



United Nations
Human Rights

OFFICE OF THE HIGH COMMISSIONER FOR HUMAN RIGHTS

Monitoring the Convention on the Rights of Persons with Disabilities

Guidance for Human Rights Monitors

Professional training series No. 17



UNITED NATIONS

New York and Geneva, 2010

Note

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the Secretariat of the United Nations concerning the legal status of any country, territory, city or area, or of its authorities, or concerning the delimitation of its frontiers or boundaries.

HR/P/PT/17

Contents

Foreword	05
I. Understanding disability as a human rights issue	07
II. The Convention on the Rights of Persons with Disabilities	12
A. The need for a convention	12
B. Defining disability	15
C. The Convention's principles	17
D. The rights of persons with disabilities	24
E. The Convention's monitoring mechanisms	30
III. Monitoring the rights of persons with disabilities: an overview	33
A. The central role and involvement of persons with disabilities in monitoring	33
B. Identifying and mapping "duty-bearers" and partner organizations	34
C. Building capacity of persons with disabilities and their representative organizations	36
D. The twin-track approach to monitoring the Convention	38
IV. Monitoring in practice	40
A. Collecting information	40
B. Legal and information analysis	54
C. Reporting and follow-up	63
Selected bibliography	65

Foreword

Women, men and children with disabilities are too often amongst the most marginalized in all societies and face unique challenges in the enjoyment of their human rights. For a long time it was assumed that such challenges were the natural and unavoidable consequence of their physical, mental, intellectual or sensory impairment.

The adoption and the entry into force of the Convention on the Rights of Persons with Disabilities and its Optional Protocol challenge such attitudes and mark a profound shift in existing approaches towards disability. In the Convention, the focus is no longer on a perceived “wrongness” of the person, with the impairment seen as a matter of deficiency or disease. On the contrary, the Convention views disability as a “pathology of society”, that is, as the result of the failure of societies to be inclusive and to accommodate individual differences. Societies need to change, not the individual, and the Convention provides a road map for such change.

Human rights monitoring can play a key role in supporting States to effectively implement the Convention at national level and in empowering persons with disabilities to become increasingly aware of their rights, therefore bringing about positive change in the lives of persons with disabilities across regions.

Human rights work requires preparation, technical skills and substantive knowledge in order to be effectively conducted. The purpose of this publication is to assist United Nations human rights officers and other human rights monitors—including from Governments, national

human rights institutions and non-governmental organizations—to engage in monitoring the rights of persons with disabilities, in line with the Convention. This publication provides an explanation of the paradigm shift that the Convention enshrines and of the scope, standards and principles recognized by it. Furthermore, it proposes a methodology for monitoring the rights of persons with disabilities, and provides useful advice on issues to consider when working with persons with disabilities.

Persons with disabilities have historically been invisible in the human rights system and have been overlooked in human rights work. This is no longer acceptable. This publication will assist those engaged in human rights monitoring to effectively include the perspective of persons with disabilities in their activities, by not only integrating persons with disabilities in general monitoring work, but also by paying specific attention to monitoring the situation and enjoyment of rights by persons with disabilities where required.

A handwritten signature in black ink, appearing to read "N. Pillay". The signature is fluid and cursive, with a long horizontal stroke at the end.

Navanethem Pillay

United Nations High Commissioner for Human Rights

I. Understanding disability as a human rights issue

It is estimated that over 650 million people, 10 per cent of the world's population, have a disability. Eighty per cent live in developing countries. Some women, men and children with disabilities are fully integrated in society, and are participating in and actively contributing to all areas of life. However, the great majority face discrimination, exclusion, isolation and even abuse. Many persons with disabilities live in extreme poverty, in institutions, without education or employment opportunities and face a range of other marginalizing factors. In some countries they are denied the right to own property and it is common for persons with disabilities to be denied the right to make decisions for themselves. The discrimination they face is widespread, cutting across geographical boundaries and affecting people in all spheres of life and all sectors of society.

The entry into force of the Convention on the Rights of Persons with Disabilities and its Optional Protocol in May 2008 marked the beginning of a new era in the efforts "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" (art. 1). Although persons with disabilities have always been entitled to the same rights as everyone else, it is the first time that their rights are set out comprehensively in a binding international instrument.

The development of the Convention reflects the shift that has taken place in the way disability and persons with disabilities are seen. Historically, disability has been considered to be a personal condition

I. Understanding disability as a human rights issue

residing in the individual. As an individual deficit, the status of “being disabled” has been viewed as the natural cause for some people being unable to attend a regular school, get a job or participate in social life. When disability is perceived in this way, society’s responses are restricted to only one of two paths: individuals can be “fixed” through medicine or rehabilitation (medical approach); or they can be cared for, through charity or welfare programmes (charity approach). According to this old model, the lives of persons with disabilities are handed over to professionals who control such fundamental decisions as where they will go to school, what support they will receive and where they will live.

Over the past few decades, there has been an important change in the way disability is understood. The focus is no longer on what is wrong with the person. Instead, disability is recognized as the consequence of the interaction of the individual with an environment that does not accommodate that individual’s differences and limits or impedes the individual’s participation in society. This approach is referred to as the social model of disability. The Convention on the Rights of Persons with Disabilities endorses this model and takes it forward by explicitly recognizing disability as a human rights issue.

From this perspective, the social, legal, economic, political and environmental conditions that act as barriers to the full exercise of rights by persons with disabilities need to be identified and overcome. For example, their marginalization and their exclusion from education are not the result of their inability to learn but of insufficient teacher training or inaccessible classrooms; their exclusion from the labour market might be due to a lack of transport to the workplace or

For example, instead of asking: What is wrong with persons with disabilities?

Ask: What is wrong with society? What social, economic, political and/or environmental conditions need to be changed to facilitate the full enjoyment of all rights by all persons with disabilities?

For example, instead of asking: Is it difficult for you to understand people because you are deaf?

Ask: Is it difficult for you to understand people because they are not able to communicate with you?

Questions adapted from: Michael Oliver, *The Politics of Disablement* (Basingstoke, Macmillan, 1990).

negative attitudes among employers and colleagues that a person with disabilities is unable to work; and their inability to participate in public affairs might result from the lack of electoral material in accessible formats such as Braille or voting booths that are physically inaccessible to persons with disabilities.

Viewing disability from a human rights perspective involves an evolution in thinking and acting by States and all sectors of society so that persons with disabilities are no longer considered to be recipients of charity or objects of others' decisions but holders of rights. A rights-based approach seeks ways to respect, support and celebrate human diversity by creating the conditions that allow meaningful participation by a wide range of persons, including persons with disabilities. Protecting and promoting their rights is not only about providing disability-related services. It is about adopting measures to change attitudes and behaviours that stigmatize and marginalize

I. Understanding disability as a human rights issue

The following terms capture the difference between considering persons with disabilities as holders of rights rather than objects of charity:

Charity approach	Human rights approach
Option	Obligation
External control	Autonomy
Disempowerment	Empowerment
Fixing weakness	Fixing the environment
Limiting activity	Facilitating activity
Belittling	Dignifying
Dependence	Independence
Discrimination	Equality
Institutionalization	Inclusion
Segregation	Integration

persons with disabilities. It is also about putting in place the policies, laws and programmes that remove barriers and guarantee the exercise of civil, cultural, economic, political and social rights by persons with disabilities. To achieve a genuine exercise of rights, the policies, laws and programmes that limit rights need to be replaced, such as: immigration laws that prohibit entry to a country based on disability; laws that prohibit persons with disabilities to marry; laws that allow the administration of medical treatment to persons with disabilities without their free and informed consent; laws that allow detention on the basis of mental or intellectual disability; and policies that deny medical care to a person because he or she has a disability. Moreover, programmes, awareness-raising and social support are necessary to change the way society operates and to dismantle the barriers that prevent persons with disabilities from participating fully in society. Furthermore, persons with disabilities need to be provided with the opportunities to participate fully in society and with the adequate means to claim their rights.

II. The Convention on the Rights of Persons with Disabilities

II. The Convention on the Rights of Persons with Disabilities

A. The need for a convention

The core international human rights instruments that precede the Convention on the Rights of Persons with Disabilities recognize the rights of all, including persons with disabilities. While these instruments offer significant potential to promote and protect the human rights of persons with disabilities, this potential has not yet been fully realized.¹

The Convention on the Rights of Persons with Disabilities marks the end of a long struggle by persons with disabilities and their representative organizations to have disability fully recognized as a human rights issue, which began back in 1981, with the International Year of Disabled Persons and the World Programme of Action concerning Disabled Persons, adopted as the outcome of that Year. The adoption, in 1993, by the United Nations General Assembly of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, the reports of the Special Rapporteurs on Disability and of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, and a series of resolutions by the Commission on Human Rights in 1998, 2000 and 2002, contributed significantly to paving the way for a human rights approach.

¹ See G. Quinn and T. Degener, *Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability* (New York and Geneva, United Nations, 2002) (HR/PUB/02/1). This study concluded that the United Nations treaty bodies and civil society had not used existing human rights instruments and monitoring mechanisms to their full potential to protect and promote the rights of persons with disabilities.

Other important landmarks were general recommendation No. 18 (1991) on disabled women by the Committee on the Elimination of Discrimination against Women, general comment No. 5 (1994) on persons with disabilities by the Committee on Economic, Social and Cultural Rights and the adoption of regional instruments, such as the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (1999).

The Convention on the Rights of Persons with Disabilities supersedes these instruments as the most recent, specialized and comprehensive treaty to recognize the human rights of persons with disabilities and to clarify the obligations of States to respect, protect and fulfil those rights. By so doing, the Convention enshrines the social and human rights model of disability.

II. The Convention on the Rights of Persons with Disabilities

The nine core international human rights instruments

International Convention on the Elimination of All Forms of Racial Discrimination

International Covenant on Economic, Social and Cultural Rights

International Covenant on Civil and Political Rights

Convention on the Elimination of All Forms of Discrimination against Women

Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment

Convention on the Rights of the Child

International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families

Convention on the Rights of Persons with Disabilities

International Convention for the Protection of All Persons from Enforced Disappearance (not yet into force)

B. Defining disability

The Convention does not include a definition of disability or persons with disabilities in the strict sense but rather provides some guidance on the concept of “disability” and its relevance to the Convention. The preamble clearly endorses a social approach to disability—referred to as the social model of disability—by recognizing that “disability is an evolving concept and that disability results from 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 explicit reference to the barriers that are external to the subject as constituting factors of disability represents an important step away from notions that equated disability to the existence of functional limitations.² Accordingly, article 1 states: “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” (emphasis added). From this perspective, persons with disabilities’ participation in society—be it having a job, going to school, visiting a doctor or running for elections—is limited or excluded not because of their having an impairment, but because of various barriers, which might include physical barriers but also legislation and policies in some cases.

² See, for example, the explanation of the concept of disability contained in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (General Assembly resolution 48/96), according to which “the term ‘disability’ summarizes a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness” (para. 17).

II. The Convention on the Rights of Persons with Disabilities

For persons with physical disabilities these barriers might include uneven terrains, steps to connect different levels, heavy doors or narrow passages. For example, a person using a wheelchair might be excluded from attending a meeting if the door to the meeting room is too narrow for the wheelchair to pass, or if there is no ramp or lift. The inexistence or inadequacy of accessibility standards in building codes could also amount to a barrier.

The Convention does not preclude the use of definitions in national legislation and, in fact, definitions might be particularly necessary in some sectors, such as employment or social security. It is important, however, for such definitions to reflect the social model of disability enshrined in the Convention and for definitions based on a list or a description of impairments or on functional limitations to be revised. Monitors should observe whether national legislation: (a) recognizes that discrimination can occur in relation to mental, intellectual, sensory or physical impairments; (b) incorporates the social model by referring to disability as the result of the interaction between the person with an impairment and external barriers; (c) focuses on the prohibition of discrimination and the promotion of equality rather than on the categorization of various disabilities.

C. The Convention's principles

Article 3 of the Convention identifies a set of overarching and foundational principles. These guide the interpretation and implementation of the entire Convention, cutting across all issues. They are the starting point for understanding and interpreting the rights of persons with disabilities, providing benchmarks against which each right is measured.

General principles (art. 3)
Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
Non-discrimination
Full and effective participation and inclusion in society
Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
Equality of opportunity
Accessibility
Equality between men and women
Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

II. The Convention on the Rights of Persons with Disabilities

What do these principles mean?

Inherent dignity refers to the worth of every person. When the dignity of persons with disabilities is respected, their experiences and opinions are valued and are formed without fear of physical, psychological or emotional harm. Respect for dignity is denied when, for example, workers who are blind are forced by their employer to wear a shirt with the word “blind” printed on the back.³

A woman with a disability in India reported the following violation of her right to dignity:

“Added to all this is the behaviour of people, especially men when I have to go out on my own and have to cross roads somewhere. The people who come forward to help me do not think of this as a good deed and make it into a chance always to touch me differently and to misbehave in every way possible. For me this is an inevitable, as I would have to take someone’s help in order to cross and for them it is a chance to behave as cheaply as can be, and there is nothing I can do about this, as I cannot do without the help or support of someone when I am out on the roads all by myself and this kind of experience is something I have had to face on several occasions in my life, not once or twice.”

Source: “Monitoring the human rights of people with disabilities—country report: Andhra Pradesh, India” (Disability Rights Promotion International, 2009), available at www.yorku.ca/drpi

³ This example is taken from interviews conducted in the Philippines as part of a project by Disability Rights Promotion International (DRPI) and Katipunan ng Maykapansanan sa Pilipinas, Inc. (KAMPI) to monitor the rights of persons with disabilities in that country. The interviews contributed to “Monitoring the human rights of persons with disabilities: Preliminary report Philippines”, available at: www.yorku.ca/drpi/resources.html

Individual autonomy means to be in charge of one's own life and to have the freedom to make one's own choices. Respect for the individual autonomy of persons with disabilities means that persons with disabilities have, on an equal basis with others, reasonable life choices, are subject to minimum interference in their private life and can make their own decisions, with adequate support where required. The principle pervades the Convention and underpins many of the freedoms that it explicitly recognizes, such as the freedom from non-consensual medical intervention and the requirement that health care should be provided on the basis of free and informed consent. From this perspective, for example, a person with mental disabilities should be offered a range of options for mental health care such as psychotherapy, counselling, peer support and psychiatric medication, and should have the freedom to make a meaningful choice based on personal preferences. Likewise, a landmine survivor with a physical impairment should be provided with devices that facilitate his or her personal mobility so that he or she can enjoy as much independence as possible.

The principle of **non-discrimination** means that all rights are guaranteed to everyone without distinction, exclusion or restriction based on disability or on race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, age, or any other status. Discrimination on the basis of disability means any distinction, exclusion or restriction which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise by persons with disabilities, on an equal basis with others, of all human rights and fundamental freedoms, and includes the denial of reasonable accommodation. Discrimination occurs, for example,

II. The Convention on the Rights of Persons with Disabilities

when a woman is not allowed to open a bank account on the grounds that her disability would not allow her to manage her money.⁴ Discrimination also occurs when a man who was offered a job after an interview is later told to go home and wait for written confirmation from the administration after the employer realizes that the man has a visual impairment and needs to hold books very close to his eyes. The correspondence never arrives and the man never takes up the job.⁵ Persons with disabilities might also experience multiple forms of discrimination; for example, a woman with disabilities might experience discrimination on the basis of sex as well as disability. The recognition of the principle of non-discrimination in article 3 underlines the importance of considering discrimination in all its forms.

Equality means creating societal conditions that respect difference, address disadvantages and ensure that all women, men, girls and boys participate fully on equal terms. Equality is denied when a girl with a disability is taken out of school by her parents. Despite her good grades, her parents decide that it is useless to spend money on her education because of her disability.⁶ Achieving equality sometimes requires additional measures such as the provision of assistance to persons with psychosocial or intellectual disabilities in order to support them in making decisions and in exercising their legal capacity on an equal basis with others.

⁴ This example is taken from interviews conducted in Kenya as part of a project by DRPI, the African Union of the Blind, the Kenya Union of the Blind and the Centre for Disability Rights, Education and Advocacy to monitor the rights of persons with disabilities in that country. The interviews contributed to “State of disabled people’s rights in Kenya (2007): Report”, available at: www.yorku.ca/drpi/Kenya.html

⁵ See note 4.

⁶ See note 4.

Reasonable accommodation (art. 2)

“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 (art. 2).

“Accommodation” is the adjustment of a rule, practice, condition or requirement to take into account the specific needs of an individual with disabilities, with the aim of enabling this person to participate fully and equally. In the workplace, accommodation can include acquiring or adapting software and keyboards for an employee with a visual impairment, training or allocating extra time to complete a task. In education, reasonable accommodation might require the provision of alternative ways to fill course requirements, tutorial assistance or assistive technology.

Employers, educational institutions, service providers and others have a legal obligation to provide reasonable accommodation. In deciding whether a company or a school has taken all required measures to accommodate an employee or a pupil with a disability, the concept of “disproportionate or undue burden” is key. To establish a lawful exemption from the duty to accommodate, the employer or school must prove that accommodating the needs of an individual would impose an undue or disproportionate burden on the organization considering factors such as health, safety or cost.

II. The Convention on the Rights of Persons with Disabilities

The concepts of **full and effective participation and inclusion** and **accessibility** mean that society, both in its public and in its private dimensions, is organized to enable all people to take part fully. Being fully included in society means that persons with disabilities are recognized and valued as equal participants. Their needs are understood as integral to the social and economic order and not identified as “special”. To achieve full inclusion, an accessible, barrier-free physical and social environment is necessary. For instance, full and effective participation and inclusion mean that political election processes do not exclude persons with disabilities, ensuring, for example, that voting locations are accessible and election procedures and materials are available in multiple formats and easy to understand and use. Linked to the concept of participation and inclusion is that of universal design, which is defined in the Convention as the “design of products, environments, programmes and services that should be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (art. 2). In other words, the design phase should consider the needs of all members of society, to ensure that special adaptations are not required later on.

Respect for difference involves accepting others in a context of mutual understanding. This incorporates the acceptance of disability as part of human diversity and humanity. Despite some visible or apparent differences, all people have the same rights and dignity. In this way, for example, before pulling away from a bus stop, a bus driver will give a boy with a physical disability enough time to get up from the bench at the bus shelter, board the bus and reach his seat. Not only does the bus driver ensure that quality and safe transport is provided to all users, but the bus schedule also takes into account

various factors, including the requirements of persons with disabilities and other users of public transport. Importantly, the Convention does not seek to prevent disability—which is a medical approach—but rather to prevent discrimination on the basis of disability. Campaigns to prevent accidents and promote safe childbirth and motherhood are relevant to public safety and health. However, when such campaigns are promoted in the context of persons with disabilities, disability is perceived in negative terms, shifting attention away from respect for difference and diversity as well as from combating discrimination—the primary focus of the human rights model.

These general principles are at the core of the Convention and are central to monitoring the rights of persons with disabilities.

II. The Convention on the Rights of Persons with Disabilities

D. The rights of persons with disabilities

The Convention on the Rights of Persons with Disabilities is a wide-ranging human rights treaty covering the full spectrum of civil, cultural, economic, political and social rights. The Convention does not establish new rights for persons with disabilities; instead, it elaborates on what existing human rights mean for persons with disabilities and clarifies the obligations of States parties to protect and promote these rights. In order to ensure an environment conducive to the fulfilment of the rights of persons with disabilities, the Convention also includes articles on awareness-raising, accessibility, situations of risk and humanitarian emergencies, access to justice, personal mobility, habilitation and rehabilitation, as well as statistics and data collection.⁷

⁷ “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” (A/HRC/4/75, para 19).

Articles 10 to 30 cover the rights guaranteed to persons with disabilities**Article 10 – The right to life****Article 11 – Situations of risk and humanitarian emergencies****Article 12 – Equal recognition before the law****Article 13 – Access to justice****Article 14 – Liberty and security of the person****Article 15 – Freedom from torture or cruel, inhuman or degrading treatment or punishment****Article 16 – Freedom from exploitation, violence and abuse****Article 17 – Protecting the integrity of the person****Article 18 – Liberty of movement and nationality****Article 19 – Living independently and being included in the community****Article 20 – Personal mobility****Article 21 – Freedom of expression and opinion, and access to information****Article 22 – Respect for privacy****Article 23 – Respect for home and the family****Article 24 – Education****Article 25 – Health****Article 26 – Habilitation and rehabilitation****Article 27 – Work and employment****Article 28 – Adequate standard of living and social protection****Article 29 – Participation in political and public life****Article 30 – Participation in cultural life, recreation, leisure and sport**

II. The Convention on the Rights of Persons with Disabilities

To illustrate how rights are relevant to specific situations facing persons with disabilities, consider the following examples when monitoring the Convention:

- › **The right to equal recognition before the law** requires, inter alia, eliminating disability as a ground for depriving someone of his or her legal capacity—for example, by eliminating the practice of appointing guardians who make decisions on behalf of persons with disabilities and, instead, providing support to persons with disabilities so that they can make their own decisions;
- › **The right to liberty and security of the person** requires, inter alia, monitoring psychiatric and other institutions to ensure that no one is placed there on the basis of their disability, including mental and intellectual disabilities, unless with their free and informed consent;
- › **Freedom from torture** requires, inter alia, examining whether institutions resort to practices and treatments such as electroshock therapy and cage beds for persons with disabilities, or impose intrusive or irreversible medical treatments aimed at correcting the disability against a person's will;
- › **Freedom of movement** requires, inter alia, examining whether the State withholds travel documents from someone on the basis of his or her disability;
- › **The right to education** requires, inter alia, examining whether pupils and students with disabilities are not excluded from the general education system on the basis of their disability, that

reasonable accommodation of the pupil's requirements is provided in the general education system and that effective individualized support measures are provided to maximize academic and social development consistent with the goal of inclusion;

- › **The right to health** requires, inter alia, not only an examination of whether there is universal access to essential medicines but also whether treatments are provided on the basis of the free and informed consent of the person with a disability;
- › **The right to work** requires, inter alia, examining whether labour laws prohibit discrimination in the workplace and require employers to take positive steps to ensure physically accessible buildings as well as accessible technology such as computer and Internet technology for those persons with disabilities that may require it;
- › **The right to an adequate standard of living** requires, inter alia, an examination of social programmes and policy frameworks, poverty reduction strategies, national development plans and projects, such as projects related to the Millennium Development Goals, to ensure that they include the promotion and protection of the right to food, clothing, housing and other rights of persons with disabilities;
- › **The right to participate in public and political life** requires, inter alia, election monitoring to ensure that election materials are provided in accessible formats (such as written materials in Braille and television advertisements with sign-language interpretation) and that voting booths are accessible (for example, with ramp access);

II. The Convention on the Rights of Persons with Disabilities

- › **The right to participate in cultural life** requires, inter alia, examining whether sign languages and deaf culture are explicitly recognized and supported and whether copyright protection does not inhibit access to cultural materials such as talking books.

Civil, cultural, economic, political and social rights are indivisible, interdependent and interrelated. An understanding of this interdependence is important to monitor the rights of persons with disabilities. For example, the monitoring of institutions requires monitoring whether the persons have been deprived of their liberty based on the existence of a disability (the right to liberty and security of the person), whether the persons are subject to medical treatment without their free and informed consent (the right to health, to physical and mental integrity and to be free from torture) as well as whether persons in the institution enjoy adequate food, clothing, light, sanitary conditions and so on (the right to an adequate standard of living).

With regard to economic, social and cultural rights, the Convention on the Rights of Persons with Disabilities reaffirms the obligation of States to progressively implement them, as already recognized in article 2 of the International Covenant on Economic, Social and Cultural Rights and article 4 of the Convention on the Rights of the Child. The recognition that the full realization of economic, social and cultural rights may be constrained by limited resources is balanced by the requirement that measures should be taken to the maximum of a State's available resources and, where needed, within the framework of international cooperation (Convention on the Rights of Persons with Disabilities, arts. 4 (2) and 32).

Progressive realization of economic, social and cultural rights

Article 4 (2) states:

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.

Several aspects of the progressive realization of economic, social and cultural rights are important for monitoring purposes:⁸

- › Discrimination on any grounds, including disability, is always forbidden, regardless of the level of realization of economic, social and cultural rights;
- › States have an immediate obligation to ensure a minimum essential level of enjoyment of each economic, social and cultural right;
- › States have an obligation to take steps towards the progressive realization of these rights. A State, for example, can develop a plan of action which should include: (a) a time frame for implementing economic, social and cultural rights; (b) time-bound benchmarks of achievement; and (c) indicators of success;

⁸ See also Committee on Economic, Social and Cultural Rights, general comment No. 3 (1990) on the nature of States parties' obligations.

II. The Convention on the Rights of Persons with Disabilities

- › States are forbidden from taking regressive steps or measures that diminish the enjoyment of economic, social and cultural rights.

E. The Convention's monitoring mechanisms

The Convention includes both national and international monitoring mechanisms.

At the national level, article 33 identifies three mechanisms that are relevant for the implementation and monitoring of the Convention. First, States have to designate one or more focal points within government for matters relating to implementation; second, States have to give due consideration to the establishment or designation of a coordination mechanism within government to facilitate actions across sectors and at different levels; and third, States have to establish or designate a framework that includes one or more independent mechanisms to promote, protect and monitor the Convention's implementation.

At the international level, article 34 establishes the Committee on the Rights of Persons with Disabilities, a committee of independent experts with several functions. First, on the basis of periodic reports received from States and other interested parties such as national monitoring mechanisms and civil society organizations, the Committee engages in a constructive dialogue with States on the implementation of the Convention, and issues concluding observations and recommendations for follow-up action to improve and strengthen implementation. Second, the Committee holds days of general discussion, open to the

public, during which it discusses issues of general interest arising from the Convention. Third, the Committee may issue authoritative statements, known as general comments, to clarify specific provisions in the Convention or specific issues arising in the implementation of the Convention. Fourth, the Optional Protocol gives the Committee authority to receive complaints, known as communications, from individuals alleging violations of any of the Convention's provisions by a State that has ratified the Optional Protocol. The Committee may present its views after considering the complaint in the light of the comments from the State concerned. Fifth, the Optional Protocol also provides the Committee with an opportunity to undertake inquiries in States parties if it receives reliable information indicating grave or systematic violations of the Convention.

Human rights monitors⁹ should be aware of these mechanisms and of their functions. Monitoring activities could:

- › Provide national monitoring mechanisms with information on the state of implementation of the Convention;
- › Provide information to the Committee for its constructive dialogue with States;

⁹ For the purpose of this guidance, "human rights monitors" include United Nations human rights officers as well as staff in other intergovernmental, regional or civil society organizations, national human rights institutions, human rights defenders and other individuals or organizations engaged in human rights monitoring.

II. The Convention on the Rights of Persons with Disabilities

- › Identify potential breaches of the rights of individuals under the Convention which could form the basis of a communication to the Committee under the Optional Protocol if the State concerned has ratified it;
- › Identify reliable information on grave or systematic violations of the Convention which could be submitted to encourage the Committee to undertake an inquiry under the Optional Protocol if the State concerned has ratified it;
- › Follow up on recommendations of the national monitoring mechanisms and the Committee to strengthen implementation of the Convention.

III. Monitoring the rights of persons with disabilities: an overview

Robust, evidence-based reports by States, national human rights institutions, disability organizations and other civil society groups and United Nations offices with a relevant mandate will contribute to ensuring that the human rights guaranteed under the Convention are transformed into action and real change in the lives of persons with disabilities. Before considering the modalities of monitoring, it is important to bear in mind the following factors that should guide all monitoring activities.

A. The central role and involvement of persons with disabilities in monitoring

Persons with disabilities and their representative organizations¹⁰ played an integral role in the formulation and negotiation of the Convention under the slogan “Nothing about us without us!” The Convention recognizes that this role must continue, requiring States parties to “closely consult with” and “actively involve” persons with disabilities in decision-making processes related to them (art. 4 (3)). In particular, the Convention requires that “civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process” (art. 33 (3)). This has implications for both process and substance. In terms of process, persons with disabilities must be involved in monitoring activities, for example by having persons with disabilities among the

¹⁰ Note that sometimes representative organizations of persons with disabilities self-identify as “disabled persons’ organizations” or use the abbreviation “DPO.”

III. Monitoring the rights of persons with disabilities: an overview

monitors. By way of substance, the voices and experiences of persons with disabilities must be central in monitoring reports in recognition of the fact that persons with disabilities are the experts on their own situation.

It is also important to ensure that efforts to monitor the human rights situation of persons with disabilities do not contribute to further marginalizing persons within a particular group. Monitoring the rights of persons with disabilities must have a cross-disability and cross-society focus. That is, monitoring must involve women, men, girls and boys with the full spectrum of types of disabilities—including those with physical, mental, intellectual or sensory impairments—and from all socio-economic and ethnic backgrounds, age groups and walks of life. For example, it must reach and include those who are poor, homeless or institutionalized.

B. Identifying and mapping “duty-bearers” and partner organizations

An important first step for those engaged in monitoring the human rights of persons with disabilities is to identify and map the various actors in the monitoring process. Importantly, monitors should identify relevant “duty-bearers”, including the ministries with responsibilities related to persons with disabilities, such as the ministry of justice, attorney-generals, departments and ministries of social protection, employment and labour, culture and sport, as well as health. Given the Convention’s references to private entities, monitors might also consider employer associations and unions as potential partners in

monitoring and even actors that have responsibilities for respecting the rights of persons with disabilities.

Keep in mind the goal of ensuring a cross-disability and cross-society focus and identify organizations of persons with disabilities (DPOs) in the area being monitored. For example, note that some of these organizations will have a cross-disability membership. Others will represent people with a particular type of impairment, e.g., a visual impairment or a psychosocial disability, or particular groups of people, e.g., women with disabilities, war veterans. Monitors should also establish and promote communication networks with a broad range of additional partners. These partners can come from different regions and sectors (including universities, research institutions, NGOs, trade unions, professional groups, intergovernmental organizations) and focus on different people (including organizations working with women, children and indigenous peoples). The Inter-Agency Support Group, comprising United Nations departments, agencies, funds and programmes, seeks to coordinate United Nations work on the Convention.¹¹ Monitors might therefore consider contacting other United Nations entities or the World Bank either as partners in monitoring or as sources of information.

¹¹ The Inter-Agency Support Group on the Convention on the Rights of Persons with Disabilities (IASG) was established by the United Nations Chief Executives Board in September 2006. IASG is a mechanism for international cooperation in support of the promotion and implementation of the Convention and its Optional Protocol. Its members include the Office of the United Nations High Commissioner for Human Rights (OHCHR), the Department of Economic and Social Affairs (DESA), the United Nations Development Programme (UNDP), the United Nations Children's Fund (UNICEF), the World Health Organization (WHO), the International Labour Organization (ILO), the United Nations Population Fund (UNFPA), United Nations Mine Action and the Office of the United Nations High Commissioner for Refugees (UNHCR).

III. Monitoring the rights of persons with disabilities: an overview

C. Building capacity of persons with disabilities and their representative organizations

In many cases, engaging with DPOs will also imply building the capacity of persons with disabilities in these organizations to understand human rights principles and concepts. In other words, capacity-building is part of and complements monitoring work. In all cases, capacity-building activities must be fully accessible to all. Partner DPOs and their members will be able to inform monitors of the various measures that should be taken to ensure full accessibility.

Checklist of accessibility considerations for capacity-building and monitoring activities:

1. Printed materials (e.g., training manuals, information about the monitoring process, consent forms, questionnaires)

- Ensure production of materials in all formats and languages necessary for full participation (e.g., Braille, large print, electronic, sign languages, easy-to-read-and-understand formats)

2. Visual aids (e.g., computer slide presentations, photographs, diagrams, maps, videotapes)

- Ensure that an adequate description of the information conveyed through these aids is communicated in an accessible format (e.g., providing text and descriptions of images displayed in the slides of a computer presentation)

Checklist of accessibility considerations for capacity-building and monitoring activities: (cont.)

- 3. Verbal communications** (e.g., face-to-face and telephone meetings, training sessions, audiotapes, monitoring interviews)
- Ensure allocation of adequate time and the involvement of the necessary interpreters/facilitators to ensure that persons who are deaf, deaf-blind, with intellectual disabilities or who use augmentative and alternative communication both understand what is being said by others and can communicate their own ideas (e.g., sign-language interpretation, real-time transcription, communications assistant)
- 4. Locations** (e.g., for meetings, training sessions, interviews)
- Ensure access for those using mobility devices (e.g., avoid locations with stairs, narrow passages, cramped rooms)
 - Ensure availability of accessible toilets
 - Ensure participants can reach location by cost-effective and accessible transport
 - Ensure adequate signs in multiple formats and/or the availability of people to assist participants to reach the location (e.g., signs in Braille, greeters)
 - Remember to consult closely with partner DPOs to identify accessibility requirements. Whenever possible, consult directly with the person(s) participating in the activity to ensure that their particular requirements are met

Note that these considerations are not exhaustive. Monitors must remember to address accessibility case by case.

III. Monitoring the rights of persons with disabilities: an overview

D. The twin-track approach to monitoring the Convention

Monitoring the rights of persons with disabilities requires a twin-track approach:¹²

- › First, monitoring might warrant a specific focus on the rights of persons with disabilities in order to be effective. For example, if parliament is considering ratifying the Convention, it might be appropriate to analyse specifically whether the existing legal framework complies with the Convention and to monitor the implementation of existing laws and policies. Similarly, the particular issues related to inclusive education—unsegregated schools, accessible buildings, adequate curriculum, properly trained teachers—might warrant a monitoring activity specifically focused on the right to education of pupils and students with disabilities;
- › Second, monitoring should not reinforce an approach that considers persons with disabilities as inherently different from others. Consequently, monitoring their rights should be integrated into general human rights monitoring work. For example, monitoring freedom from torture should cover psychiatric institutions as well as prisons and should also pay attention to persons with disabilities in prisons; monitoring a development programme has to consider the impact of the project on persons with disabilities, as beneficiaries on the same grounds as other targeted groups. Importantly, many national human rights institutions, disability organizations and other

¹² This term refers to an approach that combines the mainstreaming of disability in all initiatives/projects, on the one hand, with disability-specific initiatives/projects, on the other, in order to ensure equal rights for all persons with disabilities. Several donors have included this approach in their international development and aid policies.

civil society groups and United Nations offices work in conflict or post-conflict situations. Persons with disabilities can be particularly vulnerable in such situations, confronted with specific challenges in fleeing emergencies or when displaced as a result of conflict, facing obstacles in the physical environment and being removed from personal and physical support networks. Consequently, it is important to consider their rights in human rights monitoring related to conflict, emergency and post-conflict situations.

IV. Monitoring in practice

IV. Monitoring in practice

Monitoring comprises a range of steps, from the collection of information, to legal and information analysis, documentation and reporting, corrective action and follow-up, and, finally, evaluation. These activities are interlinked in what is called the **monitoring cycle**. This chapter focuses on: (a) the collection of information; (b) legal and information analysis; and (c) documentation and reporting/corrective action and follow-up.

A. Collecting information

1. Documents-based information

The collection of information about the enjoyment by persons with disabilities of their rights typically starts with the identification of sources of information. Monitors should consider a variety of sources:

- › Constitutions, legislation and regulations are primary sources of information. In addition, monitors could also consider other sources such as parliamentary inquiries or reports;
- › State policies and programmes relating to the implementation of legislation as well as budgets;
- › Decisions of judicial and quasi-judicial bodies such as courts and national human rights institutions;

- › Media reports, studies and research from academia or other research centres and civil society organizations.

Monitors can rely on print sources (e.g., collections of official documents), electronic searches of legislation and case-law databases, and electronic search engines to monitor media reporting on disabilities.

Collecting information on **legislation**, including constitutional provisions, statutes, codes and regulations, provides a means of understanding the extent to which laws discriminate against persons with disabilities, as well as the extent to which they promote the rights of persons with disabilities. Collecting information on **policies**—State strategies or directions that might not necessarily be binding—can be vital to understand whether there is the political will to move from legislation to implementation of the Convention. In countries that have ratified the Convention, monitoring legislation and policies raises at least two kinds of questions:

- › Given the fact that many countries have adopted legislation and policies on disabilities even before ratification, a first step in monitoring is to review whether that legislation and those policies comply with the Convention. This review might identify normative gaps or laws that are in conflict with the Convention, for example by violating a prohibition.
- › If national legislation and policies comply with the Convention, it is important to monitor how they are in fact implemented, through programmes or other measures.

IV. Monitoring in practice

Collecting information on **programmes** can ensure that the practical and financial measures are in place to promote the realization of the rights of persons with disabilities recognized in legislation. The term “programmes” is broad and can refer to many measures taken to implement the Convention. For example, it could refer to development programmes or poverty-reduction programmes. In that case, monitors should identify whether such programmes include persons with disabilities and are supportive of their rights.

Furthermore, the monitoring of programmes should include budget monitoring, as some of the obligations on States require the allocation of financial and human resources to ensure that positive steps are taken to promote the rights of persons with disabilities and that they are effective.¹³ Budget analysis might be relevant to issues such as accessibility, support for persons with disabilities, including supported decision-making, inclusive education, medical services, social protection and national monitoring mechanisms. Monitors engaging in budget analysis might examine financial commitments in national disability plans of action, budgets from the ministries of education, public works or social affairs, and the budget of national human rights institutions. Some questions to bear in mind in the analysis of budgets are:

- › Is there any analysis of financial costs associated with the realization of a given right for person with disabilities?

¹³ See, generally, Jim Shultz, “Promises to keep. Using public budgets as a tool to advance economic, social and cultural rights” (Mexico, Ford Foundation and Fundar, 2002); and *Dignity counts. A guide to using budget analysis to advance human rights* (Fundar, Institute of International Education and International Budget Project, 2004).

- › Have sufficient funds been allocated to meet the requirements set to realize the right in question?
- › What is the amount allocated in a specific area to promoting the rights of persons with disabilities compared to overall expenditure in that area? For example, what percentage of the education budget is directed towards ensuring inclusive education for persons with disabilities?
- › What is the difference between budget allocation and budget spending? Has there been underspending or have budget commitments not been met?
- › Have budgets increased over time?
- › Are budget allocations and spending earmarked for disability limited to particular ministries or programmes? If so, what type?

Collecting and studying **legal cases** involving disability issues decided by courts of law, national human rights institutions and other judicial or quasi-judicial decision-making bodies provides evidence of how these bodies apply rights guarantees to particular situations and interpret and enforce legislation, policies and programmes. Monitoring legal cases can provide information to help understand the implementation of the Convention and of legislation related to the rights of persons with disabilities and how justice is, or is not, accessible to them. It is also important to look at whether decisions are then executed. For example, a court might have issued an order for the reinstatement

IV. Monitoring in practice

of a person with disabilities who was unfairly dismissed. Yet, if the employer never recalls that person, he or she will not receive redress.

Media reports, studies and research from academia, other research centres and civil society organizations can also prove very useful. In particular, collecting information through the **media** can help to monitor society's attitudes towards persons with disabilities. Societal attitudes represent a barometer of sociocultural values and influence how people choose to act and respond to others.¹⁴ In the particular context of disability, negative attitudes have led to stereotyping, labelling and discrimination. These views play an important role in facilitating, or hampering, the enjoyment of human rights by persons with disabilities. Recognizing the significant impact societal attitudes have on the perception of persons with disabilities and their contribution to society, the Convention dedicates a whole article to awareness-raising and the obligation of States to combat stereotypes, prejudices and harmful practices relating to persons with disabilities (art. 8 (1) (a)–(b)). Given the important role that the media play in both reflecting and influencing public opinion, the Convention requires States to take steps to encourage all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the Convention (art. 8 (2) (c)). In this way, monitoring societal attitudes is important to understand the human rights situation of persons with disabilities.

¹⁴ Tiffany J. McCaughey and Douglas C. Strohmer, "Prototypes as an indirect measure of attitudes toward disability groups", *Rehabilitation Counseling Bulletin*, vol. 48, No. 2 (January 2005), p. 89.

Monitoring the media

- › **Do the media report on persons with disabilities?**
- › **If so, which media do that, in which sections of their products?**
- › **Are persons with disabilities portrayed as victims or rights-holders?**
- › **Do the media represent the point of view of persons with disabilities?**
- › **Are language and images appropriate?**
- › **Does the media's message reinforce or counter stereotypes?**
- › **Has there been a change in media reporting on persons with disabilities over time? If so, in which way (e.g., more or less reporting, different approach)? Which factors contributed to the change?**
- › **Is it an accurate representation of real life?**
- › **Are the media accessible to persons with disabilities?**

IV. Monitoring in practice

2. Other sources of information: “Nothing about us without us”

There is often a significant gap between legal and policy provisions on paper and the reality of people’s everyday lives. It is therefore necessary to complement document-based materials with information from persons with disabilities on their experience and views. Consequently, key interviews with persons with disabilities, their representative organizations, policymakers, service providers and others can help to gather information on how laws and policies are being implemented and the extent to which States respect, protect and fulfil the rights of persons with disabilities.¹⁵

It is important for persons with disabilities to have their voices heard. Monitoring individual experiences should attempt to be as inclusive as possible, by adopting strategies to ensure that women, men, girls and boys with the full range of disabilities—including intellectual, physical, mental and sensory disabilities—from various socio-economic and ethnic backgrounds, age groups and walks of life, a range of community sizes, urban and rural populations, are given an opportunity to participate. To address the complex realities they face, the scope of monitoring their individual experiences must also be broad, encompassing the full spectrum of human rights—civil,

¹⁵ Working with persons with disabilities and their representative organizations in various countries, Disability Rights Promotion International (DRPI) has developed a template to assist with the collection of legislation, policy and programme data specific to the rights of persons with disabilities. The template is designed to gather data on all categories of rights (civil, cultural, economic, political and social). The template also serves as an assessment tool, facilitating the identification of gaps in legislation and policy. It includes cross references to the relevant provisions of key international human rights treaties, including the Convention. It is available on the DRPI website at: <http://www.yorku.ca/drpi/resources.html>

cultural, economic, political and social—and addressing matters in both the public and private spheres.

The most effective way to monitor individual experiences is through face-to-face interviews. Interviews can yield both quantitative and qualitative data, as persons with disabilities are given an opportunity to identify and speak about those issues that are most important to them in terms of denial of and access to rights.¹⁶

Monitors should obtain the **free and informed consent** of the interviewee, given the long history of research having been conducted “on” persons with disabilities without their consent. Monitors should also maintain the **privacy** and **safety** of interviewees and the **confidentiality** of the information provided, where necessary. Depending on the situation, interviews might have to take place without family members, carers or other people present, in a location where the conversation cannot be overheard. Family members, carers or other people might be responsible for the human rights violations experienced by the person with a disability (e.g., where the other person is responsible for physical or psychological abuse or has prevented the person with a disability from leaving the home to avoid bringing the shame attached to disability in some societies upon the family). It is important to ensure that the interviewee can speak freely and without fear of reprisal.

¹⁶ In collaboration with partner organizations of persons with disabilities, DRPI has developed monitoring tools (interview guide and other field documents) and training materials (training course and supporting manuals) to facilitate collection, analysis and reporting on such interviews. These materials are available on its website at: <http://www.yorku.ca/drpi/>.

IV. Monitoring in practice

3. Working with persons with disabilities

Two general issues are essential to bear in mind when monitoring the rights of persons with disabilities. First, remember that the aim is to monitor **the rights** of persons with disabilities and not **disability**. Thus, monitors should be asking what society has or has not done which is obstructing the full enjoyment of their rights—not how their physical or mental impairment has affected the enjoyment of their rights. For example, when monitoring the right to education, consider that poor teacher training, negative attitudes and prejudice or inaccessible schools are likely the reason why a person with disabilities does not enjoy the right to education fully, rather than the person being blind, deaf or having a psychosocial disability.

Second, remember to work directly with persons with disabilities. Given the invisibility of persons with disabilities in most societies, ask representative organizations for assistance in meeting relevant individuals. Furthermore, it is important to communicate directly with the person—not with carers, health professionals, family members or others, even if those people claim to speak for the person. Communicating directly with the individual may entail the use of assistive devices, sign-language interpreters or support persons. It is, therefore, important for monitors to be aware that the interviewee's message could be inaccurately or incompletely communicated or misunderstood (e.g., be aware of the relationship between the support person and the individual, the familiarity of the individual with the assistive device). If carers and others are trusted companions they might be able to give invaluable information but it is important

not to assume this. Some people who claim to care for persons with disabilities might intentionally or unintentionally be contributing to abuse.

The rest of the section provides some guidelines on etiquette, particularly when interviewing persons with disabilities.¹⁷

¹⁷ The material has been adapted from Victor Piñeda, “Portraying people with disabilities in the media”, *Landmine Survivors Network Media Advocacy Handbook* (Disability Media Institute, 2006).

IV. Monitoring in practice

Generally...

- › **Shake hands when introduced to someone with a disability, if handshaking is culturally acceptable. People with limited hand use or artificial limbs do shake hands;**
- › **Speak directly to the person, not through companions;**
- › **Language is important. Avoid expressions such as “disabled”, “handicapped”, “victim”, “afflicted with”, “invalid”, “normal”, “patient” or “wheelchair-bound”. Avoid overuse of words such as “courageous”, “brave” or “inspirational”. Accepted terminology according to the Convention is “persons with disabilities”, not “disabled person”; “rights of persons with disabilities”, not “disability rights”. The Convention uses the terms “mental disability” and “intellectual disability” although some prefer the term “psychosocial disability”. If a person with disabilities prefers the use of certain terminology, respect that person’s wishes, unless it can be considered derogatory or undermining dignity;**
- › **Do not be embarrassed about using phrases such as “I see what you mean” or “I hear what you are saying”, “walk this way” or “I have to run, I’m late”. These are common expressions and unlikely to offend;**
- › **If you offer help, wait until the offer is accepted;**
- › **Consider the needs of people before meeting them. If the person is in a wheelchair, try to find a room with ramp access. If the person has a companion, find a room big enough for an additional person;**
- › **Conduct interviews in a manner that focuses on the enjoyment of rights rather than on the disability;**
- › **Do not assume or act as if persons with disabilities are heroic or courageous just by virtue of having a disability. This emphasizes difference. Persons with disabilities have strengths and weaknesses just as persons without disabilities.**

When interviewing persons who are hard of hearing or deaf...

- › **Attract the person's attention by tapping on her or his shoulder or by waving;**
- › **Use sign-language interpreters when you interview sign-language users;**
- › **Address the person directly and not the interpreter;**
- › **If you are interviewing someone with a partial hearing loss, ask where it would be best for you to sit;**
- › **If the person lip-reads, look directly at her or him and speak slowly and clearly. Do not exaggerate lip movements or shout. Be expressive, as facial expressions, gestures and body language will help her or him to understand you;**
- › **Position yourself facing the light source and keep hands and food away from your mouth when speaking.**

When interviewing persons with visual disabilities...

- › **Always identify yourself and anyone else who might be present;**
- › **When offering a handshake, say "shall we shake hands?";**
- › **When offering seating, place the person's hand on the back or arm of the seat;**
- › **Let the person know if you move or need to end the conversation;**
- › **Consider whether the person might require information in Braille or any specific physical accommodation if the interview is not taking place in the interviewee's own space (Braille numbers in the lift, contrasting colours on steps and so on).**

IV. Monitoring in practice

When interviewing persons with speech disabilities...

- › **Ask short questions that require short answers when possible;**
- › **Do not feign understanding. Try rephrasing your questions, if necessary;**
- › **Is it possible to provide sign-language interpretation or cover costs for the interviewee's interpreter?**

When interviewing persons using a wheelchair or crutches...

- › **Do not lean on a person's wheelchair. The chair is part of her or his body space;**
- › **If possible, sit or otherwise place yourself at eye level with the person you are interviewing;**
- › **Make sure the interview site is accessible. Check for:**
 - ☑ Reserved parking for persons with disabilities
 - ☑ A ramp or step-free entrance
 - ☑ Accessible toilets
 - ☑ A lift if the interview is not on the ground floor
 - ☑ Water coolers and telephones low enough for wheelchair users
- › **Notify the interviewee in advance if there are problems with the location. Discuss inaccessibility with the interviewee and make alternative plans, if necessary.**

When interviewing persons with intellectual disabilities...

- › **Allocate adequate time to the interview;**
- › **Speak clearly, use plain language, explain technical terms and rephrase your questions as necessary;**
- › **Ask short but precise questions and clarify requirements/needs;**
- › **Consider in advance whether the person might require information in accessible formats, for example by rendering documents in plain language, using pictures or drawings, etc. Printed work should be in large print and double-spaced;**
- › **If the interviewee has a support person:**
 - ☑ Address the interviewee directly and not the support person
 - ☑ Ask the interviewee if you can ask questions to the support person if required
 - ☑ Ask the support persons to be in attendance, but clarify that they should not influence the interviewee.

IV. Monitoring in practice

B. Legal and information analysis

Once monitors have collected adequate information, the next step is to analyse it to consider whether States are meeting their obligations in relation to the rights of persons with disabilities. To do this, it is helpful to make reference to the obligations to **respect, protect** and **fulfil** the rights set out in the Convention. The following section provides examples of how to monitor some of the rights of persons with disabilities in this respect. It is important to note that this is only an illustrative and not an exhaustive list. Monitors should take the time to read the Convention's relevant articles and apply the "respect/protect/fulfil" framework accordingly.

1. The right to equal recognition before the law and legal capacity

General monitoring question:

Do persons with disabilities enjoy their legal capacity to act?

Obligation to respect:

Example: United Nations human rights officers monitored a case in which a judge disqualified a woman with a disability, who had allegedly been the victim of sexual violence, from giving testimony. The judge argued that she was not a credible source given her disability. This action by the judge is a clear violation of the State's obligation to respect.

- › **Is there a legal guarantee recognizing the right of persons with disabilities to enjoy legal capacity on an equal basis with others?**
- › **Are there exceptions to this legal guarantee which could be discriminatory, for instance on the basis of mental or other types of disability? (E.g., provisions could refer to exceptions for people “of unsound mind” or “who are insane”.)**
- › **Is there a legal mechanism through which persons with disabilities are fully or partially deprived of their legal capacity to act on the basis of their disability? (E.g., a legal process by which another person is appointed to represent and act on behalf of the person with the disability, full or partial guardianship.)**
- › **Does the law allow persons with disabilities to engage in legal acts on an equal basis with others? (E.g., marriage; divorce; opening bank accounts; accessing bank loans, mortgages and other forms of financial credit; voting; defending their rights in court; participating as witnesses in legal proceedings; owning or inheriting property; making wills; controlling their own medical treatment.)**

IV. Monitoring in practice

1. The right to equal recognition before the law and legal capacity (cont.)

Obligation to protect:

- › **How does the State protect persons with disabilities from abuse of their right to exercise their legal capacity? Has the State established appropriate and effective safeguards to prevent abuse of the support provided to persons with disabilities in the exercise of their legal capacity?**
- › **What redress is available to persons with disabilities if their right to exercise legal capacity is denied? (E.g., if a service provider refuses to accept a person's expression of will as valid; if the consent of a family member or guardian is required in all circumstances for a person with a disability to access medical treatment.)**

Obligation to fulfil:

- › **Has the State enacted laws, policies and programmes, including legally recognized mechanisms, to provide persons with disabilities with the support they may require in the exercise of their legal capacity?**
- › **Does the State provide persons with disabilities with support where required to directly participate in legal proceedings and exercise their legal capacity to act, including through facilitating the use of sign language, Braille or plain language? Or are they allowed to participate only through their legal guardians?**

Example: Monitors have documented cases in which persons with disabilities have been forced to live in institutions. The right to live independently requires States to ensure access by persons with disabilities to residential and other community services to support living independently in the community. Failure to do so constitutes a breach of the obligation to fulfil.

2. Living independently and being included in the community

General monitoring question:

Do persons with disabilities have the right to live in the community, with choices equal to others?

Obligation to respect:

- › **Are there legal protections recognizing the right of persons with disabilities to choose their place of residence and where and with whom they want to live on an equal basis with others?**
- › **Are there legal protections to ensure that persons with disabilities are not forced into particular living arrangements?**

Obligation to protect:

- › **Are there legal protections to ensure that persons with disabilities are not forced by family members or others into particular living arrangements?**
- › **Are there legal mechanisms and remedies that persons with disabilities can use to challenge barriers to living independently?**
- › **Has the State taken measures to enforce and monitor the implementation of the right to live independently in the community?**

Obligation to fulfil:

- › **Are there laws, policies and programmes that ensure access for persons with disabilities to a range of in-home and other community services, including personal assistance, necessary to support living and inclusion in the community?**
- › **Are there laws, policies and programmes to ensure that community services and facilities for the general public are made available on an equal basis to persons with disabilities and are responsive to their needs?**

IV. Monitoring in practice

3. Accessibility

General monitoring question:

Do persons with disabilities enjoy access on an equal basis with others to the physical environment, transport, information and communications technologies and systems and other facilities and services open to the public?

Obligation to respect:

- › **Are there legal protections to ensure access on an equal basis with others to all physical environments, transport, information and communications technologies and systems and other facilities and services open to the public?**
- › **Has the State developed minimum accessibility standards and guidelines?**
- › **Do the minimum standards and guidelines apply in both rural and urban areas?**
- › **Is the State engaging in any acts, customs or practices that create barriers to accessibility?**

Barriers to accessibility can take many forms, including:

- › **physical – barriers in the environment, particularly those in infrastructure (e.g., public toilet stalls that are too small for wheelchairs);**
- › **informational – barriers can arise from both the form and the content of information (e.g., electronic documents in formats that cannot be read using screen readers are not accessible to persons who are blind; information that is not in plain language is not accessible to many persons with intellectual disabilities, oral information not available in sign language or where there is no possibility of sign-language interpretation can be inaccessible to most deaf people).**

3. Accessibility (cont.)

Obligation to protect:

- › **Has the State taken legal action to ensure that private entities (e.g., restaurants, theatres, grocery shops, taxi companies and other businesses offering facilities and services to the public) remove existing barriers to access for persons with disabilities and do not create new ones?**
- › **Are there legal remedies and mechanisms that persons with disabilities can use when access is not available?**
- › **Has the State taken measures to enforce and monitor the implementation of minimum accessibility standards and guidelines?**

Obligation to fulfil:

- › **Does the State provide training for stakeholders on accessibility for persons with disabilities?**
- › **Has the State taken steps to provide signs in Braille and easy-to-read-and-understand forms and other types of live assistance and intermediaries (e.g., guides, readers and sign-language interpreters)?**
- › **Has the State taken measures to promote access to new information and communications technologies and systems, including the Internet, at an early stage?**

IV. Monitoring in practice

4. The right to education

General monitoring question:

Do persons with disabilities have access to inclusive education at all levels?

Obligation to respect:

- › **Does legislation expressly recognize the right to inclusive education?**
- › **Does the State refuse students with disabilities entry into the general education system?**
- › **Does the State maintain a system of segregated schools which students with disabilities are required to attend?**
- › **Are students with disabilities forced to study certain subjects or are they excluded from taking certain classes on the basis of their disability?**
- › **Are students with disabilities required to undergo any medical treatment as a condition of being admitted to school?**

Obligation to protect:

- › **Has the State adopted legislative and other measures to prevent persons with disabilities from being excluded from the general education system?**
- › **Does the State require private educational facilities to take steps to ensure the accessibility of their premises and technology with a view to removing obstacles to the inclusion of persons with disabilities in the education system?**

4. The right to education (cont.)

Obligation to fulfil:

- › **Do girls with disabilities suffer multiple discrimination in enjoying their right to education?**
- › **Has the State taken steps to provide support, including individualized support, to students with disabilities consistent with the goal of inclusive education?**
- › **Has the State taken steps to ensure the accessibility of schools, other educational facilities and technology?**
- › **Has the State taken steps to employ teachers, including teachers with disabilities, who are qualified in sign language and Braille?**
- › **Does the State provide and require the training of teachers and other professionals who can help ensure inclusive education?**

IV. Monitoring in practice

5. The right to liberty and security of the person

General monitoring question:

Are persons with disabilities deprived of their liberty on the basis of their disability?

Obligation to respect:

- › **Do persons with disabilities have the right to liberty and security on an equal basis with others?**
- › **Do laws permit the deprivation of liberty (in a prison, psychiatric institution or other facility) on account of a person having a disability, whether alone or in combination with other factors?**

Obligation to protect:

- › **Does the State prohibit third parties, such as family members, from institutionalizing persons with disabilities on the basis of their disability?**
- › **Does the State provide a remedy to persons with disabilities who are deprived of their liberty on the basis of their disability?**

Obligation to fulfil:

- › **Does the State provide reasonable accommodation for persons with disabilities who are legally deprived of their liberty (e.g., as a result of criminal proceedings)?**

Monitoring freedom from exploitation, violence and abuse

Given the abuse that persons with disabilities have suffered in institutions and through services which nominally should serve them, such as health institutions, article 16 on “freedom from exploitation, violence and abuse” specifically requires States to monitor facilities and programmes:

“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.”

C. Reporting and follow-up

The monitoring cycle also includes documentation and reporting, and corrective action and follow-up. During these two steps, it is important to bear in mind the principle of participation and the motto of persons with disabilities and their representative organizations, “Nothing about us without us”. This means that, where practicable, monitors should check with persons with disabilities and their representative organizations that reporting has adequately and correctly summarized the human rights situation as it affects individuals and that they are broadly in agreement with the recommendations for corrective action. This is important given the explicit inclusion of the principle of participation in the Convention and the fact that persons with disabilities have so long been excluded from decision-making processes affecting them. Monitors should also be aware of the difference between organizations of persons with disabilities (DPOs) and NGOs working on disability, including service providers. Careful consideration should be given to the position of DPOs, especially if organizations have diverging views.

IV. Monitoring in practice

However, monitors must also weigh the imperative of participation with the practical and political concerns of human rights work. For instance, in the context of United Nations human rights field presences, it may in some cases be appropriate for monitoring reports to remain internal for a period of time. Sometimes there may be disagreement with organizations of persons with disabilities on the content of the report or on the steps for corrective action and follow-up. It is always important to remember that, while participation remains the overall goal, the organization undertaking the monitoring is ultimately responsible for the contents, conclusions and recommendations of its report.

Monitors should therefore strike a balance between the principle of participation and respect for the mandate, confidentiality of data and witnesses, and victim protection. The difficulties of this process should not be underestimated as there is often a very high expectation on the part of persons with disabilities and their representative organizations to be included in such processes. Monitors may consider documenting the process of participation and ensure adequate reasons are provided to underpin their conclusions and recommendations for corrective action.

Selected bibliography

Publications and reports

African Union of the Blind. State of disabled people's rights in Kenya: Report. Nairobi, 2007. 130 p. Available at: www.yorku.ca/drpi

African Union of the Blind and Cameroon National Association for the Blind. Study on the rights of persons with disabilities in Cameroon. 2007. 146 p. Available at: www.yorku.ca/drpi

Degener, Theresia. Disability as a subject of international human rights: law and comparative discrimination law. *In* The human rights of persons with intellectual disabilities: Different but equal. By Herr, S., L. Gostin and H. Koh, eds. Oxford, Oxford University Press, 2003. pp. 151–184.

Disability Rights Promotion International. Phase I report: Opportunities, methodologies, and training resources for disability rights monitoring. Toronto, Disability Rights Promotion International, 2003. 70 p. Available at: <http://www.yorku.ca>

Human rights. Yes! Action and advocacy on the rights of persons with disabilities. *By* Lord, J. *and others*. Minneapolis, Human Rights Resource Center, University of Minnesota, 2007. (Human rights educations series topic book 6) Available: <http://www.umn.edu>

Selected bibliography

Katipunan ng Maykapansanan sa Pilipinas, Inc. and Disability Rights Promotion International. Monitoring the human rights of persons with disabilities; Preliminary report Philippines. 2009.
Available at www.yorku.ca/drpi/resources.html

Linqvist, B., M. Rioux and R. Samson. Moving forward: Progress in global disability rights monitoring. Toronto, Disability Rights Promotion International, 2007.
Available at: <http://www.yorku.ca>

Oliver, Michael. The politics of disablement.
Basingstoke, Macmillan, 1990.

Quinn, G. and T. Degener. Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability. New York and Geneva, United Nations, 2002. (HR/PUB/02/1)
Available at: <http://www.ohchr.org>

Rioux, Marcia. On second thought: constructing knowledge, law, disability and inequality. *In* The human rights of persons with intellectual disabilities: Different but equal. By Herr S., L. Gostin and H. Koh, eds. Oxford, Oxford University Press, 2003. pp. 287–317.

UNICEF and the Victor Piñeda Foundation. It's about ability: An explanation of the Convention on the Rights of Persons with Disabilities. New York, UNICEF, 2008.
Available at: <http://www.unicef.org>

_____ It's about ability: Learning guide on the Convention on the Rights of Persons with Disabilities. New York, UNICEF, 2009.
Available at: <http://www.unicef.org>

United Nations, Office of the United Nations High Commissioner for Human Rights and Inter-Parliamentary Union. From exclusion to equality: Realizing the rights of persons with disabilities. Handbook for parliamentarians. Geneva, United Nations, 2007. (Professional training series No. 14)
Available at: <http://www.ohchr.org>

United Nations. Convention on the Rights of Persons with Disabilities: Advocacy Toolkit. 2008. Available at: <http://www.ohchr.org>

[United Nations official documents \(available at: www.ods.un.org\)](http://www.ods.un.org)

United Nations. General Assembly. Thematic Study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities. (A/HRC/10/48)

_____ Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. (A/63/175)

_____ 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. (A/HRC/4/75)

Selected bibliography

Websites

United Nations, Enable: <http://www.un.org/disabilities/>.

Office of the United Nations High Commissioner for Human Rights:
<http://www.ohchr.org/>.