to orthotic and prosthetic services for a variety of reasons including lack of information, inability to travel alone for services, and lack of financial resources. (For more on the right to habilitation and rehabilitation, see Chapter 9, page 127).

Access to Essential Health Care

Women and girls with disabilities also face major barriers related to their right to basic health care. Obstacles in accessing general health care for women and girls with disabilities include discrimination and bias, lack of information, lack of transportation, and lack of respect for autonomy and privacy. In one U.S. study, 31% of disabled women were refused health care by doctors because of their disability.[6] The WHO reports that few schools of medicine, nursing, public health, dentistry, pharmacy, allied health professional or schools of social work offer any disability-related training or coursework and those that do are very narrowly focused on clinical and rehabilitation care.[7]

Right to Reproductive Health Care

Women with mental and physical disabilities must fight to participate in decisions about their health care. In many cases health workers persistently refuse of to advise disabled women and girls on appropriate family planning services and methods. All too frequently decisions are made for them, without their consultation or consent, leading to a variety of human rights abuses, including forced abortion, sterilization, and psychiatric drugging.[8] When seeking

5 Saxton, Marsha. "Curriculum on Abuse Prevention and Empowerment." *World Institute on Disability.* http://www.wid.org/programs/health-access-and-long-term-services/curriculum-on-abuse-prevention-and-empowerment-cape

6 Nosek, M.C. et al., *National Study of Women with Physical Disabilities: Final Report.* (Houston: Center for Research on Women with Disabilities, 1997).

7 *Draft Policy on Disability* (World Health Organization, Unpublished manuscript, 1999).

8 United States State Department Human Rights Report (February 2000).

reproductive health care, disabled women often face abusive treatment at the hands of physicians who do not understand their particular circumstances. A study in the USA, for example, showed that women with disabilities were significantly less likely to receive pelvic exams than non-disabled women.[9]

Right to Marry and Form a Family

Disabled women also face limitations on their rights to marry and found a family, and they often lose custody of their children. Women with disabilities may be regarded as unfit for parenting or be falsely informed that having a child would be unsafe or unwise because of their disability. In 1997, the Government of Japan acknowledged that some 16,500 women with disabilities were sterilized, without their consent, between 1949 and 1992 in order to prevent "against birth of defective descendants."[10] The Government rejected calls by the disability community for compensation on the basis that the procedures were legal according to the domestic law at the time. In some countries, it is also almost impossible for disabled women to adopt children.

Education and Literacy

The combination of discrimination on the basis of both gender and disability results in low literacy for women and girls with disabilities and poor rates of school attendance. In the U.S., women with disabilities are five times more likely than women without disabilities to have fewer than eight years of schooling. In many countries, schools are inaccessible or too far away or may exclude girls with disabilities (as well as boys) from attendance. Imagining that their girl will have little opportunities in life, parents may see little reason to send her to school. For girls with disabilities who do not attend school, information on reproductive health is even more limited, leading to the unsurprising result in the U.S. that young women with disabilities are significantly more likely to be mothers three to five years after leaving school than non-disabled young women. Studies also show that students with disabilities experience higher rates of sexual harassment in schools and that girls with disabilities face higher rates than boys with disabilities.[11]

Workplace Discrimination

The labor market does not adequately accommodate women with disabilities, nor are there sufficient laws to prevent and punish harassment, either sexual harassment or harassment on the basis of disability. According the United Nations only one quarter of women with disabilities worldwide are in the workforce. They are twice as unlikely to find work as men with disabilities.[12] Workplace harassment of employees with disabilities also is commonplace, and biases can be particularly severe with regard to people with "hidden disabilities," such as mental disabilities. Pervasive ignorance frequently leads potential employers to reject women with disabilities because they mistakenly assume that the women will not be able to fulfill job requirements or that reasonable accommodations will be extensive and costly. The unemployment rate for women with disabilities in developing countries is virtually 100%.[13]

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9 Rousso, Harilyn. *Girls and Women with Disabilities: An International Overview and Summary of Research*. (Disabilities Unlimited Consulting Services, 2000).

10 "Counter Report of the Report of the Japanese Government Made at the 26th Session of the Extraordinary Session of the Committee on Economic, Social and Cultural Rights, Geneva." 13-31 August 2001. *DPI Japan National Assembly of Disabled Peoples International*. http://homepage2.nifty.com/ADI/Counterreport.html

11 Rousso, Harilyn. *Girls and Women with Disabilities: An International Overview and Summary of Research.* (Disabilities Unlimited Consulting Services, 2000).

12 "Women and Girls with Disabilities." 2006. *Human Rights Watch.* http://hrw.org/women/disabled.html

13 "Factsheets on Women with Disabilities." *Dawn Ontario Disabled Women's Network Ontario.* http://dawn.thot.net/fact.html

Adequate Standard of Living

In countries where women are most valued for their productive and reproductive capacities, a woman with a disability will face even greater discrimination. Typically, she will be allocated the smallest amounts of food and other resources. As a result, the survival rate of girl children with disabilities is lower than that of boys. Few developing countries offer educational opportunities for girls with disabilities, and when opportunities for education exist in schools for children with disabilities, boys usually receive them. Women and girls with a disability living in urban slums face particularly extreme circumstances, lacking adequate shelter, clean water, and sanitation and exposure to high levels of gender-based violence and environmental pollution.

EXERCISE 16.4: Decision-making in the Family and Beyond

Objective: To identify decision-making power in the family and beyond
Time: 90 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Brainstorm:
Ask the full group to call out answers to the following question: *What decisions are made in the typical family?* Participants offer out their ideas without comment. Record their responses without comment.

2. Discuss:
Ask the group to comment on any differences in the decisions that men and women make. Add any of the following that are not included in the list:

- Whom to live with and according to what arrangement
- Whether to marry
- Whom to marry
- When to marry
- Whether to bear children
- When to begin bearing children and how many children to bear
- Whether to retain one's own nationality and citizenship in marriage
- Whether to adopt children and how many to adopt
- Whether to raise another persons' child outside of adoption
- Whether and when to divorce, and on what conditions
- Whether to own and control personal property, borrow money, or to open a business
- Whether to apply for paid employment, and what type of employment to enter.

3. Distribute & Analyze:
Distribute Article 6 and Article 3(g) of the CRPD and point out that it provides for women with disabilities to have equal rights and responsibilities on the basis of non-discrimination. In small groups or in pairs, ask participants to discuss the following questions and report back to the full group:

- What do the provisions in CRPD mean?
- Should there be recognition that women with disabilities may have different needs from men?
- How are these provisions followed or not followed in your community? In your family?

WOMEN WITH DISABILITIES AS ORGANIZERS

"It makes me feel proud that I belong to this worldwide group of disabled women. It also reminds me of when I was a little lonesome girl and very unhappy with my progressive disability and sad perspectives. But now I am no more lonesome and unhappy. We are now powerful, smart, effective leaders of our own movement. We have now knowledge and power and connection and hope to offer to each other. In a way, we do that whenever we meet a young disabled girl or woman and offer her a new way of facing the discrimination, with new knowledge and resources and a whole world of other strong disabled women connected and supporting each other".

Dinah Radtke
Women's Committee Chairperson
Disabled People International, 1999

Women with disabilities are not only taking active and leading voices in disability movements all over the world, they are also creating autonomous organizations and committees focused on the concerns of women with disabilities. These efforts are not without struggle. Issues crucial to women with disabilities are still seen as a small part of the struggle for independent living in most national and international disability organizations. Yet the community of women with disabilities has articulated on issues that affect it in an increasingly sophisticated manner. Women with disabilities have created goals that were included in diverse resolutions from the 1995 UN Women's Conference "Platform for Action" to individual country and organizational plans for addressing long-standing discrimination against women with disabilities. The efforts of women with disabilities coming together to mobilize around human rights issues is a significant aspect of global disability rights advocacy. (See text box).

INTERNATIONAL EFFORTS TO ADVANCE THE RIGHTS OF WOMEN WITH DISABILITIES

1995 International Symposium on Issues of Women with Disabilities, preceding the UN Fourth World Conference and NGO Forum on Women in Beijing, China, coordinated by Mobility International USA (MIUSA).

1995 Disabled Women's Caucus at the NGO Forum and the UN Fourth World Conference on Women, in Beijing, China, coordinated by an international caucus of women leaders with disabilities, calling themselves "Women's International Linkage on Disability".

1997 Mobility International USA (MIUSA) coordinated the **International Women's Institute on Leadership and Disability**, bringing together 35 women with disabilities from around the world for an intensive two-week leadership training program in the USA.

1997 The International Forum on Issues of Women with Disabilities, coordinated by the World Institute on Disability and Rehabilitation International, with support from the US Departments of Education and Health and Social Services.

1998 MIUSA International Symposium on Microcredit for Women with Disabilities, held in Eugene, Oregon, USA.

2000 MIUSA Global Options for Women with Disabilities in Leadership and Employment, held in Eugene, Oregon, USA.

2006 UN adopts Convention on the Rights of Persons with Disabilities. The efforts of the Women's Caucus secured a provision on women with disabilities in the Convention and other provisions on gender.

EXERCISE 16.5 Making a Commitment

Objective: To emphasize and examine that the human rights of women and girls with disabilities involve both rights and responsibilities.
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Action:

- Ask if after learning about the human right of women and girls with disabilities, the group members are 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 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 right of women and girls with disabilities to non-discrimination and equality.
- Record the commitments on chart or board to distribute a summary of actions to all participants after the training.

To plan 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.

USEFUL RESOURCES ON GENDER AND DISABILITY

- Disabled Women in Sport:
  http://www.feminist.org/sports/disability.html
- Disabled Women on the Web:
  http://www.disabilityhistory.org/dwa/
- International List for Women with Disabilities and Women Allies (D-Wild):
  http://groups.yahoo.com/group/d-wild/
- Organizations and Committees Concerned with Issues Affecting Women with Disabilities:
  http://www.dpi.org/en/resources/topics/women/02-11-05_orgs.htm

CHAPTER 17
THE HUMAN RIGHTS OF OTHER POPULATIONS OF PERSONS WITH DISABILITIES

UN Convention on the Rights of Persons with Disabilities

Preamble: (excerpts)
The States Parties to the present Convention…
(i) Recognizing further the diversity of persons with disabilities,
(k) Recognizing the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support,
(p) Concerned about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status,
(t) Highlighting the fact that the majority of persons with disabilities live in conditions of poverty, and in this regard recognizing the critical need to address the negative impact of poverty on persons with disabilities[.]

OBJECTIVES

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

- Understand the multiple forms of discrimination that sub-groups within the general population of persons with disabilities may face and to identify discrimination against them as a human rights issue
- Identify ways in which the human rights of these sub-groups have been promoted or denied
- Explain the importance of affording all persons with disabilities a voice in decision-making processes that concern their interests, including the participation of persons with disabilities in development decision-making
- Understand and apply the provisions on the human rights of persons with disabilities who may be subject to multiple forms of discrimination in the UN ***Convention on the Rights of Persons with Disabilities*** (CRPD)
- Highlight possible strategies to advance the rights of all persons with disabilities

GETTING STARTED: THINKING ABOUT THE HUMAN RIGHTS OF PERSONS WITH DISABILITIES WHO EXPERIENCE MULTIPLE DISCRIMINATION

In general, persons with disabilities are marginalized and face discrimination on account of their disability. Some groups of persons with disabilities face multiple or aggravated discrimination on account of their status or membership in a minority group. They experience discrimination due to their disability as well as other characteristic, situation or circumstance, such as age, social situation or health status. There are many attributes that may result in multiple or aggravated discrimination. These include, but are by no means limited to: race, color, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age, sexual minority status, poverty or other status. A person with a disability who requires intensive support may also experience such aggravated discrimination.

People with disabilities may face discrimination in a variety of life circumstances and situations. People with disabilities who are living in a humanitarian crisis, such as natural disaster or armed conflict, may experience discrimination on account of their disability and on the basis of their refugee or displaced status. Health status, for example the situation of a person with a disability who is living with HIV/AIDS or other communicable disease, may also result in discrimination.

These differences and a variety of other characteristics and circumstances should be taken into account when considering how best to ensure the human rights and fundamental freedoms of *all* persons with disabilities.

Identifying the Many Bases of Discrimination

In 2000, the Charter of Fundamental Rights of the European Union was adopted which includes, among other human rights provisions, one of the most far-reaching non-discrimination provisions in modern human rights law.

Article 21(1) provides: “Any discrimination based on any ground, such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited.”[1]

The non-discrimination provision in the Charter makes clear that discrimination on any grounds, including those specifically mentioned in the provision, as well as other grounds not mentioned in the provision, are prohibited.

1 See http://www.europarl.europa.eu/charter/default_en.htm

EXERCISE 17.1: What Does It Mean to Experience Multiple Discrimination?

Objective: To understand the effects of multiple discrimination
Time: 60 minutes
Materials: Slips of paper and pencils

1. Brainstorm:
Ask the group to list types of disabilities with which they are familiar (e.g., people with physical, sensory, learning, intellectual, and psycho-social disabilities). List these and have these written on separate slips of paper. Collect these slips in a container.

Next, ask the participants to name the groups in their community who experience discrimination (e.g., religious and racial minorities, indigenous people, immigrants and migrants, people of color, poor people, people with HIV/AIDS). List these and have them written on a slip of paper. Collect these slips in another container.

2. Imagine/Discuss:
Divide participants into small groups. Explain that each group will imagine a person with certain characteristics that they will choose at random, starting with that person's disability. Ask each group to draw a slip from the container containing types of disabilities and discuss what kinds of discrimination based on that disability their imagined person might face.

3. Imagine/Discuss:
After about five minutes, announce that in addition to having a disability, this person also has another characteristic that results in discrimination. Have each group draw a slip from the container with names of groups. Ask them to imagine and discuss what additional discrimination this person might now face.

4. Imagine/Discuss:
After another five minutes, announce that this person has another characteristic that causes discrimination and have each group draw a second slip from the container of group characteristics. Ask them to imagine and discuss what additional discrimination this person might now face.

5. Discuss:
Bring participants back together and ask a spokesperson from each group to "introduce" the person they have imagined and describe the multiple layers of discrimination that person might face.

6. Discuss/Strategize:
Discuss what steps might be taken to end the kinds of discrimination these imaginary persons face asking questions like these:

- Are some kinds of discrimination harder to address than others? Which ones? Why?
- Are some kinds of discrimination more harmful or painful than others?
- Do some kinds of discrimination have more far-reaching effects than others?
- What can be done to address multiple forms of discrimination experienced by people with disabilities?

WHAT DOES INTERNATIONAL HUMAN RIGHTS LAW SAY ABOUT THE RIGHTS OF PERSONS WITH DISABILITIES WHO EXPERIENCE MULTIPLE DISCRIMINATION?

The principle of non-discrimination is one of the most fundamental norms in human rights law. The rights of persons who face discrimination on account of their particular status are well recognized in human rights treaties. Indeed, the cornerstone of human rights protection as set forth in the **UN Charter** is its non-discrimination provision, which provides that the UN shall promote "universal respect for, and observance of, human rights and fundamental freedoms for all without distinction as to race, sex, language, or religion."[2] All major international human rights conventions contain non-discrimination provisions and build upon the principle of non-discrimination found in the UN Charter.

The **Universal Declaration of Human Rights** (UDHR) provides that:

> *Everyone is entitled to all the rights and freedoms set forth in [the UDHR] without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.*[3]

The **International Covenant on Civil and Political Rights** (ICCPR)[4] contains a non-discrimination clause mirroring that found in the UDHR, an equal rights provision between men and women, as well as a provision guaranteeing to persons belonging to ethnic, religious or linguistic minorities the rights, in community with other members of their group, to enjoy their own culture, to profess and practice their own religion, and to use their own language.

Specialized human rights conventions have been drafted in order to address in more detail the rights of populations who may face additional barriers to the enjoyment of their rights on account of their membership in a minority or particularly disadvantaged group. These include, for example, the **Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)**,[5] the **Convention on the Elimination of All Forms of Racial Discrimination (CERD)**,[6] the **Convention on the Rights of the Child (CRC)**,[7] and the **Convention on the Rights of Migrant Workers**.[8] The rights of indigenous people are addressed in **Convention concerning Indigenous and Tribal Peoples in Independent Countries (ILO No. 169)**[9], as well as the **Declaration on Rights of Indigenous Peoples**[10] adopted by the UN General Assembly in September 2007. Other population groups are similarly pressing for greater recognition of their human rights through the adoption of specialized conventions or non-binding instruments, including, for example, older persons.

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2 http://www.un.org/aboutun/charter
3 http://www.unhchr.ch/udhr/lang/eng.htm
4 http://www.ohchr.org/english/law/ccpr.htm
5 http://www.ohchr.org/english/law/cedaw.htm
6 http://www.ohchr.org/english/law/cerd.htm
7 http://www.ohchr.org/english/law/crc.htm
8 http://www.ohchr.org/english/law/cmw.htm
9 http://www.ohchr.org/english/law/indigenous/htm
10 http://www.ohchr.org/english/issues/indigenous/docs/draftdeclaration.pdf

The **CRPD,** in addition to recognizing and defining in some detail the discrimination that people with disabilities face on account of their disability, also recognizes that persons with disabilities may belong to sub-groups who face additional discrimination, beyond disability-based discrimination. Such persons may therefore be doubly disadvantaged and face additional barriers to their full enjoyment of human rights. The CRPD, in its Preamble, recognizes:

- The diversity of persons with disabilities
- The reality that some persons with disabilities require intensive supports and may therefore face additional barriers to their full enjoyment of human rights
- That certain sub-groups of persons with disabilities may be subjected to multiple or aggravated forms of discrimination on the basis of race, color, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status
- That persons with disabilities often live in poverty and that this status creates additional barriers for the full enjoyment of human rights.

All of the human rights set forth in the CRPD apply to all persons with disabilities, whatsoever their minority group membership, social situation or life circumstance of any kind. All of the general principles in the CRPD support a framework of human rights protection that was clearly intended by the drafters to cover all groups of persons with disabilities, whether or not they are expressly mentioned in the CRPD. Article 3 (General Principles) is accordingly an important tool for persons with disabilities who may experience multiple forms of discrimination to use in their advocacy. Several of the principles in Article 3 are of particular note:

The principle of non-discrimination: meaning that both disability discrimination and discrimination on other grounds are prohibited.

The principle of full and effective participation and inclusion in society: meaning that all persons with disabilities, whatever their minority or other status or circumstance are entitled to participate fully in their community and in decision-making where their interests are affected.

The principle of respect for difference and acceptance of persons with disabilities as part of human diversity and humanity: meaning that diversity in humankind, whether based on disability or other attribute, are to be respected and valued.

The principle of equality of opportunity: meaning that all persons with disabilities are entitled to equality of opportunity, whatever their minority or other status or circumstance.

The principle of equality between men and women: recognizing that persons with disabilities, whether men or women, are entitled to equality and providing an explicit basis on which to challenge double discrimination based on disability and sex.

The principle of respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities: recognizing the rights of the child and the issue of discrimination based on disability and age.

EXERCISE 17.2: What Rights of Persons with Disabilities Who Experience Multiple Discrimination Does the CRPD Affirm?

Objective: To review and understand the rights of persons with disabilities who experience multiple discrimination
Time: 30 minutes
Materials: Chart paper and markers or blackboard and chalk

1. Review:
Divide the participants into small groups. Ask each group to work together to paraphrase the paragraphs in the CRPD Preamble in common language and give some examples of how those provisions can help disadvantaged groups of persons with disabilities enjoy their human rights.

2. Paraphrase:
Read the CRPD sections above aloud and pause at each comma or natural section to ask different groups for their paraphrase. Discuss the meaning of each section until everyone can agree on a paraphrase. Write the final paraphrase on chart paper.

3. Give examples:
Ask for examples of how these provisions in CRPD could be enjoyed and make a difference for different groups of persons with disabilities who may experience multiple forms of discrimination.

4. Discuss:
How can these articles of the CRPD be used to set national disability rights agendas and formulate platforms of action for submission to political parties or government decision-makers?

PARTICIPATION IN DEVELOPMENT DECISION-MAKING FOR PERSONS WITH DISABILITIES LIVING IN POVERTY

Poverty is a status that leads to multiple disadvantage on many fronts. The United Nations estimates that one person in twenty has a disability, and that more than more than 75% of people with disabilities live in a developing country.[11] People with disabilities tend to be among the poorest of the poor. According to World Bank estimates, one of every five of the world's poorest persons is disabled.[12] Unfortunately, the multitude of barriers that limit the access of people with disabilities to education, employment, housing, health care and rehabilitation, transportation and recreation also serve to limit their participation in development planning decisions that could improve their lives. Ensuring the full participation of people with disabilities in the planning, design, implementation and evaluation of development programs is essential in order to ensure the success of poverty reduction strategies. Disabled peoples organizations and their allies are working to ensure that international development becomes more inclusive of the voices and needs of people with disabilities.

11 Helander, E. "Prejudice and Dignity; an introduction to community based rehabilitation." UNDP, 1992.
12 Elwan, Ann. "Poverty and Disability; a background paper for the World Development Report," World Bank, October 1999.

Including people with disabilities in development decision-making is critical to achieving the promise of poverty reduction and responsible development. The **CRPD** recognizes that development processes need to take into account disability issues. Article 33 stresses the important role of international cooperation for realizing the rights of people with disabilities and calls on States to take measures "[e]nsuring that international cooperation, including international development programs, is inclusive of and accessible to persons with disabilities."

International development organizations tend to emphasize that the participation of the people most directly affected by a development project must have the opportunity to participate in its planning from its earliest stage. All too often people with disabilities are left out of these efforts. The World Bank and other development actors are currently addressing this exclusion and are trying to ensure that people with disabilities participate in the various forms of development at the planning stage (see text box). It will take the active efforts of disabled peoples organizations to ensure that inclusive development is a reality.

EXERCISE 17.3: Speaking Out for Participation and Inclusion in Development Decision-making

Objective: To examine the right of people with disabilities to participate in development decision-making
Time: 60+ minutes
Materials: Chart paper and markers or blackboard and chalk

1. Brainstorm:
Ask participants to list areas where they experience barriers in participating in development decision-making in their community (e.g., with international development organizations, with local governments, with community leaders, with religious leaders). Divide participants into small groups and ask each group to choose an area of exclusion from development decision-making on which they wish to concentrate (e.g., planning of a development project, purchase of inaccessible buses, or policies on health, social welfare, or education).

2. Plan:
Ask each group to prepare a five-minute presentation to a "panel of community development leaders" on their problem. Each presentation should –

- Describe the exclusion of people with disabilities in a specific development decision-making process and identify the group of people with disabilities that it impacts and if possible the cause(s) of the problem.
- Relate the problem to the human rights of people with disabilities
- Clarify how the problem affects the lives of people with disabilities (and their families where relevant).
- Show how addressing the problem can improve their lives.
- Propose specific actions that should be taken to address the problem.
- Show how members of the community can get involved in addressing the problem.

Ask each group to choose a spokesperson to make the presentation and one or two to serve as the "panel of community development leaders." While the groups plan their presentations, the panel of leaders meets to decide on their roles, representing probable attitudes within the community leadership.

3. Role Play:
The spokesperson from each group makes a presentation and members of the panel listen and respond, asking questions and offering comments, objections or suggestions in keeping with their chosen roles.

4. Discuss:
After the presentations and role play, discuss:

- How did the spokespersons feel when presenting the problem?
- How did the "community leaders" respond to the presentation? What attitudes in the community were they representing?
- How did the audience, composed of the rest of the group, respond to the presentations?
- Did any spokesperson discuss the problem as a human rights violation? Did putting the problem in this context strengthen the argument?
- Are any of the ideas put forward feasible in your community? Why or why not?

5. Conclude:
Challenge the participants to evaluate their knowledge of the problem and inclusiveness of perspective:

- How did you obtain your information on the barriers to participation and their impact? Was it accurate and complete? If not, what additional information does you need and how can you obtain it?
- Did you consult the people with disabilities involved about problem and how it affects them? About the actions that could improve the problem?
- Why is it important in real-life human rights advocacy to include the active participation of those directly involved and affected?
- How can you apply the example of this exercise to planning and implementing advocacy for people with disabilities in your community?

PRSPs and Inclusive Development

The term Poverty Reduction Strategy Paper (PRSP) refers to an important development document devised by the World Bank and the International Monetary Fund in 1999 in order to help low-income, highly indebted countries to formulate a national plan on how to reduce poverty in their country and improve living conditions. Once a country has adopted a national PRSP, it may apply for debt relief from the World Bank, the IMF and donor countries, and may gain access to new credits, loans and grants for development projects. The PRSP provides an important roadmap for development and sets priorities for target actions to reduce poverty. This tool and others like it are used by many international development partners. The process by which PRSPs are developed are intended to be highly participatory and include a wide range of country stakeholders. A key principle of the process is the active involvement of civil society in the formulation, implementation, and evaluation of a country's national poverty reduction strategy. Unfortunately people with disabilities have too often been left out of this important process. The World Bank is working with disability organizations to improve the participation of persons with disabilities in development decision-making.[13]

13 "Making PRSP Inclusive." Jan. 2006. *Handicap International Christoffel-Blindenmission*. http://siteresources.worldbank.org/DISABILITY/Resources/280658-1172608138489/MakingPRSPInclusive.pdf

EXERCISE 17.4: Making a Commitment to Promote the Rights of People with Disabilities Who Experience Multiple Discrimination

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about the human rights of people with disabilities who experience multiple forms of discrimination, 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 rights of people with disabilities who experience multiple discrimination.

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.

ADDITIONAL RESOURCES ON THE HUMAN RIGHTS OF OTHER POPULATIONS OF PERSONS WITH DISABILITIES

- Children and Disability: http://www.un.org/esa/socdev/enable/comp501.htm
- DFID, Disability, Poverty and Development: http://www.dfid.gov.uk.pubs/files/disability.pdf
- Ethnic Minorities and Disability: http://www.un.org/esa/socdev/enable/comp507.htm
- Global Action on Aging: http://www.globalaging.org
- HelpAge International: http://www.helpage.org/Home
- Indigenous People and Disability: http://www.un.org/esa/socdev/enable/comp506.htm
- International Work Group for Indigenous Affairs: http://www.iwgia.org
- Migrant Workers and Disability: http://www.un.org/esa/socdev/enable/comp509.htm
- Older Persons and Disability: http://www.un.org/esa/socdev/enable/comp503.htm
- People Living in Poverty and Disability: http://www.un.org/esa/socdev/enable/comp508.htm
- People Living with HIV/AIDS and Disability:
- Refugees and Disability: http://www.un.org/esa/socdev/enable/comp505.htm
- World Bank, HIV/AIDS and Disability: Capturing Hidden Voices, Report of the World Bank Yale University Global Study on HIV/AIDS and Disability. (Washington, DC, 2004): http://cira.med.yale.edu/globalsurvey/
- Women and Disability: http://www.un.org/esa/socdev/enable/comp/504.htm

PART 3:

ADVOCACY!
TAKING ACTION FOR THE HUMAN RIGHTS OF PEOPLE WITH DISABILITIES

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PART 3: ADVOCACY!
TAKING ACTION FOR THE HUMAN RIGHTS OF PEOPLE WITH DISABILITIES

CONTINUING YOUR START: ADVOCACY AND ACTION

Advocacy is action to create positive change. It usually involves many people and/or organizations working together toward a shared vision for change.

The best advocates for disability rights are self-advocates, people with disabilities themselves. It takes the active and collaborative efforts of persons with disabilities and their allies to ensure that their human rights are respected and to effectively create social change.

ESSENTIALS OF ADVOCACY

Awareness of Rights

Awareness of Self

Action

AWARENESS OF RIGHTS

All people should be aware of their rights and liberties! The first two parts of this manual are intended to make you aware of the human rights that persons with disabilities are entitled to under international law, as affirmed by the **Convention on the Rights of Persons with Disabilities** (CRPD). Persons with disabilities and their allies need to be able to analyze and navigate the social and political environment within which they live from this human rights perspective. Such awareness increases consciousness and mobilizes people to take action, to advocate against discrimination, and to fight for the rights to which they are entitled.

Using a Human Rights Approach for Advocacy

A rights-based approach to disability regards the limitations placed on people with disabilities by their social and physical environments as a violation of their fundamental human rights. A right-based approach can transform the needs of people with disabilities into rights they can claim and advocate.

AWARENESS OF SELF

Self-knowledge and effective communication are key to becoming strong self-advocates. Persons with disabilities need to know their own strengths and needs, and have the ability to effectively communicate those needs when advocating for their rights. Like any skill, advocacy must be practiced and, as a result, it improves with time. Practice explaining what you need in order to access your community and enjoy your rights.

ACTION

Awareness does not create change. ACTION does!

You now have the knowledge and are building the skills to advocate successfully for your rights. *Commitment* is essential to taking action. Start with small attainable steps. Participation in disability organizations can help. It can provide an important environment to practice advocacy skills and promote a sense of belonging, identity, and connection to others who share similar life experiences.

Advocacy can be used for many purposes: for personal needs, for the needs of others with disabilities, or for the needs of the disability community as a whole. Advocacy can take place at many levels too: locally, nationally, and internationally. Examples of advocacy actions include:

Educational Action

- **Educating ourselves:** gathering the information we need to understand the issue and analyzing what we have learned;
- **Educating others:** drawing the attention of allies and the general public to an issue that needs to be addressed and showing how we want to create change;
- **Changing attitudes:** addressing stereotypes and misconceptions about a particular issue and about people with disabilities generally.

Political Action

- **Addressing policy-makers:** influencing them to consult with and include the concerns of people with disabilities when making public policies;
- **Addressing law-makers:** lobbying for supports and fulfillment of the human rights of people with disabilities;
- **Addressing public officials:** pressuring for enforcement of laws and policies that respect and protect the human rights of people with disabilities;
- **Social and community service providers:** effectively communicating for service delivery. For example: navigating the service delivery system through communication with bankers, grocers, social workers, and/or medical professionals.

Legal Action

- **Creating new law:** participating in advocacy for new laws on disability rights and taking part in the drafting of such laws. For example: advocating for comprehensive disability rights legislation consistent with international law, including the CRPD.
- **Repealing negative law:** taking action to repeal laws that stand in the way of the enjoyment of disability rights. For example: advocating to repeal discriminatory marriage laws that bar people with disabilities from exercising their right to marry.

- **Working to implement disability rights law:** For example: Taking action to highlight non-compliance with accessibility standards in new building construction, or training employers on how to provide reasonable accommodations to employees with disabilities.

Advocacy benefits from the collective action of individuals and groups working together to achieve a shared goal. Wise advocates recognize that creating lasting change takes time, especially when old attitudes and habits must be overcome. They plan and commit themselves to a sustainable, long-term effort, but they also set short-term goals and benchmarks.

Celebrate your achievements together and take care to nurture your shared vision and working relationships.

ACTION PLANS

Working collaboratively, people can create action plans that take advantage of the skills and resources each partner, whether it be another individual or an organization, has to contribute. Partners also regularly evaluate their plan in light of successes and failures, as well as unfolding events and opportunities.

Action planning can be simple, just remember the **"**WH questions":

- **What?** For example: *What type of issue is the group addressing? What type of actions are necessary?*
- **Who?** For example: *Who will take action?*
- **When?** For example: *When will the action be complete*?
- **Where?**
- **Why** and/or how? For example: *How will you obtain the financial, material, and/or human resources that may be needed to take action*?

Asking these questions will make sure that everybody understands what is going to happen next. The next step in action planning is making sure that the plan is ***feasible*** and ***reasonable***. Once you complete the action, it is important to follow-up with additional questions:

- When was the action taken?
- What happened as a result of the action?
- What are your next steps?

STEPS TOWARD ADVOCACY

STEP 1: DEFINE THE CHANGE YOU WANT TO MAKE (30 minutes)

1. Discuss/List:

- What are the main issues or barriers to the human rights of people with disabilities in your community? Brainstorm a list and record it on chart paper.
- If you could create change on any one of these issues or barriers, which would make the most difference in the lives of people with disabilities? Mark these with a star.

2. Analyze:
Ask participants to break into small groups according to the starred items that they would most like to work on. If many people want to work on the same issue or barrier, encourage several small groups rather than a single large one.

Give each group a question sheet to guide their discussions.

Handout 1

Defining the Change You Want to Make

1. What is the specific change you wish to bring about? Write this in a few sentences on chart paper.

2. Does this change involve having the right –
   - **Respected** (that is, having the right recognized, stopping people and institutions from denying or limiting the right)?
   - **Protected** (that is, having law and measures to ensure the right is not violated and prevent its violation)?
   - **Fulfilled** (that is, given sufficient recognition, funding, and other positive acts that enable and assist enjoyment of that right)?

3. Analyze possible underlying causes of the situation you wish to change. Look at each from as many perspectives as you can imagine. For example:
   - Attitudes
   - Laws
   - Society
   - Religion and culture
   - Government
   - Health care system
   - Individuals and families
   - Other perspectives?

4. Of the underlying causes identified for each challenge, which seem to be the most significant?

3. Report:
Ask each group to post and briefly explain their analysis of the change they wish to make. Ask for comments and suggestions from the whole group.

STEP 2: ARTICULATING THE CHANGE YOU WANT TO MAKE (2 hours)

1. Plan:
Once you have a clear vision of the change you want to make, you need to develop the skills to communicate your vision articulately and convincingly to others, both potential supporters and opponents.

Ask each group to prepare a five-minute presentation to a "panel of community leaders" on their chosen problem. Each presentation should try to include most of the following points

Note to Facilitator: Allow plenty of time for planning and practice. Emphasize that although some members of the group may naturally be better public speakers, everyone should participate in the planning and be able to explain their vision for change.

Handout 2

Articulating the Change You Want to Make

1. Describe the problem. If possible mention –
   - how this problem may intersect with other kinds of human rights violations many people with disabilities experience;
   - the group(s) of people with disabilities it principally affects;
   - the possible cause(s) of the problem.

2. Relate the problem to the human rights of people with disabilities, referring to specific articles of the CRPD and if possible to other human rights documents.

3. Clarify how the problem affects the lives of people with disabilities (and their families where relevant).

4. Show how addressing the problem can improve the lives of people with disabilities and the community in general.

5. Propose specific actions that should be taken to address the problem.

6. Show how members of the community can get involved in addressing the problem.

Ask each group to choose one or two spokespersons to make the presentation and two or three to serve as the "panel of community leaders." While the groups practice their presentations, the "panel of leaders" meets to decide on their roles, representing probable attitudes within the community leadership (for example, a hostile mayor, a supportive community leader, a religious authority). Alternatively, ask one or two people from each group to come together to form the panel for all presentations.

2. Role Play:
The spokesperson(s) from each group makes a presentation and members of the panel listen and respond, asking questions and offering comments, objections or suggestions in keeping with their chosen roles.

Note to Facilitator: Time the presentations carefully: most presenters have difficulty filling the full five minutes. Also limit the panel's responses in order for all groups to have sufficient time.

3. Discuss:
After the presentations and role play, discuss:

- How did the spokespersons feel when presenting the problem?
- How did the "community leaders" respond to the presentation? What attitudes in the community were they representing?
- How did the audience, composed of the rest of the group, respond to the presentations?
- Did any spokesperson discuss the problem as a human rights violation? Did putting the problem in this context strengthen the argument?
- Are these ideas for improving this specific right feasible in your community? Why or why not?

4. Conclude:
Challenge the participants to evaluate their knowledge of the problem and inclusiveness of perspective:

- How would you change your presentation in a real-life situation?
- How did you obtain your information on the barriers to participation and their impact? Was it accurate and complete? If not, what additional information do you need and how can you obtain it?
- Did you consult the people with disabilities involved about the problem and how it affects them? About the actions that could improve the problem?
- Why is it important in real-life human rights advocacy to include the active participation of those directly involved and affected?
- How can you apply the lessons learned from this exercise to planning and implementing advocacy for people with disabilities in your own community?

Emphasize that while articulating your vision for change is a critical skill for effective advocacy, it is also one that develops through practice. The more you do it, the better you get. Encourage participants to make and take opportunities to speak out about the change they want to make.

Note to Facilitator: If the technology is available, arrange to video the presentations and let the speakers privately critique their performances.

STEP 3: PREPARING FOR ACTION

A. Conducting a SWOT Analysis (45 minutes)

Now that you have articulated the change you want to make, analyze it in terms of your and your organization's strengths, weaknesses, opportunities, and threats. Write down answers to the following questions. Where appropriate feel free to modify questions:

Strengths:

- What are your advantages?
- What do you do well?
- What do other people see as your strengths?
- What unique resources do you have?

Consider strengths from your organization's and/or your personal point of view and from the point of view of the people you deal with. Do not be modest: be realistic!

Weaknesses:

- What could you improve?
- What do you do badly?
- What should you avoid?
- Where do you have fewer resources than others?
- What are others likely to see as your weaknesses?

Again, consider this from an internal and external basis: do other people seem to perceive weaknesses that you do not see? It is best to be realistic now and face any unpleasant truths as soon as possible.

Opportunities:

- What are the good opportunities facing you?
- What are the interesting trends you are aware of?
- Who are your potential allies?

Threats:

- What obstacles do you face?
- Does your group have all the required skills for the job?
- Do competitors or opponents already exist?[1]

B. Surveying the Field

1. Consider these questions about your present and future work:
   - On which of these challenges are you or others already working to change? How?
   - Does your work address the underlying causes of the situation? How?
   - Which of the identified challenges might be easily added to existing work being done by or on behalf of people with disabilities? Why?
   - Would some of these challenges for people with disabilities be especially difficult, disadvantageous, or even dangerous to address? Why?

2. Consider these questions about allies and potential allies:
   - Who are the most likely allies to support your action? Why?
   - Do you share the same goals?
   - How can your work and theirs complement and support each other?
   - What do you and/or your organization have to offer the collaboration?
   - What do you and/or your organization have to gain from the collaboration?
   - Are there potential problems with collaboration with any group?
   - How can you establish this collaboration?

1 Source: Mind Tools: http://www.mindtools.com/swot.html

C. Gathering Information

1. What statistics are available about people with disabilities in your community, your country, and in the world (for example, their numbers, ages, income levels, etc.)?
   - What additional statistics do you need to take action?

2. What laws and official policies does your country have that directly affect people with disabilities?
   - Do you consider these laws and policies to be adequate and effective?
   - Do they adequately protect the rights of people with disabilities?
   - Are these laws and policies consistently enforced and implemented? If not, why not?
   - Are further laws needed? If so, what new laws would you recommend?

3. Has your country **ratified** and is thus **legally bound** to uphold any of the international human rights **treaties** affecting people with disabilities? For more information on ratification, see the Disabled Peoples' International Ratification Toolkit: http://www.icrpd.net/ratification/en/index.htm.

4. Has your country ratified the Convention on the Rights of Persons with Disabilities (CRPD)?
   - If no, why not? What can you do to change this decision?
   - If yes, what steps has your government already taken in that direction?
   - Are any groups in your country already advocating ratification of the CRPD? What are they doing? How can you help?

5. Does your country have a national human rights commission and/or a national disability commission?[2] For more information on implementation, see the Disabled Peoples' International Implementation Toolkit: http://www.icrpd.net/implementation/en/index.htm

6. Are these institutions part of the government or independent of it, that is, part of "civil society"?
   - What, if anything, are these institutions doing to improve human rights and/or the lives of people with disabilities?
   - How can you work with these institutions to see that human rights standards are enforced for people with disabilities?
   - Find out what government ministries and agencies are working on the rights and needs of people with disabilities. Do they have disability policies and/or disability focal points?
   - Are any of these governmental bodies especially encouraging or discouraging of advocacy on the rights of people with disabilities?

2 CRPD, Article 33, obligates States Parties to "designate one or more focal points within government," and "maintain, strengthen, designate or establish" one or more independent mechanisms to "promote, protect and monitor implementation" of the Convention. Persons with disabilities and their representative organizations must be "involved and participate fully in the monitoring process."

STEP 4: MAKING YOUR ACTION PLAN

Now that you have gone through Steps 1-3, choose and complete an action planning form (pages 240-242). Choose or create one most suitable to your group and specific action. You may wish to have one action plan for actions aimed at long term goals and several others for individual, short-term actions. Remember to include a section on follow-up and evaluation.

Congratulations! You have now completed the following steps:

STEP 1: DEFINING THE CHANGE YOU WANT TO MAKE
STEP 2: ARTICULATING THE CHANGE YOU WANT TO MAKE
STEP 3: PREPARING FOR ACTION
STEP 4: MAKING YOUR ACTION PLAN

Now it is time for:

STEP 5: TAKING ACTION

Follow your action plan and use the skills you've gained to clearly address social change no matter how small the step. Give yourself a reasonable amount of time to accomplish your goal and set a date to follow-up.

STEP 6: FOLLOWING-UP

Once you have begun to take action, reconnect with your group regularly. Communicate the successes or challenges you faced when taking action. Review the following questions:

1. Did you follow the action plan? What successes did you have? What challenges did you encounter?

2. If you met your goal:
   - What factors contributed to your success?
   - How can you build on this success?
   - Should you repeat this strategy?

3. If your goal was not met:
   - What revisions need to be made to the action plan?
   - Does additional research need to be completed?
   - Are additional resources needed?

4. What are your next steps for action?
   - Do you have another action to take?

It is important to monitor and keep track of your actions. Record your progress on the action planning forms and celebrate your successes!

Working and advocating in concert with one another as individuals or organized groups is the most effective way to create social change. Collaborative work can be challenging. It requires working through conflict to achieve a consensus or agreement, but it is vital to enabling the human rights and fundamental freedoms of all.

Remember:

> *"A small group of thoughtful people could change the world. Indeed, it's the only thing that ever has."* – Margaret Mead

ADVOCACY ACTION PLAN

We recommend completing one Action Plan per meeting per group.
Action Group: _____
Date: _____

Issue	Actions	By Whom	By When	Resources needed	Date action taken	Follow-up
What type of issue is the group addressing?	What type of actions are necessary?	Who will take action?	By what date will the action be done?	What financial, material, and human resources are needed to take action?	When was the action taken?	What happened as a result of the action?

Balcazar, F.E. (2005) Advocacy action planning guide. Department of Disability and Human Development, University of Illinois at Chicago.

YOUR LOGO HERE

Advocacy Action Plan Template

We recommend completing one Action Plan per meeting per group

Action Group: _____ Date: _____

Change to Make: _____

Specific Actions: _____

By Whom: _____ By When: _____

Resources Needed: _____

Date Action Taken: _____ Follow-up: _____

Instructions

Change – What type of change do you want to make?
Actions – What types of actions are necessary?
By Whom – Who will take action?
By When – By what date will the action be done?
Resources Needed – What financial, material, and human resources are needed to take action?
Date Action Taken – When was the action taken?
Follow-up – What happened as a result of the action? Next steps?

Goals should always be:
S – Specific **M** – Measurable **A** – Achievable **R** – Realistic **T** – Time Bound

1. **Goal/Objective**. Briefly describe each goal/objective and when the goal/objective should be met or accomplished.
2. **Measurement**. How will the goal/objective be evaluated? Did you complete the action?
3. **Importance**. Rank the goal as Essential, Important, or Desirable as follows:

   Essential – required to access human rights
   Important – helpful for accessing human rights
   Desirable – asset for accessing human rights

1st Goal/Objective

Description:

Measurement:

Importance: Essential Important Desirable

2nd Goal/Objective

Description:

Measurement:

Importance: Essential Important Desirable

3rd Goal/Objective

Description:

Measurement:

Importance: Essential Important Desirable

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UNIVERSAL DECLARATION OF HUMAN RIGHTS

Adopted and proclaimed by General Assembly Resolution 217 A (III) of 10 December 1948

On December 10, 1948 the General Assembly of the United Nations adopted and proclaimed the Universal Declaration of Human Rights, the full text of which appears in the following pages. Following this historic act the Assembly called upon all Member countries to publicize the text of the Declaration and "to cause it to be disseminated, displayed, read and expounded principally in schools and other educational institutions, without distinction based on the political status of countries or territories."

PREAMBLE

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people,

Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law,

Whereas it is essential to promote the development of friendly relations between nations,

Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom,

Whereas Member States have pledged themselves to achieve, in co-operation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms,

Whereas a common understanding of these rights and freedoms is of the greatest importance for the full realization of this pledge,

Now, therefore, the General Assembly

Proclaims this Universal Declaration of Human Rights as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.

Article 1.

All human beings are born free and equal in dignity and rights.They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Article 2.

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

Article 3.
Everyone has the right to life, liberty and security of person.

Article 4.
No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

Article 5.
No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

Article 6.
Everyone has the right to recognition everywhere as a person before the law.

Article 7.
All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

Article 8.
Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.

Article 9.
No one shall be subjected to arbitrary arrest, detention or exile.

Article 10.
Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of his rights and obligations and of any criminal charge against him.

Article 11.
(1) Everyone charged with a penal offence has the right to be presumed innocent until proved guilty according to law in a public trial at which he has had all the guarantees necessary for his defence.
(2) No one shall be held guilty of any penal offence on account of any act or omission which did not constitute a penal offence, under national or international law, at the time when it was committed. Nor shall a heavier penalty be imposed than the one that was applicable at the time the penal offence was committed.

Article 12.
No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

Article 13.
(1) Everyone has the right to freedom of movement and residence within the borders of each state.
(2) Everyone has the right to leave any country, including his own, and to return to his country.

Article 14.
(1) Everyone has the right to seek and to enjoy in other countries asylum from persecution.
(2) This right may not be invoked in the case of prosecutions genuinely arising from non-political crimes or from acts contrary to the purposes and principles of the United Nations.

Article 15.
(1) Everyone has the right to a nationality.
(2) No one shall be arbitrarily deprived of his nationality nor denied the right to change his nationality.

Article 16.
(1) Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.
(2) Marriage shall be entered into only with the free and full consent of the intending spouses.
(3) The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

Article 17.
(1) Everyone has the right to own property alone as well as in association with others.
(2) No one shall be arbitrarily deprived of his property.

Article 18.
Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.

Article 19.
Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Article 20.
(1) Everyone has the right to freedom of peaceful assembly and association.
(2) No one may be compelled to belong to an association.

Article 21.
(1) Everyone has the right to take part in the government of his country, directly or through freely chosen representatives.
(2) Everyone has the right of equal access to public service in his country.
(3) The will of the people shall be the basis of the authority of government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.

Article 22.
Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

Article 23.
(1) Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.
(2) Everyone, without any discrimination, has the right to equal pay for equal work.
(3) Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.
(4) Everyone has the right to form and to join trade unions for the protection of his interests.

Article 24.
Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.

Article 25.
(1) 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.
(2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

Article 26.
(1) Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.
(2) Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace.
(3) Parents have a prior right to choose the kind of education that shall be given to their children.

Article 27.
(1) Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.
(2) Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

Article 28.
Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.

Article 29.
(1) Everyone has duties to the community in which alone the free and full development of his personality is possible.
(2) In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.

(3) These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.

Article 30.
Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.

UNIVERSAL DECLARATION OF HUMAN RIGHTS

(Plain language version)

Article 1, **Right to equality:**
You are born free and equal in rights to every other human being. You have the ability to think and to tell right from wrong. You should treat others with friendship.

Article 2, Freedom from discrimination:
You have all these human rights no matter what your race, skin colour, sex, language, religion, opinions, family background, social or economic status, birth or nationality.

Article 3, Right to life, liberty and personal security:
You have the right to live, to be free and to feel safe.

Article 4, Freedom from slavery:
Nobody has the right to treat you as a slave, and you should not make anyone your slave.

Article 5, Freedom from torture and degrading treatment:
Nobody has the right to torture, harm or humiliate you.

Article 6, **Right to recognition as a person before the law:**
You have a right to be accepted everywhere as a person according to law.

Article 7, **Right to equality before the law:**
You have a right to be protected and treated equally by the law without discrimination of any kind.

Article 8, Right to remedy by capable judges:
If your legal rights are violated, you have the right to fair and capable judges to uphold your rights.

Article 9, Freedom from arbitrary arrest and exile:
Nobody has the right to arrest you, put you in prison or to force you out of your country without good reasons.

Article 10, Right to fair public hearing:
If you are accused of a crime, you have the right to a fair and public hearing.

Article 11, **Right to be considered innocent until proven guilty:**
1) You should be considered innocent until it can be proved in a fair trial that you are guilty.
2) You cannot be punished for doing something that was not considered a crime at the time you did it.

Article 12, Freedom from interference with privacy, family, home and correspondence:
You have the right to be protected if someone tries to harm your good name or enter your house, open your letters or email or bother you or your family without good reason.

Article 13, **Right to free movement:**
1) You have the right to come and go as you wish within your country.

2) You have the right to leave your country to go to another one, and you should be able to return to your country if you want.

Article 14, Right to protection in another country:
1) If someone threatens to hurt you, you have the right to go to another country and ask for protection as a refugee.
2) You lose this right if you have committed a serious crime.

Article 15, Right to a nationality and the freedom to change it:
1) You have the right to belong to a country and have a nationality.
2) No one can take away your nationality without a good reason. You have a right to change your nationality if you wish.

Article 16, Right to marriage and family:
1) When you are legally old enough, you have the right to marry and have a family without any limitations based on your race, country or religion. Both partners have the same rights when they are married and also when they are separated.
2) Nobody should force you to marry.
3) The family is the basic unit of society, and government should protect it.

Article 17, Right to own property:
1) You have the right to own things.
2) Nobody has the right to take these things from you without a good reason

Article 18, Freedom of thought, conscience and religion:
You have the right to your own thoughts and to believe in any religion. You are free to practice your religion or beliefs and also to change them.

Article 19, Freedom of opinion and information:
You have the right to hold and express your own opinions. You should be able to share your opinions with others, including people from other countries, through any means of communication.

Article 20, Right to peaceful assembly and association:
1) You have the right to meet peacefully with other people.
2) No one can force you belong to a group.

Article 21, Right to participate in government and elections:
1) You have the right to participate in your government, either by holding an office or by electing someone to represent you.
2) You and every one have the right to serve your country.
3) Governments should be elected regularly by fair and secret voting.

Article 22, Right to social security:
The society you live in should provide you with social security and the rights necessary for your dignity and development.

Article 23, Right to desirable work and to join trade unions:
1) You have the right to work, to choose your work and to work in good conditions.
2) People who do the same work should get the same pay.
3) You should be able to earn a salary that allows you to live and support your family.
4) All people who work have the right to join together in unions to defend their interests.

Article 24, Right to rest and leisure:
You have the right to rest and free time. Your workday should not be too long, and you should be able to take regular paid holidays.

Article 25, Right to adequate living standard:
1) You have the right to the things you and your family need for your health and well-being, including food, clothing, housing, medical care and other social services. You have a right to help if you are out of work or unable to work.
2) Mothers and children should receive special care and help.

Article 26, Right to education:
1) You have the right to go to go to school. Primary schooling should be free and required. You should be able to learn a profession or continue your studies as far as you can.
2) At school, you should be able to develop all your talents and learn to respect others, whatever their race, religion or nationality.
3) Your parents should have a say in the kind of education you receive.

Article 27, Right to participate in the cultural life of community:
1) You have the right to participate in the traditions and learning of your community, to enjoy the arts and to benefit from scientific progress.
2) If you are an artist, writer or scientist, your work should be protected and you should be able to benefit from it.

Article 28, Right to a social order:
You have a right to the kind of world where you and all people can enjoy these rights and freedoms.

Article 29, Responsibilities to the community
1) Your personality can only fully develop within your community, and you have responsibilities to that community.
2) The law should guarantee human rights. It should allow everyone to respect others and to be respected.
3) These rights and freedoms should support the purposes and principles of the United Nations.

Article 30, Freedom from interference in these human rights:
No person, group or government anywhere in the world should do anything to destroy these rights.

Source: *Compasito - manual on human rights education for children* (Council of Europe, 2007).

UNIVERSAL DECLARATION OF HUMAN RIGHTS
(Summary)

Article 1
Right to Equality

Article 2
Freedom from Discrimination

Article 3
Right to Life, Liberty, and Personal Security

Article 4
Freedom from Slavery

Article 5
Freedom from Torture and Degrading Treatment

Article 6
Right to Recognition as a Person before the Law

Article 7
Right to Equality before the Law

Article 8
Right to Remedy by Competent Tribunal

Article 9
Freedom from Arbitrary Arrest and Exile

Article 10
Right to Fair Public Hearing

Article 11
Right to be Considered Innocent until Proven Guilty

Article 12
Freedom from Interference with Privacy, Family, Home and Correspondence

Article 13
Right to Free Movement in and out of the Country

Article 14
Right to Asylum in other Countries from Persecution

Article 15
Right to a Nationality and the Freedom to Change It

Article 16
Right to Marriage and Family

Article 17
Right to Own Property

Article 18
Freedom of Belief and Religion

Article 19
Freedom of Opinion and Information

Article 20
Right of Peaceful Assembly and Association

Article 21
Right to Participate in Government and in Free Elections

Article 22
Right to Social Security

Article 23
Right to Desirable Work and to Join Trade Unions

Article 24
Right to Rest and Leisure

Article 25
Right to Adequate Living Standard

Article 26
Right to Education

Article 27
Right to Participate in the Cultural Life of Community

Article 28
Right to a Social Order that Articulates this Document

Article 29
Community Duties Essential to Free and Full Development

Article 30
Freedom from State or Personal Interference in the above Rights

CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

(Adopted by the UN General Assembly 13 December 2006;

opened for signature 30 March 2007)

Preamble

The States Parties to the present Convention,

(a) *Recalling* the principles proclaimed in the Charter of the United Nations which recognize the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world,

(b) *Recognizing* that the United Nations, in the Universal Declaration of Human Rights and in the International Covenants on Human Rights, has proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind,

(c) *Reaffirming* the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination,

(d) *Recalling* the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the Convention on the Rights of the Child, and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families,

(e) *Recognizing* that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,

(f) *Recognizing* the importance of the principles and policy guidelines contained in the World Programme of Action concerning Disabled Persons and in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in influencing the promotion, formulation and evaluation of the policies, plans, programmes and actions at the national, regional and international levels to further equalize opportunities for persons with disabilities,

(g) *Emphasizing* the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development,

(h) *Recognizing also* that discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person,

(i) *Recognizing further* the diversity of persons with disabilities,

(j) *Recognizing* the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support,

(k) *Concerned* that, despite these various instruments and undertakings, persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world,

(l) *Recognizing* the importance of international cooperation for improving the living conditions of persons with disabilities in every country, particularly in developing countries,

(m) *Recognizing* the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty,

(n) *Recognizing* the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices,

(o) *Considering* that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them,

(p) *Concerned* about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status,

(q) *Recognizing* that women and girls with disabilities are often at greater risk, both within and outside the home of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation,

(r) *Recognizing* that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child,

(s) *Emphasizing* the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities,

(t) *Highlighting* the fact that the majority of persons with disabilities live in conditions of poverty, and in this regard recognizing the critical need to address the negative impact of poverty on persons with disabilities,

(u) *Bearing in mind* that conditions of peace and security based on full respect for the purposes and principles contained in the Charter of the United Nations and observance of applicable human rights instruments are indispensable for the full protection of persons with disabilities, in particular during armed conflicts and foreign occupation,

(v) *Recognizing* the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms,

(w) *Realizing* that the individual, having duties to other individuals and to the community to which he or she belongs, is under a responsibility to strive for the promotion and observance of the rights recognized in the International Bill of Human Rights,

(x) *Convinced* that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities,

(y) *Convinced* that a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities will make a significant contribution to redressing the profound social disadvantage of persons with disabilities and promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities, in both developing and developed countries,

Have agreed as follows :

Article 1, Purpose
The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Article 2, Definitions
For the purposes of the present Convention:

"Communication" includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology;

"Language" includes spoken and signed languages and other forms of non-spoken languages;

"Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation;

"Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;

"Universal design" means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

Article 3, General principles
The principles of the present Convention shall be:
(a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
(b) Non-discrimination;
(c) Full and effective participation and inclusion in society;
(d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

(e) Equality of opportunity;
(f) Accessibility;
(g) Equality between men and women;
(h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Article 4, General obligations

1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:
(a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;
(b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
(c) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;
(d) To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;
(e) To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;
(f) To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;
(g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;
(h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;
(i) To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.

2. With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.

3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

4. Nothing in the present Convention shall affect any provisions which are more conducive to

the realization of the rights of persons with disabilities and which may be contained in the law of a State Party or international law in force for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent.

5. The provisions of the present Convention shall extend to all parts of federal states without any limitations or exceptions.

Article 5, Equality and non-discrimination

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

Article 6, Women with disabilities

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.

2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

Article 7, Children with disabilities

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Article 8, Awareness-raising

1. States Parties undertake to adopt immediate, effective and appropriate measures:

(a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
(b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
(c) To promote awareness of the capabilities and contributions of persons with disabilities.

2. Measures to this end include:
(a) Initiating and maintaining effective public awareness campaigns designed:
(i) To nurture receptiveness to the rights of persons with disabilities;
(ii) To promote positive perceptions and greater social awareness towards persons with disabilities;
(iii) To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;
(b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;
(c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;
(d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.

Article 9, Accessibility
1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to 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, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:
(a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
(b) Information, communications and other services, including electronic services and emergency services.

2. States Parties shall also take appropriate measures to:
(a) Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
(b) Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
(c) Provide training for stakeholders on accessibility issues facing persons with disabilities;
(d) Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;
(e) Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
(f) Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
(g) Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
(h) Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

Article 10, Right to life
States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

Article 11, Situations of risk and humanitarian emergencies
States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

Article 12, Equal recognition before the law
1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Article 13, Access to justice
1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

Article 14, Liberty and security of the person
1. States Parties shall ensure that persons with disabilities, on an equal basis with others:

(a) Enjoy the right to liberty and security of person;
(b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.

2. States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation.

Article 15, Freedom from torture or cruel, inhuman or degrading treatment or punishment

1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.

2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

Article 16, Freedom from exploitation, violence and abuse

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.

3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.

4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Article 17, Protecting the integrity of the person
Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

Article 18, Liberty of movement and nationality
1. States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including by ensuring that persons with disabilities:
(a) Have the right to acquire and change a nationality and are not deprived of their nationality arbitrarily or on the basis of disability;
(b) Are not deprived, on the basis of disability, of their ability to obtain, possess and utilize documentation of their nationality or other documentation of identification, or to utilize relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement;
(c) Are free to leave any country, including their own;
(d) Are not deprived, arbitrarily or on the basis of disability, of the right to enter their own country.

2. Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.

Article 19, Living independently and being included in the community
States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:
(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 20, Personal mobility
States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:
(a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
(b) Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
(c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;
(d) Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.

Article 21, Freedom of expression and opinion, and access to information
States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:
(a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;
(b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;
(c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
(d) Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;
(e) Recognizing and promoting the use of sign languages.

Article 22, Respect for privacy
1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.

2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

Article 23, Respect for home and the family
1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:
(a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
(b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;
(c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide

early and comprehensive information, services and support to children with disabilities and their families.

4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

Article 24, Education

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning directed to:
(a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
(b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
(c) Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:
(a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
(b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
(c) Reasonable accommodation of the individual's requirements is provided;
(d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
(e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:
(a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
(b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;
(c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign

language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to 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.

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.

Article 27, Work and employment
1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:
(a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;
(b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;
(c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;
(d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;
(e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;
(f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;
(g) Employ persons with disabilities in the public sector;
(h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;
(i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;
(j) Promote the acquisition by persons with disabilities of work experience in the open labour market;
(k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

Article 28, Adequate standard of living and social protection
1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take

appropriate steps to safeguard and promote the realization of this right, including measures:
(a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;
(b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;
(c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;
(d) To ensure access by persons with disabilities to public housing programmes;
(e) To ensure equal access by persons with disabilities to retirement benefits and programmes.

Article 29, Participation in political and public life
States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake to:
(a) Ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:
(i) Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;
(ii) Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;
(iii) Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;
(b) Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:
(i) Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;
(ii) Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

Article 30, Participation in cultural life, recreation, leisure and sport
1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:
(a) Enjoy access to cultural materials in accessible formats;
(b) Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;
(c) Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.

2. States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only

for their own benefit, but also for the enrichment of society.
3. States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials.

4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

5. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures:
(a) To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;
(b) To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;
(c) To ensure that persons with disabilities have access to sporting, recreational and tourism venues;
(d) To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;
(e) To ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.

Article 31, Statistics and data collection
1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:
(a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;
(b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Article 32, International cooperation
1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:
(a) Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;

(b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;
(c) Facilitating cooperation in research and access to scientific and technical knowledge;
(d) Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.

2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.

Article 33, National implementation and monitoring
1. States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.

2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.

3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

Article 34, Committee on the Rights of Persons with Disabilities
1. There shall be established a Committee on the Rights of Persons with Disabilities (hereafter referred to as “the Committee”), which shall carry out the functions hereinafter provided.

2. The Committee shall consist, at the time of entry into force of the present Convention, of twelve experts. After an additional sixty ratifications or accessions to the Convention, the membership of the Committee shall increase by six members, attaining a maximum number of eighteen members.

3. The members of the Committee shall serve in their personal capacity and shall be of high moral standing and recognized competence and experience in the field covered by the present Convention. When nominating their candidates, States Parties are invited to give due consideration to the provision set out in article 4.3 of the present Convention.

4. The members of the Committee shall be elected by States Parties, consideration being given to equitable geographical distribution, representation of the different forms of civilization and of the principal legal systems, balanced gender representation and participation of experts with disabilities.

5. The members of the Committee shall be elected by secret ballot from a list of persons nominated by the States Parties from among their nationals at meetings of the Conference of States Parties. At those meetings, for which two thirds of States Parties shall constitute a quorum, the persons elected to the Committee shall be those who obtain the largest number

of votes and an absolute majority of the votes of the representatives of States Parties present and voting.

6. The initial election shall be held no later than six months after the date of entry into force of the present Convention. At least four months before the date of each election, the Secretary-General of the United Nations shall address a letter to the States Parties inviting them to submit the nominations within two months. The Secretary-General shall subsequently prepare a list in alphabetical order of all persons thus nominated, indicating the State Parties which have nominated them, and shall submit it to the States Parties to the present Convention.

7. The members of the Committee shall be elected for a term of four years. They shall be eligible for re-election once. However, the term of six of the members elected at the first election shall expire at the end of two years; immediately after the first election, the names of these six members shall be chosen by lot by the chairperson of the meeting referred to in paragraph 5 of this article.

8. The election of the six additional members of the Committee shall be held on the occasion of regular elections, in accordance with the relevant provisions of this article.

9. If a member of the Committee dies or resigns or declares that for any other cause she or he can no longer perform her or his duties, the State Party which nominated the member shall appoint another expert possessing the qualifications and meeting the requirements set out in the relevant provisions of this article, to serve for the remainder of the term.

10. The Committee shall establish its own rules of procedure.

11. The Secretary-General of the United Nations shall provide the necessary staff and facilities for the effective performance of the functions of the Committee under the present Convention, and shall convene its initial meeting.

12. With the approval of the General Assembly, the members of the Committee established under the present Convention shall receive emoluments from United Nations resources on such terms and conditions as the Assembly may decide, having regard to the importance of the Committee's responsibilities.

13. The members of the Committee shall be entitled to the facilities, privileges and immunities of experts on mission for the United Nations as laid down in the relevant sections of the Convention on the Privileges and Immunities of the United Nations.

Article 35, Reports by States Parties

1. Each State Party shall submit to the Committee, through the Secretary-General of the United Nations, a comprehensive report on measures taken to give effect to its obligations under the present Convention and on the progress made in that regard, within two years after the entry into force of the present Convention for the State Party concerned.

2. Thereafter, States Parties shall submit subsequent reports at least every four years and further whenever the Committee so requests.

3. The Committee shall decide any guidelines applicable to the content of the reports.

4. A State Party which has submitted a comprehensive initial report to the Committee need not, in its subsequent reports, repeat information previously provided. When preparing reports to the Committee, States Parties are invited to consider doing so in an open and transparent process and to give due consideration to the provision set out in article 4.3 of the present Convention.

5. Reports may indicate factors and difficulties affecting the degree of fulfilment of obligations under the present Convention.

Article 36, Consideration of reports

1. Each report shall be considered by the Committee, which shall make such suggestions and general recommendations on the report as it may consider appropriate and shall forward these to the State Party concerned. The State Party may respond with any information it chooses to the Committee. The Committee may request further information from States Parties relevant to the implementation of the present Convention.

2. If a State Party is significantly overdue in the submission of a report, the Committee may notify the State Party concerned of the need to examine the implementation of the present Convention in that State Party, on the basis of reliable information available to the Committee, if the relevant report is not submitted within three months following the notification. The Committee shall invite the State Party concerned to participate in such examination. Should the State Party respond by submitting the relevant report, the provisions of paragraph 1 of this article will apply.

3. The Secretary-General of the United Nations shall make available the reports to all States Parties.

4. States Parties shall make their reports widely available to the public in their own countries and facilitate access to the suggestions and general recommendations relating to these reports.

5. The Committee shall transmit, as it may consider appropriate, to the specialized agencies, funds and programmes of the United Nations, and other competent bodies, reports from States Parties in order to address a request or indication of a need for technical advice or assistance contained therein, along with the Committee's observations and recommendations, if any, on these requests or indications.

Article 37, Cooperation between States Parties and the Committee

1. Each State Party shall cooperate with the Committee and assist its members in the fulfilment of their mandate.

2. In its relationship with States Parties, the Committee shall give due consideration to ways and means of enhancing national capacities for the implementation of the present Convention, including through international cooperation.

Article 38, Relationship of the Committee with other bodies

In order to foster the effective implementation of the present Convention and to encourage international cooperation in the field covered by the present Convention:
(a) The specialized agencies and other United Nations organs shall be entitled to be represented at the consideration of the implementation of such provisions of the present

Convention as fall within the scope of their mandate. The Committee may invite the specialized agencies and other competent bodies as it may consider appropriate to provide expert advice on the implementation of the Convention in areas falling within the scope of their respective mandates. The Committee may invite specialized agencies and other United Nations organs to submit reports on the implementation of the Convention in areas falling within the scope of their activities;

(b) The Committee, as it discharges its mandate, shall consult, as appropriate, other relevant bodies instituted by international human rights treaties, with a view to ensuring the consistency of their respective reporting guidelines, suggestions and general recommendations, and avoiding duplication and overlap in the performance of their functions.

Article 39, Report of the Committee
The Committee shall report every two years to the General Assembly and to the Economic and Social Council on its activities, and may make suggestions and general recommendations based on the examination of reports and information received from the States Parties. Such suggestions and general recommendations shall be included in the report of the Committee together with comments, if any, from States Parties.

Article 40, Conference of States Parties
1. The States Parties shall meet regularly in a Conference of States Parties in order to consider any matter with regard to the implementation of the present Convention.

2. No later than six months after the entry into force of the present Convention, the Conference of the States Parties shall be convened by the Secretary-General of the United Nations. The subsequent meetings shall be convened by the Secretary-General of the United Nations biennially or upon the decision of the Conference of States Parties.

Article 41, Depositary
The Secretary-General of the United Nations shall be the depositary of the present Convention.

Article 42, Signature
The present Convention shall be open for signature by all States and by regional integration organizations at United Nations Headquarters in New York as of 30 March 2007.

Article 43, Consent to be bound
The present Convention shall be subject to ratification by signatory States and to formal confirmation by signatory regional integration organizations. It shall be open for accession by any State or regional integration organization which has not signed the Convention.

Article 44, Regional integration organizations
1. “Regional integration organization” shall mean an organization constituted by sovereign States of a given region, to which its member States have transferred competence in respect of matters governed by this Convention. Such organizations shall declare, in their instruments of formal confirmation or accession, the extent of their competence with respect to matters governed by this Convention. Subsequently, they shall inform the depositary of any substantial modification in the extent of their competence.

2. References to “States Parties” in the present Convention shall apply to such organizations within the limits of their competence.
3. For the purposes of article 45, paragraph 1, and article 47, paragraphs 2 and 3, any instrument deposited by a regional integration organization shall not be counted.

4. Regional integration organizations, in matters within their competence, may exercise their right to vote in the Conference of States Parties, with a number of votes equal to the number of their member States that are Parties to this Convention. Such an organization shall not exercise its right to vote if any of its member States exercises its right, and vice versa.

Article 45, Entry into force
1. The present Convention shall enter into force on the thirtieth day after the deposit of the twentieth instrument of ratification or accession.

2. For each State or regional integration organization ratifying, formally confirming or acceding to the Convention after the deposit of the twentieth such instrument, the Convention shall enter into force on the thirtieth day after the deposit of its own such instrument.

Article 46, Reservations
1. Reservations incompatible with the object and purpose of the present Convention shall not be permitted.

2. Reservations may be withdrawn at any time.

Article 47, Amendments
1. Any State Party may propose an amendment to the present Convention and submit it to the Secretary-General of the United Nations. The Secretary-General shall communicate any proposed amendments to States Parties, with a request to be notified whether they favour a conference of States Parties for the purpose of considering and deciding upon the proposals. In the event that, within four months from the date of such communication, at least one third of the States Parties favour such a conference, the Secretary-General shall convene the conference under the auspices of the United Nations. Any amendment adopted by a majority of two thirds of the States Parties present and voting shall be submitted by the Secretary-General to the General Assembly for approval and thereafter to all States Parties for acceptance.

2. An amendment adopted and approved in accordance with paragraph 1 of this article shall enter into force on the thirtieth day after the number of instruments of acceptance deposited reaches two thirds of the number of States Parties at the date of adoption of the amendment. Thereafter, the amendment shall enter into force for any State Party on the thirtieth day following the deposit of its own instrument of acceptance. An amendment shall be binding only on those States Parties which have accepted it.

3. If so decided by the Conference of States Parties by consensus, an amendment adopted and approved in accordance with paragraph 1 of this article which relates exclusively to articles 34, 38, 39 and 40 shall enter into force for all States Parties on the thirtieth day after the number of instruments of acceptance deposited reaches two thirds of the number of States Parties at the date of adoption of the amendment.

Article 48, Denunciation
A State Party may denounce the present Convention by written notification to the Secretary-General of the United Nations. The denunciation shall become effective one year after the date of receipt of the notification by the Secretary-General.

Article 49, Accessible format
The text of the present Convention shall be made available in accessible formats.

Article 50, Authentic texts
The Arabic, Chinese, English, French, Russian and Spanish texts of the present Convention shall be equally authentic.

In witness thereof the undersigned plenipotentiaries, being duly authorized thereto by their respective Governments, have signed the present Convention.

CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES
(Unofficial Plain-language Version)

PREAMBLE

The countries that agree to this document recognize:

a. The founding documents of the UN say that we are all equal and we are all members of the human family. This is important for freedom, justice, and peace in the world,
b. We are all equal, and all of us have the same human rights,
c. All human beings everywhere in the world have all human rights. These rights cannot be divided. People with disabilities must enjoy all human rights and fundamental freedoms, and they must not be discriminated against,
d. There are seven other international agreements that promote and protect human rights,
e. Disability is something that changes all the time. It is the environment and people's attitudes that create disability,
f. It is important to keep in mind what the Standard Rules and the World Programme of Action concerning Disabled Persons are trying to achieve when trying to make laws, rules, decisions, programs, and practice better for people with disabilities,
g. It is very important to make sure that the situation of people with disabilities is always equally taken into consideration when governments and international organizations make plans about a country's growth (for example, about how to get people out of poverty or get them jobs),
h. When someone discriminates against people with disabilities, he or she takes away their dignity and value as human beings,
i. There are many differences among people with disabilities,
j. All people with disabilities must have their rights, including people with disabilities who need extra support,
k. The rights of people with disabilities are still being taken away, even though there are agreements that protect their rights,
l. It is important that countries work with one another to make life better for people with disabilities, especially in poor countries,
m. If people with disabilities are fully included and enjoy their rights, they help make their countries better,
n. It is very important that people with disabilities are free to make their own decisions,
o. People with disabilities should be included in the making of policies and programs, especially those that are directly related to them,
p. People with disabilities are not only discriminated against because of their disabilities, but also for many other reasons, including their race and sex.
q. Women and girls with disabilities are more often abused, beaten, injured, or taken advantage of,
r. Children with disabilities have the same rights as all other children, and that the international agreement on children's rights also applies to them,
s. It is important for a country to consider the situations of both women and men in everything it does for the human rights of people with disabilities,
t. It is also very important to remember that most people with disabilities are poor, and it is necessary to find out how their poverty affects them,
u. We must have peace and security to make sure people with disabilities can have their rights, especially when they live in war zones or in countries that are not run by their own government,

v. It is very important for people with disabilities to be able to enjoy all areas of life, to have good health care, to go to school, and to have the information they need so that they can use their rights,
w. Every person has the duty to make sure everyone else enjoys his or her rights,
x. The family is the main group in a society, and people with disabilities and their families should get the protection and help they need to be able to work for their human rights,
y. An Agreement that covers all areas of life will be very helpful in making lives of people with disabilities better and in making sure that people with disabilities are treated equally and equally included in all areas of life, and in poor and richer countries.

Because of all the things listed here, the countries that decide to be part of this Agreement agree to the following:

ARTICLE 1: PURPOSE

This Agreement is made is to make sure that

- the human rights and freedoms of all people with disabilities are enjoyed, promoted, and protected;
- respect for the dignity of people with disabilities is promoted.

People with disabilities include those who have long-term impairments (for example, physical, psycho-social, intellectual) and who are not included in society for different reasons (for example, because of barriers like attitudes, language, physical barriers, laws).

ARTICLE 2: DEFINITIONS

"Communication" means all the ways that people can communicate (for example, spoken language, sign language, text, Braille, touch, large print, written, audio, plain language, human reader).

"Language" means all kinds of languages (for example, spoken, signed, and types of language that are not spoken).

"Discrimination on the basis of disability" means a person may be excluded, shut out, or prevented from doing things because of their disability. This discrimination can be in all areas of life.

"Reasonable Accommodation" means that a person may need to have changes made so they are able to enjoy their rights (for example, changes where they live or work). If some changes are too expensive or too difficult, then they may not have to be made.

"Universal Design" means that things are made, programs created, and places designed so that they can be used by all people. Sometimes someone with a particular type of disability may need something specially made so they can enjoy their rights.

ARTICLE 3: GENERAL PRINCIPLES

This Agreement is based on these principles:

- Dignity
- Ability to choose
- Independence
- Non-discrimination
- Participation
- Full inclusion

- Respect for difference
- Acceptance of people with disabilities as part of humanity
- Equality of opportunity
- Accessibility
- Equality of men and women
- Respect for children.

ARTICLE 4: GENERAL OBLIGATIONS

1. The countries that agree to this Agreement promise to make sure that all human rights apply to all people, without discrimination because of disability. To fulfill this promise, they will:
    a. Make new laws, policies, and practices in their country that are like those in this Agreement;
    b. Change or get rid of old rules, laws, and customs that discriminate against people with disabilities;
    c. Make sure that the human rights of people with disabilities are included in all policies and programs;
    d. Not do anything that goes against this Agreement, and make sure others respect the Agreement;
    e. Take action to stop individuals, organizations, or businesses from discriminating because of disability;
    f. Work on developing and making available affordable goods, services, equipment, and facilities that people with disabilities all over the world can use;
    g. Work on developing affordable new technologies in all aspects of life that are useful for people with disabilities;
    h. Provide information about all types of assistance, including technologies, in a way that all people with disabilities can understand;
    i. Promote trainings about the rights in this Agreement for those who work with people with disabilities.
2. Put into practice laws and rules that relate to economic, social, and cultural rights as much as they can with resources they have. If need be, they can cooperate with other countries to put these rights into practice. All other rights must be put into practice right away.
3. When making laws and rules about this Agreement, the countries will talk to and involve people with disabilities, including children with disabilities, through the organizations that represent them.
4. Not let this Agreement change any laws or rules that are better for the rights of people with disabilities. Countries must not use the Agreement as an excuse to not put into practice human rights that already exist.
5. Apply this Agreement to the country as a whole.

ARTICLE 5: EQUALITY AND NON-DISCRIMINATION

1. All people with disabilities are equal before the law and protected by the law without any discrimination.

2. Discrimination because of a disability will not be allowed and people with disabilities will be protected from such discrimination.

3. If a person with a disability needs changes made to his or her environment in order to enjoy his or her rights, then those changes will be made.

4. If people with disabilities need special actions in order to become equal to others, this

type of treatment is not unfair to others.

ARTICLE 6: WOMEN WITH DISABILITIES

1. Women and girls with disabilities face many kinds of discrimination. Countries will make sure girls and women enjoy full and equal human rights and freedoms.

2. Countries will take action to support the growth and empowerment of women with disabilities so that they can use and enjoy their rights.

ARTICLE 7: CHILDREN WITH DISABILITIES

1. Children with disabilities have the same rights as other children.

2. Anything concerning children with disabilities must be done for the good of the child.

3. Children with disabilities have the right to give their opinions and have their opinions listened to. Children with disabilities should get the help they need to give their opinions.

ARTICLE 8: AWARENESS-RAISING

1. The countries will:
   a. Help families and all people in society be more aware of the issues facing people with disabilities. They will work to make sure that the rights and dignity of people with disabilities are respected;
   b. Fight against stereotypes and prejudices about people with disabilities; (Stereotypes are general and incorrect beliefs that some people have about other people. These beliefs are often damaging and lead to discrimination.)
   c. Help everyone be aware what people with disabilities can do and how they can help the country grow.

2. The countries will also:
   a. Make everyone aware of the rights of people with disabilities:
      I. Show that people with disabilities have the same rights as everyone else;
      II. Highlight disability in the community and change misunderstandings about disability;
      III. Show the skills of people with disabilities and how they can be put to use.
   b. Make sure that schools teach respect for the rights of people with disabilities;
   c. Encourage media (for example, radio, television, newspapers and magazines) to show images of people with disabilities that promote the rights of people with disabilities;
   d. Promote training programs to make people aware of the rights of people with disabilities.

ARTICLE 9: ACCESSIBILITY

1. The countries will get rid of barriers that people with disabilities face. This way people with disabilities can live independently and fully live their lives.

   The countries will get rid of barriers in;
   a. Buildings, roads, transportation and indoor and outdoor objects (for example, in schools, housing, hospitals, health centers, and workplaces);
   b. Information, communications, and other services (for example, electronic services and emergency services).

2. The countries will also;
    a. Set standards for accessibility of public places and services;
    b. Make sure that private businesses and organizations open to the public are accessible;
    c. Train people about what people with disabilities need when it comes to accessibility;
    d. Have Braille signs and easy to read and understand information in public buildings;
    e. Provide help so people with disabilities can access buildings open to the public (for example, readers, sign language interpreters, and guides);
    f. Provide other types of help people with disabilities need to get access to information;
    g. Promote to new technologies for people with disabilities;
    h. Promote new technology that improve access to information and communications for people with disabilities.

ARTICLE 10: RIGHT TO LIFE

All people with disabilities have the right to life. The countries will act to make sure people with disabilities can use this right.

ARTICLE 11: SITUATIONS OF RISK AND HUMANITARIAN EMERGENCIES

The countries will make sure that people with disabilities are protected in times of war, natural disasters, or other emergencies.

ARTICLE 12: EQUAL RECOGNITION AS A PERSON BEFORE THE LAW

1. People with disabilities have the right to be recognized as people before the law.

2. People with disabilities are capable like all other people on legal issues in all areas of their lives.

3. People with disabilities have a right to get support if they need it to make decisions about legal issues.

4. When people with disabilities need support on legal or financial issues:
    - They will be protected from abuse;
    - Their rights and their choices will be respected;
    - People who give support will not pressure people with disabilities into making a decision;
    - They get the help they need, only for the time they need it and only as much as they need;
    - The courts will review the support received.

5. The countries will make sure that people with disabilities:
    a. Have the right to own or get property;
    b. Have the right to control their money or other financial affairs;
    c. Have the same opportunities as other people to get bank loans, mortgages and credit;
    d. Cannot have property taken away without a reason.

ARTICLE 13: ACCESS TO JUSTICE

1. The countries will make sure that people with disabilities can access the justice system in their countries just like all other people. Any rules about how things should be done should be adapted so that people with disabilities can be involved in all stages of legal processes, (for example, being a witness).

2. People working in the justice system (for example, police and prison staff) should have training in how to improve access for people with disabilities.

ARTICLE 14: LIBERTY AND SECURITY

1. The countries will:
   a. Make sure that people with disabilities have the same right to liberty and security as all other people;
   b. Make sure that this right is not taken away from people with disabilities because they have a disability or in any illegal way.

2. The countries will make sure that if a person has had his or her liberty taken, he or she will be protected by law. They will also make sure that changes are made to the individual's environment if they are needed for that person to enjoy his or her human rights.

ARTICLE 15: FREEDOM FROM TORTURE OR CRUEL, INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT

1. Nobody will be tortured, or be treated or punished in a cruel, inhuman or degrading way. Nobody will be forced to take part in medical or scientific experiments.

2. The countries agree to pass laws, and take other action to make sure that people with disabilities are protected from torture just like all other people.

ARTICLE 16: FREEDOM FROM EXPLOITATION, VIOLENCE AND ABUSE

The countries will:

1. Pass laws and take other action to make sure people with disabilities are not exploited or abused, both inside and outside their home.

2. Take action to prevent abuse of people with disabilities by giving help and appropriate information to people with disabilities and their families.

3. Make sure that places and programs serving people with disabilities are regularly looked at to make sure there is no violence or abuse.

4. Support people with disabilities with their recovery and reintegration into society if they have been victims of violence and abuse.

5. Create laws and policies to investigate and punish people who abuse or mistreat people with disabilities. These laws and policies will include the needs of women and children.

ARTICLE 17: PROTECTING INTEGRITY

People with disabilities have the same right as everyone else to have their physical and mental selves respected.

ARTICLE 18: FREEDOM OF MOVEMENT AND NATIONALITY

1. People with disabilities have the same rights as others to move around in their country or between countries, to choose where they live, and to have a nationality.

   The countries will make sure that people with disabilities:
   a. Have the right to get and to change their nationality. Nobody can take away their

nationality without a reason or because of a disability;
b. Cannot have their passports or other identification of nationality taken away without a reason or because of a disability, and that they are allowed to try to move to another country;
c. Are free to leave their own country and any other country;
d. Cannot be stopped from entering their own country without a reason or because of a disability.

2. Children with disabilities will be registered immediately after they are born. They will have the right to a name, to a nationality, and as much as possible the right to know their parents and be raised by their own parents.

ARTICLE 19: LIVING INDEPENDENTLY AND BEING INCLUDED IN THE COMMUNITY
All people with disabilities have the same right as anyone else to live in the community, to be fully included and to participate in the community.

The countries will make sure that people with disabilities:
a. Have the same opportunities as other people to choose whom they live with and where they live. They should not be forced to live in institutions or in other living arrangements that they do not like;
b. Have a range of choices on where and how to live in the community, including personal assistance to help with inclusion in the community and prevent them from being isolated;
c. Can use community services that are available to the public, which may need to be adapted to a particular person's needs.

ARTICLE 20: PERSONAL MOBILITY
The countries will make sure that people with disabilities can move around with the greatest possible independence, including:
a. Assisting people to move around in the way at the time they choose, and at a cost that they can afford;
b. Assisting people with disabilities to access mobility aids and technology, including making sure they do not cost a lot;
c. Providing training in mobility skills for people with disabilities and staff working with them;
d. Encouraging those that produce mobility aids and technology to take into account all aspects of movement.

ARTICLE 21: FREEDOM OF EXPRESSION AND OPINION AND ACCESS TO INFORMATION
The countries will make sure that people with disabilities have the right to say what they think through Braille, sign language, or any other types of communication that they choose.

The countries will make sure people with disabilities have the same right as other people to give and receive information, including:
a. Providing information intended for the general public to people with disabilities in formats that are adequate for them without extra cost (for example, Braille);
b. Accepting the use of different ways people with disabilities communicate in official situations;
c. Encouraging private businesses and organizations that serve the public to make their

services more accessible for people with disabilities;
d. Encouraging the media to make their information accessible to people with disabilities;
e. Agreeing to, and promoting the use of, sign language.

ARTICLE 22: RESPECT FOR PRIVACY

1. No matter where people with disabilities live, no one can interfere in their private life, enter their home, open their mail, bother their family, or harm their good name without a good reason. People with disabilities have the right to be protected by the law from such attacks.

2. Information about people with disabilities, their health, and rehabilitation is private and protected.

ARTICLE 23: RESPECT FOR HOME AND THE FAMILY

1. The countries will stop discrimination against people with disabilities when it comes to marriage and family relations and make sure that:
   a. People with disabilities have the same right as other people to marry and have a family;
   b. People with disabilities have the same rights as other people to have children and to decide how many children to have and when to have them. They should get information on reproduction and family planning and help to understand this information;
   c. People with disabilities have the same right as everyone else to keep their fertility.

2. People with disabilities have the rights and responsibilities related to caring for or adopting children, with the most important concern being what is best for the child. The countries will give people with disabilities any help they need to raise their children.

3. Children with disabilities have the same rights as everyone else to a family life. To prevent abuse, the countries will provide information, services, and support to children with disabilities and their families.

4. Children must not be taken away from their parents against their will, unless it is best for them and is done legally. A child cannot be separated from parents because of the parent's or the child's disability.

5. If close family members cannot care for a child with a disability, the countries will look for another relative or someone in the local community to care for the child.

ARTICLE 24: EDUCATION

1. All people with disabilities have the right to education. The countries will make sure that the entire education system includes people with disabilities, and that the educational system works to:
   a. develop everyone's human potential, sense of dignity, and self worth, as well as respect for human rights, freedoms, and diversity;
   b. develop the personality and talents of people with disabilities to their fullest potential;
   c. make it possible for people with disabilities to be involved in society.

2. To do this, the countries will make sure that:
   a. People with disabilities are not kept out of education because of their disability, and children with disabilities are not kept out of free and required primary or from sec-

ondary education because of their disability;
   b. All people with disabilities can choose education that includes them, is accessible and is in their own community;
   c. Reasonable changes are made to make sure that people with disabilities get the most out of their education;
   d. People with disabilities get the help they need to get the most out of their education;
   e. The individual needs of students with disabilities receive are met.

3. The countries will make it possible for people with disabilities to learn social and life skills they need to go to schools and be in the community. They will do this by:
   a. Arranging that students learn skills for communication (for example, Braille) and movement, and that they get support from other people with disabilities of their own age;
   b. Teaching sign language;
   c. Making sure that especially children who are blind, deaf or deafblind are educated in the most appropriate types of communication so that they get the most out of their education.

4. To help make sure that these rights are put into practice, the countries will hire teachers who are people with disabilities, teachers who are qualified in Braille and sign languages, and will train teachers and staff at all levels of education on how to give quality education to people with disabilities.

5. Countries will make sure that people with disabilities have equal access to vocational training, to universities and to lifelong learning like all other people, and will make any changes needed to make that happen.

ARTICLE 25: HEALTH

All people with disabilities have the same right to quality health care, without discrimination because of their disability.

The countries will make sure that health and rehabilitation services are available, including:

a. Making sure that people with disabilities get the same variety, quality, and standard of free and affordable health care as other people;
b. Making sure that people with disabilities can get services they need because of their disability and to protect them from further disability;
c. Having health services in people's own communities;
d. Making sure through training and standards that health workers give the same quality care to people with disabilities as to others, including getting their agreement;
e. Stopping discrimination against people with disabilities about health insurance and life insurance;
f. Making sure that people with disabilities will not be discriminated against and denied health care or health services, or food and fluids, because of their disability.

ARTICLE 26: HABILITATION AND REHABILITATION

1. The countries will take action (for example, by promoting peer support) to make it possible for people with disabilities to enjoy maximum independence, their full abilities, and inclusion in all aspects of life. To make sure this happens, the countries will make available services that cover all areas of life, both in habilitation and rehabilitation, so that they:
   a. Begin as early as possible, and are suited to a person's strengths and needs;

b. Help people with disabilities be involved in the community and are voluntary and available as close as possible to their communities.
(Habilitation is a process that helps people who are born with a disability or acquire a disability at an early age get new skills, abilities, and knowledge. Rehabilitation refers to the process of re-gaining lost skills or abilities.)

2. The countries will promote training for people working in habilitation and rehabilitation services.

3. The countries will promote the use of assistive devices and other types of aid as they relate to habilitation and rehabilitation.

ARTICLE 27: WORK AND EMPLOYMENT

1. People with disabilities have the same right to work as other people. They have the right to earn a living from work they choose in a work environment that is open and accessible to all people. The countries will pass laws and take other action needed to:
   a. Stop discrimination because of disability in all work situations, including trying to get jobs, getting hired, keeping a job, being promoted and working in safe and healthy conditions;
   b. Protect the rights of people with disabilities to equal pay for equal work, equal opportunity, safe and healthy working conditions, and the ability to make complaints;
   c. Make sure that people with disabilities can organize and join labor unions and trade unions like everyone else;
   d. Make it possible for people with disabilities to get career counseling and job trainings;
   e. Promote job opportunities and promotions and help people with disabilities to find and keep jobs;
   f. Promote self-employment, business opportunities, cooperatives, and start-up businesses;
   g. Hire people with disabilities in the government;
   h. Encourage and help employers to hire people with disabilities;
   i. Make it easy for people with disabilities to be in the work place and work environment by making sure reasonable adjustments are made for them;
   j. Make sure that people with disabilities can gain work experience in the labor market;
   k. Promote programs to support people with disabilities to return to work and keep their jobs.

2. The countries will make sure that people with disabilities are not made slaves. They will protect people with disabilities from forced labor as all other people are protected.

ARTICLE 28: ADEQUATE STANDARD OF LIVING AND SOCIAL PROTECTION

1. People with disabilities have the right to a good standard of living for themselves and their families. This includes enough food, clothing, housing, and continued improvement of their living conditions.

2. People with disabilities have the right to social protection by the government, without discrimination because of disability. The countries will protect this right, including by making sure that:
   a. People with disabilities can get the services, equipment, and help they need;
   b. People with disabilities have access to financial assistance and programs that help

them get out of poverty. This especially applies to women and girls and older people with disabilities;
c. People with disabilities and their families who live in poverty get help from the government to be able to pay for expenses related to their disability;
d. People with disabilities have access to government housing programs;
e. People with disabilities can get pensions.

ARTICLE 29: PARTICIPATION IN POLITICAL AND PUBLIC LIFE

People with disabilities have the rights same political rights as all other people. The countries will:

a. Make sure that people with disabilities can be fully involved in political and public life, for example by having the right to vote and be elected. To do this they should make sure:
   I. That voting is easy to understand and accessible;
   II. That people with disabilities can vote in secret and to be elected and hold office;
   III. That people with disabilities can get help in voting from someone of their choice.
b. Encourage people with disabilities to be involved in the government and public affairs, including:
   I. Being involved in non-governmental organizations and associations focused on the activities of political parties and civil society;
   II. Making and belonging to organizations to represent people with disabilities internationally, nationally, regionally and locally.

ARTICLE 30: PARTICIPATION IN CULTURAL LIFE, RECREATION, LEISURE AND SPORT

1. People with disabilities have the right to take part in cultural life. The countries will take action to make sure that:
   a. People with disabilities have access to literature and the arts in formats they can use;
   b. People with disabilities can get television programs, film, theatre and other cultural activities in a way that they will understand, for example with captioning and sign language;
   c. People with disabilities can access cultural performances and services such as libraries, museums, theatres and important places.

2. The countries will make it possible for people with disabilities to develop and use their creative, artistic, and intellectual talents.

3. The countries will make sure that laws that protect documents and other writings and inventions from forgery or copying do not discriminate against people with disabilities.

4. People with disabilities have the right, just like everyone else, to have their culture and language recognized, for example sign languages and deaf culture.

5. People with disabilities have the same right as others to take part in recreation, leisure and sports. The countries will take action to:
   a. Promote and encourage people with disabilities to take part in sports with people without disabilities at all levels;
   b. Make sure that people with disabilities have a chance to organize and participate in sport activities, and to receive the same training and support as other people;
   c. Make sure that people with disabilities can get to sports and recreation arenas as other people can;

d. Make sure that children with disabilities can participate in play and sports at school like other children;
e. Make sure that person with disabilities can get services to help organize recreational and sporting activities.

ARTICLE 31: STATISTICS AND DATA COLLECTION

1. The countries will collect and look at information about people with disabilities to put into practice this Agreement. In collecting and using this information they will:
   a. Respect people's right to privacy. The information should be given only if people agree;
   b. Respect human rights and ethics.

2. The information collected will be put in useful groups so that the countries can learn more about barriers that exist for people with disabilities and understand better how to put this Agreement into practice.

3. The countries are responsible for giving out this information and making sure that people with disabilities can read and understand it.

ARTICLES 32 – 50: DUTIES OF GOVERNMENTS

These articles explain how people and governments should work together to make sure all people with disabilities get all their rights

The main ideas are:

- The countries should they work together to put this Agreement into practice.
- People with disabilities and their organizations must be included in this work.
- A UN Committee on the Rights of People with Disabilities will be created to make sure the countries keep their promises to this Agreement
- The countries will write regular reports for the Committee telling how they're putting this Agreement into practice.
- The Committee will report regularly to the UN General Assembly and other groups and make suggestions on how this Agreement is being respected.
- The countries that sign this agreement have the responsibility to put it into practice. However, they can decide not to accept certain parts that they disagree with.
- This agreement should be made available in ways that people with disabilities can read or understand it.

Note: The United Nations General Assembly adopted this Agreement in December, 2006. Countries are now promising to put it into practice. When enough countries have done this, the Agreement will become international law.

People with disabilities have the same rights as all people. Countries will take action to ensure these rights.

A Summary of the United Nations

CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES:

All people with disabilities are equal before the law. Not just men, but women and girls — and children with disabilities, too.

If you need changes made to your surroundings in order to enjoy these rights, those changes will be made.

RESPECT
FOR THE INDIVIDUAL

INCLUSION
IN THE COMMUNITY

CHANGE
IN THE SOCIETY

What Is the Convention on Rights of Persons with Disabilities?
It is an agreement between countries of the world. The goal is to make sure that people with disabilities have the same rights and freedoms as all people.

If Countries Sign the Convention, What Will They Do?
When countries sign this agreement, they are promising to take action to end discrimination based on disability! They will:

- change laws and make new ones
- protect people's rights
- include people with disabilities in planning these actions
- make progress reports to the United Nations
- educate the public

When Will This Agreement Become Law?
The United Nations General Assembly adopted this agreement in 2007. That was only the first step. Now, countries must promise to put it into practice. When enough countries have made this promise, the agreement will become international law.

About this Summary
The United Nations says that this agreement should be made available in ways that people with disabilities can read and understand. This summary covers most of the main points in four pages. The original Convention is very long and can be hard to read.

This document provided by

ACT
Advocating Change Together
www.selfadvocacy.org
[illegible]

• Dignity • Ability to choose • Independence • Non-discrimination • Participation • Full inclusion • Respect for difference •
• Acceptance of disability as part of everyday life • Equality of opportunity • Accessibility • Equality of men and women • Respect for children •

People with disabilities have the same rights as all people. Countries will take action to ensure these rights.

RESPECT FOR THE INDIVIDUAL

People with disabilities have these rights:

Life
The RIGHT to life.

Equal Before Law
THE RIGHT to be recognized as a capable person before the law. You can own property and control your own money. THE RIGHT to get support when you have legal or money issues.

Freedom
THE RIGHT to liberty and security, just like all other people. No one can keep you somewhere against your will.

Safety
THE RIGHT to be safe from being harmed by others. You cannot be treated in a cruel way. You cannot be forced to take part in medical experiments. Your government will punish abusers, educate the public and pass laws to keep you safe from abuse.

Citizenship
THE RIGHT to a name and a country. THE RIGHT to know who your parents are and to be raised by them. THE RIGHT to move around freely within your country.

Privacy
THE RIGHT to privacy, no matter where you live. Information about you is also private.

Family
THE RIGHT to marry and have a family. You can keep your family by having children and raising them – with support if you need it.

Your Government Will Take Action to Make Sure You Have These Rights

People with disabilities have the same rights as all people. Countries will take action to ensure these rights.

INCLUSION IN THE COMMUNITY

People with disabilities have these rights:

Community Inclusion

THE RIGHT to live in the community, to be included in community life. You can choose whom you live with and where you live. You can have an assistant to help you be part of your community.

Getting Around

THE RIGHT to get help to move around in the way you choose and at a cost that you can afford. Things like wheelchairs or crutches should not cost a lot.

Speaking Out

THE RIGHT to say what you think, in the way you communicate best.
THE RIGHT to public information presented in a way you can understand

Education

THE RIGHT to the same education as others. THE RIGHT to get the help you need to get the most out of your education. Schools should build your self worth and your talents.

Health Care

THE RIGHT to good—and affordable—health care. Your government will make sure that health workers know how to give quality care to meet your needs.

Life Skills

THE RIGHT to training that gives you skills for independence and inclusion in all parts of life. Your government will train people who can teach you these skills and also help you get and use things to help you live your life.

A Good Job

THE RIGHT to work. THE RIGHT to earn a decent living from work you choose. THE RIGHT to work in a setting that is accessible to you.

Standard of Living

THE RIGHT to enough food, clothing and housing. THE RIGHT to the help you need to pay bills, pay rent and get out of poverty.

People with disabilities have the same rights as all people. Countries will take action to ensure these rights.

CHANGE IN THE SOCIETY

Countries will take action to ensure your rights:

Attitudes

YOUR GOVERNMENT WILL WORK to teach all people about the issues facing people with disabilities, about harmful attitudes, and about what people with disabilities can do. This is your right.

Barriers

YOUR GOVERNMENT WILL WORK to get rid of barriers that people with disabilities face—to be sure you use public buildings, private businesses and services. This is your right.

Emergency Situations

YOUR GOVERNMENT WILL WORK to make sure that you have equal protection in the case of war, floods, earthquakes or other emergencies. This is your right.

Legal System

YOUR GOVERNMENT WILL WORK so that you can use the justice system in your country just like all other people. This is your right.

Voting and Politics

YOUR GOVERNMENT WILL WORK to make sure voting is easy to understand and accessible. You have the same right to vote and be elected as anyone else. You can get help in voting from someone of your choice. This is your right.

Culture and Sports

YOUR GOVERNMENT WILL WORK to make sure that you can take part equally in cultural, sports and recreation events. Your culture and language should be recognized. Your talents should be developed. You can take part in sports with people who don't have disabilities, and sports where only people with disabilities play. This is your right.

Your Government Will Take Action to Make Sure You Have These Rights

HUMAN RIGHTS INSTRUMENTS

The following are the internet addresses for the principal instruments cited in *Human Rights. YES!*

- **The African Charter on Human and Peoples' Rights**
  http://www1.umn.edu/humanrts/instree/z1afchar.htm

- **Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment** (CAT)
  http://www.unhchr.ch/html/menu3/b/h_cat39.htm

- **Convention Concerning Indigenous and Tribal Peoples in Independent Countries** (ILO No. 169)
  http://www.ohchr.org/english/law/indigenous/htm

- **Convention on the Elimination of All Forms of Discrimination against Women** (CEDAW)
  http://www.ohchr.org/english/law/cedaw.htm

- **International Convention on the Elimination of All Forms of Racial Discrimination** (ICERD)
  http://www.unhchr.ch/html/menu3/b/9.htm

- **Convention on the Rights of the Child** (CRC)
  http://www.ohchr.org/english/law/crc.htm

- **International Convention for the Protection of the Rights of Migrant Workers and Members of Their Families** (ICRMW)
  http://www.ohchr.org/english/law/cmw.htm

- **Convention on the Rights of Persons with Disabilities** (CRPD)
  http://www.ohchr.org/english/law/disabilities-convention.htm

- **Declaration on the Rights of Indigenous Peoples**
  http://www.ohchr.org/english/issues/indigenous/docs/draftdeclaration.pdf

- **European Convention for the Protection of Human Rights and Fundamental Freedoms**
  http://conventions.coe.int/Treaty/en/Treaties/Html/005.htm

- **ILO Convention 159 (concerning Vocational Rehabilitation and Employment (Disabled Persons)**
  http://www.ilo.org/ilolex/english/convdisp1.htm

- **Inter-American Convention on Human Rights**
  http://www1.umn.edu/humanrts/oasinstr/zoas3con.htm

- **International Covenant on Civil and Political Rights** (ICCPR)
  http://www.ohchr.org/english/law/ccpr.htm

- **International Covenant on Economic, Social and Cultural Rights** (ICESCR)
  http://www.unhchr.ch/html/menu3/b/a_cescr.htm

- **Universal Declaration of Human Rights** (UDHR)
  http://www.unhchr.ch/udhr/

- **UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** (Standard Rules)
  http://www.un.org/esa/socdev/enable/dissre00.htm

ANNEX 2
FACILITATING HUMAN RIGHTS EDUCATION

Human Rights. YES! calls for a way of learning in which the participants are at the center of the experience and share authority and "ownership" for their own learning. The learning activities do not need a teacher but a *facilitator,* for everyone in the group is a learner engaged in a common effort towards a shared goal. Together they examine their own experiences and seek to come to individual conclusions. Because people cannot be told what to think, the goal of a learning activity is not some "right answer" or even agreement, but a cooperative exploration of ideas and issues.

Because this methodology assumes that everyone has the right to an opinion and respects individual differences, it is especially appropriate to a human rights learning. It encourages critical analysis of real-life situations and can lead to thoughtful and effective action to create change.

THE ROLE OF THE FACILITATOR

Facilitation does not usually come naturally. Mastering the art of facilitation requires both practice and a clear understanding of the role of the facilitator:

- **To establish a relationship of equality and cooperation with participants**. The facilitator is "first among equals," but responsibility for learning rests with the whole group;
- **To create an environment of trust and openness**. The facilitator helps everyone feel safe to speak honestly in a situation where differences of opinion, as well as differences in ability, are respected;
- **To ensure that everyone feels included** and is enabled to participate;
- **To provide a structure for learning**, which might include setting and observing meeting times, opening and closing sessions, and keeping to an agenda. The facilitator continually consults participants about the effectiveness of the structure.
- **To make sure the logistics are handled appropriately**. This might include gathering and preparing materials, setting up the meeting space, notifying participants, and seeing that necessary preparations are made. Facilitating learning for people with disabilities also includes providing accommodations so that everyone can participate fully.

A facilitator is NOT –

- **a teacher** or "the person in charge": The whole group is responsible for learning. The facilitator's role is to help that learning happen more effectively. The facilitator is a co-learner, exploring all subjects as an equal partner and contributing individual experience to that of others.
- **a judge**: In active learning no one, least of all the facilitator, determines that some opinions are "correct" or "better."
- **necessarily an expert**: Although preparing each session, the facilitator may not know as much about a subject as some other members of the group.
- **the center of attention**: A good facilitator generally speak less than other participants;

instead she or he draws others into the discussion.

- **the housekeeper**: While the facilitator takes initial leadership in coordinating the sessions, she or he should not become the only person who takes responsibility.

As with any skill, the best way to learn to facilitate learning is to practice often and have a self-critical attitude, always seeking to improve.

INTERACTIVE LEARNING

The process of learning is more important than the content! The activities in *Human Rights. Yes!* are designed to actively involve participants in their own learning and acknowledge the differences in the ways that adults learn. Each session seeks to encourage participants in –

- **concrete experience**: to involve themselves fully and without bias in new experiences;
- **reflective observation**: to observe and to reflect on these experiences from many perspectives;
- **abstract conceptualization:** to create concepts that integrate their observations into coherent theories;
- **active experimentation**: to use these theories to make decisions, solve problems and take action.

The effectiveness of interactive learning techniques has been interpreted quantitatively by the National Training Laboratories in Bethel, Maine, USA in an analysis that measured and contrasted average retention rates across a variety of teaching styles.

Method	Average Retention Rate
Lecture	5%
Reading	10%
Audio Visual	20%
Demonstration	30%
Group Discussion	75%
Teaching Others	80%

LEADING DISCUSSION

Discussion is one of the most important ways for people to participate in their own learning. Therefore every facilitator needs to learn to lead discussion skillfully.

1. **Ask open or leading questions**. Most of the questions for discussion in *Human Rights. YES!* fall into these categories.

   An open question encourages a wide range of answers from the personal ("This reminds me of a time when I was a little girl …") to the objective ("I have heard that in some countries people with disabilities are not allowed to marry"). Open questions cannot be answered by "yes" or "no." For example, these are open questions:
   - How do you define "reasonable accommodation"?
   - Can a leader also be a follower?

   Leading questions take participants step by step towards a learning goal. Each question builds on the previous answer and leads to another question. Because the Greek

philosopher Socrates used leading questions in his teaching, it is sometimes called the "Socratic method." For example, this is a series of leading questions:

- Do you remember a time when you were not consulted about your opinion on something important that concerned you?
- How might things have turned out differently if you had been consulted?
- What are some results of this failure to permit you to express an opinion?
- Why do you think that the CRPD has emphasized the right of people with disabilities to an opinion?

Avoid too many subjective questions, which invite a strictly personal response and do not necessarily lead to dialogue or discussion. For example (e.g., *Did I summarize what you said accurately? Are you ready for a break*?). Also avoid closed questions that can be answered with a fact or just "yes" or "no" (e.g., *What time is it? Did you enjoy that activity?*).

2. **Respect all answers or opinions**. The role of the facilitator is not to judge, and all participants need to have their opinions acknowledged and respected, regardless of what the facilitator thinks personally. However, comments that are disrespectful of other participants or contrary to the ethics of the learning partnership need to be addressed.

3. **Repeat and restate**. The facilitator often needs to acknowledge that participants' comments were heard and understood. Sometimes the facilitator may need to restate a comment to make sure that it was understood, but it is important to get the participant's assent that the restatement was accurate ("*Did I understand what you just said?*").

4. **Signal attention**. In addition to verbal responses, the facilitator can communicate attention in many ways, including tone of voice, "body language," writing down comments, and making eye contact,

5. **Resist imposing opinions**. The facilitator's role is to invite sharing of opinions, not impose his or her opinions. As co-learner, facilitators may, of course, add their own views to the discussion, but only with discretion and tact.

6. **Control the traffic**. The facilitator needs to ensure that no one dominates the conversation, that everyone gets a chance to speak, and that the discussion stays on topic.

ACCOMMODATING PARTICIPANTS WITH DISABILITIES

1. **Before the Workshop**
   - If possible, find out well in advance who will attend and what accommodations they may need in order to participate fully.
   - Adapt your learning materials, agenda, and activities to ensure that everyone can participate (e.g., large print, Braille, plain language handouts.
   - Arrange any aids to communication that may be needed (e.g., sign language interpreters).
   - Brief any speakers or additional facilitators on making their presentations accessible.
   - Consider the safety and accessibility of the location:
     - Transportation to and from the meeting place
     - Access to the building
     - Access to and inside all meeting rooms
     - Access to bathrooms and eating areas.

2. **During the Workshop**
   - Ask at the beginning if anyone is aware of barriers you have not anticipated.

- Invite participants to let you know during the workshop if new barriers arise.
- Be sensitive to differences among participants.
- As a general practice, both write and speak aloud important points made by both you and participants.
- Ask participants to decide when and for how long breaks will occur.
- Plan extra time for participants with limited mobility to break into groups.
- Be creative. Be prepared with more than one way of explaining important concepts, processes and instructions.

3. Concluding and Following up the Workshop

- Encourage participants to find ways to take action appropriate to their concerns, disabilities, and advocacy.
- In your evaluation ask everyone whether they felt they were able to participate fully and equally.
- Ask for feedback and advice on how to make future workshop more accessible.

PLANNING WORKSHOPS

Although workshops differ in their purpose, setting and duration, the chart below shows the basic component of any interactive workshop and may serve as a planning tool.

OPENING AND INTRODUCTIONS

- Plan what happens when participants arrive (e.g., how they are greeted, get information, orient themselves). Be prepared to accommodate different kinds of disability.
- Plan how participants will get to know each other. Consider using several modes (e.g., verbal such as self-introductions, visual such as nametags).

GOALS AND EXPECTATIONS

- State the purpose and goals of the workshop orally and in writing.
- Some goals may be general and process orientated: to understand, to appreciate, to now, to recognize. It is usually difficult to evaluate your learning impact with goals of this type (e.g., at the end of the workshop participants will understand shared leadership).
- Other goals deal with concrete skills that you hope participants will acquire: to make, to write, to plan, to construct, to produce, to identify, to compare, to assemble, to draw, to solve, to measure.

PARTICIPANT EXPECTATIONS

- Allow a time at the beginning for participants to state what they wanted to get out of the workshop.
- Be willing to admit that some expectations are not possible to meet, (e.g., not within the capacity of the staff, the needs of the organization or the limitations for the funders), but also be willing to change the direction of the workshop to include expectations where possible, especially if many participants express that expectation.

AGENDA SETTING

- Post a written agenda with times and names of presenters so participants know what to expect.
- The agenda belongs to the group. Consult with participants about the agenda. Does it meet their needs (e.g., for covering the topic, allowing for breaks and rest)?
- Especially in a workshop of several days, consult daily about the content and structure of the agenda.
- Read this aloud at the start of every session on the agenda.

PRESENTATIONS AND LEARNING ACTIVITIES

- If possible, have several different speakers and facilitators.
- Use a variety of methodologies, keeping in mind that participants will have many different learning styles.
- Adapt activities to the needs, interests and abilities of the participants.
- Anticipate sleepy after-lunch and early-morning periods.

OPPORTUNITIES FOR REFLECTION AND QUESTIONING

- Plan on time within the workshop for participants to reflect on what they are learning and experiencing. This might be some kind of journal, discussion in pairs or small groups, or simply a period of quiet.
- Encourage participants to interject their questions or responses during the course of the workshop and/or set aside several periods for open comments.

SUMMING UP AND EVALUATION

- At the end of the workshop (or every day in a long workshop), remind participants of the original goals and the activities and presentations that they have experienced in pursuit of that goal.
- Prepare some anonymous method for participants to evaluate the workshop, both in terms of accomplishing its goals but also from the perspective of their individual experience. Make available alternatives to written evaluations for those who need it.
- Summarize and keep the evaluation feedback from very workshop you do. Use it to improve your facilitation skills.

FOLLOWING UP

- Provide a method for participants to stay in touch with each other and you and your organization if they wish.
- Evaluations done several weeks after a workshop can give you a different and often more accurate sense of the effectiveness of your facilitation.

SAMPLE WORKSHOPS

With the adoption of the UN Convention on the Rights of Persons with Disabilities, disability rights are now on the agenda of many groups and disability advocates are likely be called upon to teach or lead workshops on human rights. Workshops based on the exercises and materials provided in *Human Rights. YES!* may be highly effective for education and advocacy for a wide range of groups, including:

- Disabled people's organizations
- Mainstream human rights organizations
- Parliamentary human rights committees
- National human rights institutions
- Election officials
- Primary and high school teachers
- Employer associations
- Tourism authorities
- Faith-based communities
- Development and humanitarian organizations

A more detailed set of sample workshops will be provided on the *Human Rights. YES!* website (http://www.humanrightsyes.org). The following examples, which are derived from successful workshops, provide some basic models for building workshops:

1. HALF-DAY/ 3 1/2 - HOUR WORKSHOP MODEL

The Human Right of Persons with Disabilities to Education

> **Topic**: The human right of persons with disabilities to education
> **Setting**: In-service workshop for high school teachers
> **Participants**: High school teachers
> **Objective**: To raise awareness about inclusive education

Introductions **10 minutes**
Each participant can pair off with another and share who they are and what brought them to the workshop and/or what they hope to get from it. Then each partner introduces the other to the whole group.

Agenda and Objectives of Workshop **5 minutes**
Facilitator reviews the workshop agenda and objectives, commenting on how it can or cannot fulfill participants' expectations.

Exercise 13.2: Experiencing Education **45 minutes**
Exercise is designed for participants to share personal stories of the education system and persons with disabilities and evaluate ideas for how it ought to be.

Presentation: Introduction to the CRPD **15 minutes**

Exercise 13.1: What Rights to Education Does the Convention on the Rights of People with Disabilities Affirm? **30 minutes**
Exercise introduces participants to the provisions and key concepts on education in the CRPD.

BREAK **10 minutes**

Exercise 13.3: Identifying the Causes of Discrimination in Education **30 minutes**
Exercise encourages participants to examine discrimination in education systems and consider how to take action against it

Exercise 13.4: Speaking Up for Education **30 minutes**
Exercise allows participants to examine discrimination in education systems and consider how to take action against it.

Closing Exercise 13.5: Making a Commitment **30 minutes**
Closing exercise allows participants to reflect on the notion that human rights involve both rights and responsibilities and encourages them to take action to support the right of people with disabilities to an education.

Evaluation **5 minutes**
Distribute evaluation forms and collect.

2. ONE-DAY/ 6-HOUR WORKSHOP MODEL

An Introduction to the Human Rights of Persons with Disabilities

Topic: Introduction to the human rights of persons with disabilities
Setting: National Disability Conference workshop
Participants: Disability advocates with little previous human rights education
Objectives: 1) To understand and explore human rights concepts and advocacy strategies;
2) To build human rights learning environments for disability advocates to advance their advocacy around human rights issues;
3) To learn skills that participants can apply to their home communities.

Introductions **10 minutes**
Each participant can pair off with another and share who they are and what brought them to the workshop and/or what they hope to get from it. Then each partner introduces the other to the whole group.

Agenda and Objectives of Workshop **5 minutes**
Facilitator briefly reviews the workshop agenda and objectives, commenting on how it can or cannot fulfill participants' expectations.

Exercise 1.1: The Impact of Myths and Stereotypes about Persons with Disabilities **45 minutes**
Exercise designed to allow participants to share lived experiences with discrimination based on myths and stereotypes and begin thinking about their impact on human rights.

Presentation: The Human Rights Framework **15 minutes**
To introduce the fundamentals of human rights,

Exercise 1.2: The Interdependence of Rights **45 minutes**
Exercise designed to examine the fundamental human rights contained in the UDHR and to raise awareness of how these rights relate to each other.

BREAK **15 minutes**

Presentation: The CRPD **15 minutes**
To introduce the CRPD and rights-based approach to disability.

Exercise 1.3: Tree of Rights **45 minutes**
Exercise designed to identify the range of human rights to which people with disabilities are entitled.

Exercise 5: Language & Rights **45 minutes**
Exercise to help understand the role that language can play in supporting both positive and negative attitudes about the role of people with disabilities in society.

LUNCH **1 hour**

Energizer **5 minutes**
Re-engage the group with a quick energizer activity, such as "Calling the Names" in which the group forms a circle and thinks of individuals who support, inspire or guide them in their work. Each member calls out the name of that person, one by one. (Source: Nancy Flowers, The Human Rights Education Handbook, 2000: http://www1.umn.edu/humanrts/edumat/hreduseries/hrhandbook/activities/6.htm).

Exercise 13.1: What Rights to Education Does the Convention on the Rights of People with Disabilities Affirm? **30 minutes**
Exercise introduces participants to the provisions and key concepts on education in the CRPD.

BREAK **10 minutes**

Exercise 13.4: Speaking Up for Education **60 minutes**
Exercise allows participants to examine discrimination in education systems and consider how to take action against it.

Closing Exercise 13.5: Making a Commitment **45 minutes**
Closing exercise allows participants to reflect on the notion that human rights involve both rights and responsibilities and encourages them to take action to support the right of people with disabilities to an education.

Evaluation **5 minutes**
Distribute evaluation forms and collect.

ANNEX 3
GENERAL RESOURCES

Web-based International Human Rights Law Libraries

Office of the High Commissioner for Human Rights (International Human Rights Instruments):
http://www.unhchr.ch/html/intlinst.htm

University of Minnesota Human Rights Library:
http://www1.umn.edu/humanrts

General Resources on Human Rights and Disability

ACT (Advocating Change Together) (Information on disability rights advocacy particularly for self-advocates with developmental disabilities):
http://www.selfadvocacy.org

Theresia Degener and Yolan Koster-Dreese, eds., *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments* (Martinus Nijhoff Publishers 1995).

Disabled Peoples' International, *Ratification Toolkit* (On ratification advocacy for the Convention on the Rights of Persons with Disabilities):
http://www.icrpd.net/ratification/en/index.htm

Disabled Peoples' International, *Implementation Toolkit* (On implementation advocacy for the Convention on the Rights of Persons with Disabilities):
http://www.icrpd.net/implementation/en/index.htm

Harvard Project on Disability, Harvard Law School (Information on the range of law, policy and advocacy initiatives of the Project): (website pending at time of publication)

National Council on Disability, *Understanding the Role of an International Convention on the Human Rights of People with Disabilities: An analysis of the legal, social, and practical implications for policy makers and disability and human rights advocates in the United States* (May 2002):
http://www.ncd.gov/newsroom/publications/unwhitepaper_05-23-02.html

Gerard Quinn and Theresia Degener, et. al., *Human Rights Are for All: A Study on the Current Use and Future Potential of the UN Human Rights Instruments in the Context of Disability* (OHCHR, February 2002):
http://www.ohchr.org/english/issues/disability/study.htm

United Nations Department of Economic and Social Affairs (Website offering info on the UN Program on Disability and disability specific resources):
http://www.un.org/disabilities

World Enable (Internet accessibility initiative providing information on a range of topics, including the Convention on the Rights of Persons with Disabilities):
http://www.worldenable.net

ANNEX 4:
A GLOSSARY FOR DISABILITY AND HUMAN RIGHTS

Note: Terms in this glossary are found in bold-face type in the text of Human Rights. YES!

Adoption: Usually refers to the initial diplomatic stage at which the official text of a **treaty** is accepted (in the case of a UN treaty, by the General Assembly). After adoption, a treaty must usually be **ratified** by individual governments.

Affirmative action (also **positive discrimination, reverse discrimination):** Action taken by a government or private institution to make up for past discrimination in education, employment, or promotion on the basis of gender, race, ethnic origin, religion, or disability.

African Charter on Human and People's Rights (African Charter)**:** A regional human rights treaty for the African continent adopted by the Organization of Africa Unity (OAU) in 1981.

American Convention on Human Rights (American Convention, Pact of San Jose, Costa Rica)**:** A regional human rights treaty **adopted** by the Organisation for American States (OAS) in 1969. It covers North, Central and South America.

Americans with Disabilities Act (ADA): Passed in 1990, this US Federal law provides comprehensive civil rights protections with the aim of achieving full integration in society of people with disabilities. By far the most forward-thinking disability legislation of its time, the ADA has become a model for legislation in many other countries.

Article: A numbered section of a legal document such as a **treaty** or **declaration.** For example, Article 7 of the **Convention on the Rights of Persons with Disabilities** addresses children with disabilities.

Basic Principles for the Treatment of Prisoners: Adopted by the UN General Assembly in 1990, this document sets out standards of good practice in the treatment of prisoners and management of penal institutions. The main emphasis is on the need to safeguard the human rights of the inmates.

Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment: Adopted by the UN General Assembly in 1992, this document sets out standards for treatment of people held in any form of imprisonment, whether in a state prison or some other form of detention.

Committee on Economic, Social and Cultural Rights: The body of independent experts that monitors implementation of the **International Covenant on Economic, Social and Cultural Rights** (ICESCR) by its **States Parties**.

Convention: Legally binding agreement between states; used synonymously with **Treaty** and **Covenant**. Conventions are stronger than **declarations** because they are legally binding for governments that have ratified them. When the UN General Assembly adopts a convention, it creates international norms and standards. Once a convention is adopted by the UN General Assembly, **Member States** can then **sign** and **ratify** the convention, promising to uphold it. Governments that violate the standards set forth in a convention can then be censured by the UN.

Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT Torture Convention) (adopted 1984; entered into force 1987)**: Treaty** defining and prohibiting torture.

Convention on the Elimination of All Forms of Discrimination against Women (CEDAW, Women's Convention) (adopted 1979; entered into force 1981): The first legally binding international document prohibiting discrimination against women and obligating governments to take **affirmative action** to advance the equality of women.

Convention on the Rights of Persons with Disabilities (CRPD) (adopted 2006; opened for signing 2007)**:** Treaty defining the rights of persons with disabilities under international human rights law; first international treaty on disability rights.

Convention on the Rights of the Child (CRC, Children's Convention) (adopted 1989; entered into force 1990)**: Treaty** setting forth a full spectrum of civil, cultural, economic, social, and political rights for children.

Covenant: Binding agreement between states; used synonymously with **convention** and **treaty**. The major international human rights covenants, both **adopted** by the General Assembly in 1966, are the **International Covenant on Civil and Political Rights (ICCPR)** and the **International Covenant on Economic, Social and Cultural Rights (ICESCR)**.

Declaration: Document stating agreed-upon standards but which is not legally binding. UN conferences (e.g., the1993 UN Conference on Human Rights in Vienna, the 1995 World Conference for Women in Beijing) usually produce two sets of declarations: an official document written by government representatives and an unofficial document written by Nongovernmental Organizations (NGOs). The UN General Assembly often issues influential but legally **nonbinding** declarations.

Declaration on the Rights of Persons Belonging to National, or Ethnic, Religious and Linguistic Minorities (adopted 1992): Instrument that recognizes and protects the existence and the national or ethnic, cultural, religious and linguistic identity of minorities.

De facto equality: Equality that exists in practice and people's lived experience as well as in law. De facto equality is achieved only when discrimination is truly absent and people enjoy their rights on an equal basis with others.

Entry into force: The process through which a **treaty** becomes fully binding on the states that have **ratified** it. This happens when the minimum number of **ratifications** called for by the treaty has been achieved.

Equality of opportunity: Equality based on people's ability to be included and enjoy opportunities on the same basis as all other people.

European Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention, European Convention on Human Rights, ECHR): A regional human rights treaty adopted in 1950 by the Council of Europe. All Council of Europe member states are party to the ECHR, and new members are expected to ratify the convention at the earliest opportunity.

Formal equality: Concept of equality that people who are alike should be treated equally and judged on their actual characteristics. Formal equality in employment, for example, would demand that applicants for a job be evaluated on their relevant experience, background, and skills, and that the selection process neither favor nor disfavor anyone based on other factors, such as race, social standing, family connections or other non-relevant matters.

Fulfill human rights: The obligation to "fulfill" human rights means that States must take positive action to ensure that everyone, including people with disabilities can exercise their

human rights. They must adopt laws and policies that promote human rights. They must develop programs and take other measures to implement these rights. They must allocate the necessary resources to enforce laws and fund programmatic efforts.

General Comment: A written statement by the committee that monitors a UN **treaty** (e.g., **Committee on Economic, Social and Cultural Rights)** advising States Parties how best to fulfill their obligations under that treaty. They also analyze and interpret the meaning, content and scope of a treaty.

Habilitation: Effective and appropriate measures aimed to help people attain and maintain maximum independence and full inclusion and participation in all aspects of life and for the benefit of people who are born with a disability or acquire a disability at an early age, to empower them to reach their full potential as they learn and grow. By contrast, **rehabilitation** refers to re-gaining and maintaining maximum independence and full inclusion after acquiring a disability or a change in one's disability.

Human Rights Committee: The body of independent experts that monitors implementation of the **International Covenant on Civil and Political Rights** by its **States Parties.**

Inalienable: Refers to the principle that human rights belong to every person and cannot be taken from a person under any circumstances. Human rights automatically belong to each human being. They are not given to people by their government or any other authority, nor can they can be taken away.

Inclusive education: The education of all children, youth and adults - with and without disabilities - in the general education system of their community. Inclusion involves having access to education with appropriate networks of support and changing the policies, practices, and attitudes within the school system to remove barriers to their learning.

Independent living movement: Part of global advocacy for disability rights, the independent living movement is based on the premise that any person with disabilities should have the choice of living in the community. This can be accomplished through the creation of personal assistance services allowing an individual to manage his or her personal care, to keep a home, to have a job, go to school, worship, and otherwise participate in the life of the community.

Indivisible: Refers to the principle that each human right is of equal importance. A person cannot be denied a right because someone decides it is "less important" or "nonessential."

Informed consent: Refers to the process by which a person is provided with the information necessary to fully participate in decisions about his or her health care. Based on a patient's right to direct what happens to his or her body and the ethical duty of the physician to involve the patient in decision-making.

Inherent: Principle that human rights are a natural part of who you are. The text of Article 1 of the **Universal Declaration of Human Rights** (UDHR) begins "All human beings are born free and equal in dignity and rights."

Instrument: A formal, written, official document, such as a **treaty** or **declaration**, in which a State expresses its intention to uphold certain human rights principles or norms. May be legally binding or **nonbinding**. May be global, regional, or national.

Integrated Education: Placing children with disabilities in the general education system with the expectation that they adapt or "fit in" to the existing system and culture and without providing necessary supports and removing barriers to their learning; differs from **inclusive**

education, which supplies these supports and accommodations.

Inter-American Convention on the Elimination of all forms of Discrimination against Persons with Disabilities: Treaty adopted by the Organisation for American States (OAS) in 1999; first regional treaty specifically addressing disability rights.

Interdependent: Refers to the complementary and interrelated framework of human rights law. For example, your ability to participate in your government is directly affected by your right to express yourself, to get an education, and even to obtain the necessities of life.

Intergovernmental organizations (IGOs)**:** Organizations sponsored by several governments that seek to coordinate their efforts; some are regional (e.g., the Council of Europe, the Organisation of American States), some are alliances (e.g., the North Atlantic Treaty Organization); and some are dedicated to a specific purpose (e.g., the **World Health Organisation, International Labour Organisation**).

International Bill of Human Rights: The combination of the **Universal Declaration of Human Rights (UDHR)**, the **International Covenant on Civil and Political Rights (ICCPR)** and its **Optional Protocol**, and the **International Covenant on Economic, Social, and Cultural Rights (ICESCR)**.

International Convention on the Elimination of All Forms of Racial Discrimination (ICERD, Race Convention) (adopted 1965; entered into force 1969)**: Treaty** defining and prohibiting racial discrimination.

International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (ICRMW) (adopted 1990; entered into force 1998)**: Treaty** defining the rights of migrant workers and their families.

International Covenant on Civil and Political Rights (ICCPR)(Adopted 1966; entered into force 1976)**:** The ICCPR declares that all people have a broad range of civil and political rights. One of the components of the **International Bill of Human Rights** .

International Covenant on Economic, Social, and Cultural Rights (ICESCR) (Adopted 1966; entered into force 1976)**:** The ICESCR declares that all people have a broad range of economic, social, and cultural rights. One of the components of the **International Bill of Human Rights.**

International humanitarian law: Part of international law that applies in times of armed conflict; creates protected status for certain persons including civilians, help for victims and limits to methods of warfare to minimize destruction, loss of life and unnecessary human suffering. Mainly comprises the Geneva Conventions of 1949.

International Labor Organisation (ILO): An **intergovernmental organization** established in 1919 as part of the Versailles Peace Treaty to improve working conditions and promote social justice; the ILO became a Specialized Agency of the UN in 1946.

Interrelated: Refers to the concept that human rights are complementary and affect each other.

Legal capacity: 1) the recognition of someone as a person before the law; ensures that people are legally considered persons and not just objects or the property of others; and 2) the capacity to act; ensures that people are able to exercise their legal capacity, for example regarding financial matters.

Nonbinding: A document, like a **declaration**, that carries no formal legal obligations. It may, however, carry moral obligations or attain the force of law as customary international law.

Nongovernmental organization (NGO): An organization formed by people outside of government. NGOs monitor the proceedings of human rights bodies such as the Human Rights Committee. Some are large and international (e.g., the Red Cross/Crescent, Amnesty International, the Scouts); others may be small and local (e.g., an organization to advocate for people with a particular kind of disability in a particular city). NGOs play a major role in influencing UN policy; many of them have official consultative status at the UN.

Office of the High Commissioner for Human Rights (OHCHR): An office of the United Nations Secretariat mandated to promote and protect all rights established in international human rights laws and **treaties**. Located in Geneva, the OHCHR works to prevent human rights violations, secure respect for all human rights, promote international cooperation to protect human rights, and coordinate related activities throughout the United Nations.

Protocol: A treaty which relates to or modifies another treaty (e.g., adding additional procedures or substantive provisions); Called an "optional protocol" because a government that has ratified the original treaty can choose whether or not to ratify the changes made in the protocol.

Positive discrimination: See **affirmative action.**

Protect human rights**:** The obligation to "protect" human rights means that the State is required to protect everyone, including people with disabilities, against abuses by non-State actors, such as individuals, businesses, institutions, or other private organizations.

Ratification, Ratify: Process by which the legislative body of a state confirms a government's action in signing a treaty; formal procedure by which a state becomes bound to a treaty after acceptance.

Reasonable accommodation: Necessary and appropriate modifications or adjustment to a practice, program, or physical environment so that it is accessible, appropriate, and usable for a person with disabilities on an equal basis with others. Under US law such modifications should not involve "undue hardship" on the person or entity required to provide it.

Rehabilitation: Effective and appropriate measures aimed at helping people attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life as a result of acquiring a disability or a change in one's disability or circumstances. By contrast, **habilitation** refers to helping people who are born with a disability or acquire one at an early age attain and maintain maximum independence and full inclusion.

Respect for human rights: The obligation to "respect" human rights means that States must not interfere with the exercise and enjoyment of the rights of people with disabilities. They must refrain from any action that violates human rights. They must also eliminate laws, policies and practices that are contrary to human rights.

Reverse discrimination: See **affirmative action**.

Signing, Sign: In human rights the first step in ratification of a treaty; to sign a Convention, or one of the Covenants constitutes a promise to refrain from undermining the principles in the document and to honor its spirit.

Special Rapporteur: A person chosen by the UN to report on a particular theme (e.g., on the sale of children, child prostitution and child pornography; on violence against women) or on the human rights situation in a particular country. In 1993 the **Standard Rules** established a Special Rapporteur on Disability, who reports annually on the implementation of the Standard Rules and whose mandate is subject to periodic renewal.

Standard Rules: See **UN Standard Rules on the Equalization of Opportunity for Persons with Disabilities.**

State: Often synonymous with "country"; a group of people permanently occupying a fixed territory having common laws and government and capable of conducting international affairs.

State Party (plural **States Parties):** Those countries that have Ratified a Covenant or a Convention and are thereby bound to conform to its provisions.

Treaty: Formal agreement between states that defines and modifies their mutual duties and obligations; used synonymously with Convention and Covenant. When conventions are adopted by the UN General Assembly, they create legally binding international obligations for the Member States who have signed the treaty. When a national government ratifies a treaty, the articles of that treaty become part of its domestic legal, constitutional obligations.

United Nations Charter: Initial document of the UN setting forth its goals, functions, and responsibilities; adopted in San Francisco in 1945.

UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules): Adopted by the General Assembly in 1993, this **nonbinding** instrument represents a strong moral and political commitment of governments to take action to attain equalization of opportunities for persons with disabilities. Its 22 rules cover all aspects of life of disabled persons and serve as a basis for policy-making and technical and economic cooperation.

A **Special Rapporteur** monitors the implementation of the Rules.

Universal: Human rights apply to every person in the world, regardless of their race, color, sex, ethnic or social origin, religion, language, nationality, age, sexual orientation, disability, or other status. They apply equally and without discrimination to each and every person. The only requirement for having human rights is to be human.

Universal Declaration of Human Rights (UDHR) (Adopted by the UN General Assembly on December 10, 1948)**:** Primary UN document establishing human rights standards and norms. All UN Member States have agreed to uphold the UDHR. Although the UDHR was intended to be **nonbinding**, through time its various provisions have become so respected by states that it can now be said to be customary international law. One component of the **International Bill of Rights.**

Universal design: the design of products, environments, programs and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. A curb cut, for example, serves many people (e.g., parents with strollers, people with rolling luggage, wheelchair users, blind people on the curb, cyclists).

World Health Organisation (WHO): an intergovernmental organization under the auspices of the United Nations that works to promote health worldwide.

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