Disability Rights Promotion International

A Guide to Disability Rights Monitoring

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In developing its training resources, DRPI has worked in partnership with members of organizations of persons with disabilities who have participated in pilot projects in Bolivia, Cameroon, Canada, India, Kenya, New Zealand and the Philippines, along with participating monitors, site coordinators and project coordinators from each of those countries. All have contributed to the content and organization of this manual. Many students in the Critical Disability Studies graduate program at York University, Canada also worked on aspects of the manual.

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Disability Rights Promotion International

www.yorku.ca/drpi

This publication has been produced by Disability Rights Promotion International (DRPI). In November 2000, the United Nations Special Rapporteur on Disability, Bengt Lindqvist, hosted an international seminar at the Almåsa Conference Centre in Sweden. Twenty-seven experts from around the world discussed measures to strengthen the protection and promotion of the human rights of persons with disabilities. The seminar was attended by representatives of all the major international disability organisations, the UN Office of the High Commissioner for Human Rights and the UN Secretariat, disability rights activists and experts on human rights. Seminar participants recommended the creation of a global system to monitor disability rights – that is, to collect, track and report on information about ways in which persons with disabilities are enjoying their human rights. The DRPI project was designed and developed by Bengt Lindqvist and Marcia Rioux to work towards creating a global disability rights monitoring system.

As governments of countries around the world ratify the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol, it is important to make sure that the rights guaranteed to persons with disabilities on paper are achieved in their daily lives. For the CRPD to have a real and positive impact on the lives of persons with disabilities, governments need to have a baseline of information so that they can identify gaps in whether and how persons with disabilities are exercising their rights. This information makes it possible to measure how the situation is improving. Collecting, tracking and reporting on information about whether persons with disabilities are enjoying their rights, also called 'monitoring' rights, plays an important role in this process.

Working collaboratively with persons with disabilities, their organizations and allies, DRPI has developed tools and methods to facilitate disability rights monitoring as well as supporting materials and courses to build capacity in monitoring. DRPI has adopted the twin-track approach to advancing the rights of persons with disabilities, that is, recognizing the importance of universal ratification, implementation and monitoring of the CRPD to achieving the full enjoyment of rights by persons with disabilities while also acknowledging the important role to be played by other human rights treaties that apply to persons with disabilities, for example, the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the International Covenant on Civil and Political Rights (ICCPR). In keeping with the twin-track approach, DRPI's tools and methods can be used to monitor both the CRPD and the other international and regional human rights treaties that apply to persons with disabilities.

DRPI has its International Coordination Centre at York University in Toronto, Canada and regional centres in Africa (Kigali, Rwanda), Asia-Pacific (Bangkok, Thailand), Europe (Belgrade, Serbia), Latin America (Buenos Aires, Argentina) and North America (Toronto, Canada). It has partnered with organizations of persons with disabilities, national human rights institutions, universities and research centres around the world to conduct disability rights monitoring projects lead by persons with disabilities, in 10 countries located across all continents. DRPI monitoring reports from Kenya (2007), Cameroon (2007), India (2009), Bolivia (2009), Philippines (2009) Canada (2010) and New Zealand (2010), submissions made to the UN Commission on the Status of Women (2008) and Human Rights Council (2010), as well as DRPI's disability rights monitoring tools, training materials and information about current monitoring activities are all available on the project website: http://www.yorku.ca/drpi/.

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Module 1: Human Rights, Disability & Monitoring

This module looks at disability as a human rights issue and monitoring the human rights of persons with disabilities.

1.1 Introduction to the Global Situation of Persons with Disabilities

1. The Global Picture of Disability

Here are some facts from international organizations about the lives of persons with disabilities around the world:

- There are approximately 785 to 975 million persons with disabilities (over age 15) in the world. In some countries they make up more than 15.6% of the population. Persons with disabilities are the world's largest minority group (WHO World Report on Disability, 2011).

- 80% of persons with disabilities live in developing countries. (UN Development Programme, 2011)

- 20% of the world's poorest people have some kind of disability and tend to be regarded in their own communities as the most disadvantaged. Persons with disabilities are often the "poorest of the poor". (World Bank, 2008)

- 80% of persons with disabilities live in rural areas. (UN Department of Economic and Social Affairs, Factsheet)

- Women and girls with disabilities are recognized as having multiple disadvantages. They experience exclusion because of both their gender and their disability. They are particularly vulnerable to abuse. (UNENABLE, Factsheet, 2011).

- 30% of youth who live rough (that is, live on the streets) have some kind of disability (UNENABLE, Factsheet, 2011).

- Death rates for children with disabilities may be as high as 80% in some countries. (UN CRPD, Factsheet, 2006)

- In countries with life expectancies over 70 years, people spend an average of 8 years living with disabilities. (UNENABLE, Factsheet, 2011)

- Only 45 countries have anti-discrimination or other disability-specific laws. (UNENABLE, Factsheet, 2011)

- By September, 2011, 149 countries had signed and 103 had ratified the United Nations *Convention on the Rights of Persons with Disabilities.* Similarly, 90 countries had signed and 62 had ratified its *Optional Protocol*. (UN Enable website, 2011)

2. Discrimination Faced by Persons with Disabilities around the World

Many children and adults with disabilities are ignored. Their rights are not recognized. They do not have chances to participate in the activities of their communities. Schools refuse to accept them as children. Employers do not hire them as adults.

Persons with disabilities continue to face discrimination in both the richest and poorest countries of the world. Here are examples of some of the many ways that the human rights of persons with disabilities are violated on a daily basis:

- *A man in India says that he has not been paid properly for any of the jobs that he has held because he is a person with a disability.*
- *A woman in Bolivia enters a hospital to deliver her baby and the nurses will not take care of her.*
- *A child in the United States is denied the right to go to school with her brothers and sisters because she has an intellectual disability.*
- *A young man with a disability is put on the street to beg in Hong Kong.*
- *A man who is blind falls off a bridge with a broken guardrail in Jamaica and is severely injured.*
- *A man in Kenya explains his experience of discrimination on the basis of disability: "Sometimes I feel that I am in prison."*
- *A woman in Canada is left to lie for hours in her soiled bed by an abusive personal attendant.*
- *A woman with a psychiatric disability in Uruguay has been in a hospital for 20 years "waiting for her sister to pick her up."*
- *A young man with an intellectual disability in Sudan is tied to the ground by a rope inside a tent. His family does not want him to get lost and they don't know what to do or where to take him.*
- *A woman in Nepal is abandoned by her husband after he has taken her dowry.*

Causes of Discrimination

Persons with disabilities are often denied basic human rights. There are many reasons why this happens including:

- Myths/Misinformation
- Attitudes
- Language
- Social and Legal Barriers
- Environmental Barriers

Myths/Misinformation:

In many societies, what people think about persons with disabilities comes from myths and misinformation that consider persons with disabilities as:

- sick, deformed or undesirable
- throwaways
- non-people
- menaces (bringing disease, danger)
- people to make fun of

These myths have been used to deny rights and entitlements to persons with disabilities. Even though most people will experience some form of disability at some point in their lives, people who do not have disabilities often treat people who have disabilities as “others” (that is, as a separate group, different from others and isolated.

Attitudes:

Over time, persons with disabilities have been seen in many negative ways. For example, persons with disabilities have been considered carriers of sin, demons, bad luck, helpless dependents, in need of charity and second class citizens.

When people have negative attitudes or ideas toward persons with disabilities they put up invisible barriers that limit the experiences and opportunities of persons with disabilities. For example, because of negative attitudes, persons with disabilities have been:

- isolated in institutions and special schools or in their homes
- taught to be ashamed of themselves and their disabilities
- controlled by caregivers by being told what to do, and when and how to do it.

In all countries, these negative attitudes have led to the exclusion of persons with disabilities through social, legal and environmental barriers including degrading language.

Language:

An important way that people are left out is through language. Words that highlight the differences between persons with disabilities in a negative way – whether used by professionals like doctors, therapists and teachers, written in newspapers or spoken in the street - make people feel that they are not valued. This language often leads to people making fun of or shunning persons with disabilities because of those differences.

Consider these different ways of talking about persons with disabilities:

Instead of…	**Use…**
• disabled, handicapped, crippled	• person(s) with a disability
• lame	• person who has a mobility impairment
• confined, bound, restricted to, or dependent on a wheelchair	• person who uses a wheelchair
• deaf and dumb	• person who is deaf or hard of hearing
•	•

Social and Legal Barriers:

In many places, laws, policies and practices put in place by governments and others in the community or country have meant that persons with disabilities have been denied their basic human rights including such rights as:

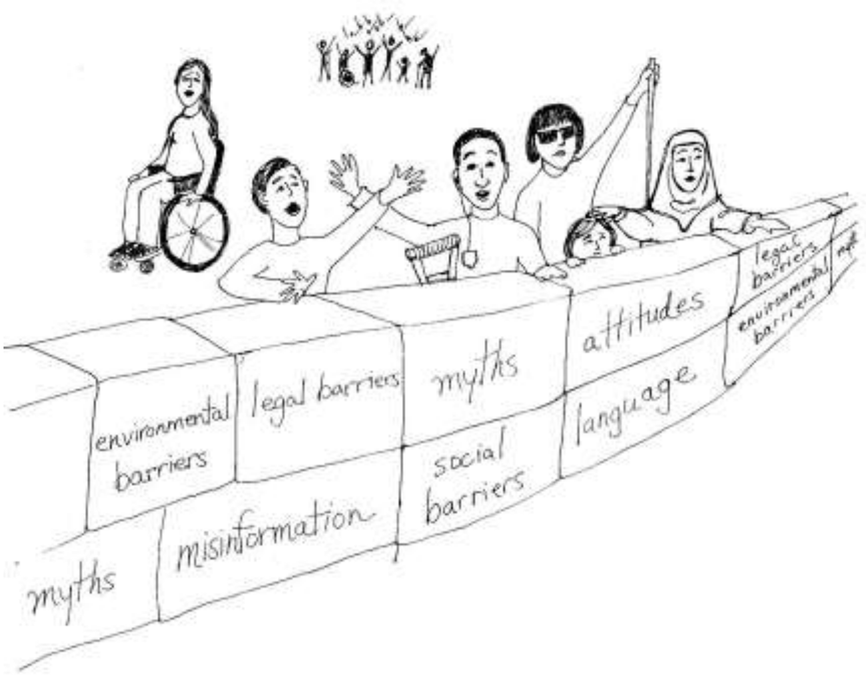
- the right to live;
- the right to vote
- the right to marry;
- the right to work;
- the right to have children and raise families;
- the right to inherit property;
- the right to go to school
- the right to access the same services that other people have and specific services that persons with disabilities need

Environmental Barriers:

Environmental barriers have also resulted in exclusion. An environmental barrier is created when buildings, products, services or open spaces are designed or work in a way that makes it difficult for persons with disabilities to use them.

Environmental barriers create obstacles that prevent persons with disabilities from equal participation in their communities and their societies. For example, a person with a psycho-social disability might have difficulty dealing with the amount of information found in a grocery store. A person who uses a wheelchair might not be able to travel on a sidewalk or road that has potholes. A person who is blind might have difficulty finding his doctor's office in a building that does not have Braille signs or door markers.

Universal design is an approach to the design of products, services and environments that makes them usable by as many people as possible regardless of age, ability or situation. Universal design recognizes that many different people live in a communitiy and takes that into acount from the beginning. However, no matter how good universal design is, it still might not accommodate all persons with disabilities. To be sure that everyone is included, it is important to keep looking for additional adaptations.



Over the past forty years, persons with disabilities around the world have stopped seeing themselves as "sick," "tragic" or "different". They are seeing themselves as people like everyone else and members of their communities. Through their involvement in the disability rights movement, persons with disabilities have come to recognize that often the way they are treated is unfair and discriminatory. Disability is another characteristic just like gender, age, and race. There is nothing "abnormal" about persons with disabilities. Everyone is different in some way and so are persons with disabilities. The world is like a patchwork quilt – each piece of the quilt is different but all people are part of the quilt.

1.2 Disability as a Human Rights Issue

1. Changing Ways of Looking at Disability

Over the last forty years, there has been an important change in the way persons with disabilities are seen. Ideas about disability are changing.

(a) The Old Way: Seeing Disability as a Problem of the Person

For centuries, disability has been seen as a ’problem’ of the person who has a particular impairment or something that people regard as being ‘wrong with them’ (for example, having only one leg, low vision, a difficulty learning, etc.). The person with an impairment is thought to have to change, or be “fixed” in order to fit into society – to be able to access their community. Because disability was viewed then as an illness or a pathology, it became the job of the professionals to diagnose what to do about the condition, to fix the problem. This has meant that control over the lives of persons with disabilities has been handed over doctors or others seen as experts. For example, sometimes, doctors, rehabilitation experts or psychologists have decided what support persons with disabilities would receive, where they would live, if they would be ignored, whether they would get food or whether someone without a disability would be given the little food that is available. Sometimes, if the professionals could not “fix” the impairment, a person was ignored and rejected because they didn’t fit into their communities. For example, a child with an intellectual disability was not allowed to go to school because it was assumed he or she could not learn. People were denied the opportunity to work without even being given the chance to show what skills they had for the job. This still happens in many countries and communities.

Seeing disability as the problem of the person affects the way that persons with disabilities are treated by society and by their communities. It means that persons with disabilities may be:

- considered to be less important than persons without disabilities
- treated like helpless victims needing care and protection
- assumed not to deserve or be able to manage the same rights and responsibilities as everyone else

Seeing disability as the problem of the person affects what the society does about the discrimination people with disabilities face. Seeing disability as a ‘personal problem’:

- Makes it the responsibility of the person with the disability and his or her family to find ways to get included in society
- Considers that people with medical knowledge, such as medical researchers and other experts, are authorities on disability and whose scope extends beyond medical issues.
- Overshadows the expertise brought forward by people with disabilities on their own lived experiences and knowledge.

Approaches that start with the idea that disability is an individual problem can be divided into two models: biomedical model and functional model.

(i) Biomedical Model:

Disability = medical, biological issue, pathology
Person with Disability = a person who has something wrong with them and needs medical treatment or a cure
Experts = doctors, medical researchers
Solution = eliminate disabilities through cures or treatment

(ii) Functional Model:

Disability = personal issue, something that is not ‘normal’, a pathology
Person with Disability = someone who is unable to “function” in society because they have an impairment, something is wrong with the individual
Experts = physiotherapists, vocational trainers, social workers, rehabilitation professionals, service providers
Solution = improve or provide comfort with rehabilitation, physiotherapy, occupational therapy, life-skills training, counseling, special education, special housing

(b) Rethinking Disability:
Seeing Disability as an Interaction between the Person & Society

More recently, a new way of looking at disability has developed. Instead of searching for what is wrong with the person with the disability, this approach changes the focus to what is wrong with society. Thinking this way does not deny that people have impairments but it also recognizes that persons with disabilities are people who have human rights and who are entitled to participate and be involved in their communities. Instead of trying to cure or “fix” individuals, this approach looks for ways that political, social, economic and physical environments and systems exclude persons with disabilities. Disability is not a problem of a particular person, but a result of the way that society and communities are set up and function. Thinking this way, including persons with disabilities in all aspects of society is a public responsibility and something that concerns all members of society.

Approaches that look at disability as a social problem can be divided into two models: an environmental model and a human rights model.

(i) Environmental Model:

Disability = caused by social/physical environments that do not allow for difference
Person with Disability = a person with differences in a diverse population of people
Experts = people with disabilities
Solution = eliminate systemic barriers, e.g. adapt physical and social environments to accommodate people with disabilities

(ii) Human Rights Model:

Disability = dimension of human culture / part of the human patchwork quilt
Person with Disability = a person with differences entitled to the rights enjoyed by other people
Experts = persons with disabilities
Solution = recognize that persons with disabilities have the same rights as everyone else meaning that human variation must be taken into account by making laws and policies that include everyone

Disability as a Personal Problem	**Disability as a Result of the Way Societies and Communities are Set Up**
Can you tell me what is wrong with you?	Can you tell me what is wrong with society?
What condition makes it difficult for you to hold, grip or turn things?	What problems in the design of everyday equipment like jars, bottles and tins make it difficult for you to hold, grip or turn them?
Is it difficult for you to understand people because you are deaf?	Is it difficult for you to understand people because they are not able to communicate with you?
Do you have a scar, or some physical characteristic, that limits your daily activities?	Do other people’s reactions to your scar or physical characteristic limit your daily activities?
Did you go to a special school because of a disability?	Did you go to a special school because of your community’s policy of sending people with your disability to these places?
Does your disability stop you from going out as often or as far as you would like?	What is it about the area where you live that makes it difficult for you to get around in your neighbourhood?
Does your disability cause problems at work?	Do you have problems at work because of the physical environment or the attitudes of others?
Do you need to live with relatives or someone else who can help or look after you because of your disability?	Are the services in your community so poor or so limited that you need to rely on relatives or someone else to provide you with the right level of personal assistance?
Have you had to adapt where you live because of your disability?	Did the poor design of your home mean that you had to have it adapted to suit your needs?
This exercise has been adapted from: Oliver, M. (1990) *The Politics of Disablement*. Macmillan, Basingstoke.)	

2. From Charity to Rights

Thinking about disability from a human rights approach has meant a shift from seeing persons with disabilities as people who receive charity to people who hold rights.

Consider the differences:

When persons with disabilities are seen as:	
Recipients of Charity	**Rights-Holders**
The person giving charity has the power to decide what to give. The person receiving charity is expected to be happy with any gift that he or she receives. *For example, the charity-giver wants to donate a coat to a person in need.*	The rights-holder has the power to say what types of things she or he needs. *The rights-holder can say: "I don't want a coat. I want shoes." Or, "I don't want a coat because I live in a warm country where coats aren't needed".*
The person giving charity decides what type of gift will be given. The person receiving charity is expected to be happy with any gift that he or she receives. *For example, an institution run by a charity provides the same type of food (rice and beans) every day.*	The rights-holder has the power to choose what he or she prefers. *The rights-holder is able to choose the type of food that he or she will eat.*
There is no law that requires that the person receiving charity must get any resources so they must rely on the whim of the charity-giver. *For example, if the charity-giver decides not to provide clothes or food one year, the charity-recipient will get none.*	There are laws that make sure that the rights-holder gets resources equal to those enjoyed by everyone else. *The rights-holder does not have to worry about the generosity of the charity-giver. Adequate clothing and food are considered essential to survival, and rights that everyone is entitled to.*

To achieve full recognition of persons with disabilities as rights-holders people need to understand that:

- ***the needs of persons with disabilities are not "special"***. If someone owns a car and wants to drive on a highway, we don't say they have a "special" need for a highway. In the same way, if someone has a wheelchair and needs a sidewalk without potholes to move on, that should not be considered a "special" need.

- ***the issues are politicized.*** Discrimination and injustice are present when persons with disabilities can't go to school, don't get jobs and live in poverty.

- ***separate but equal is not equal***. Services that limit a person’s freedom do not support a person’s autonomy (independent choice), dignity (sense of self-worth) and human rights.

- ***persons with disabilities have to be recognized as decision-makers***. There is no need for other people to decide what they want or what is good for them. They know best what they need and want.

Look at the following contrasting terms. The first term in the pair is from a charity perspective, the second is from a disability rights perspective:

CHARITY		**DISABILITY RIGHTS**
Disempowerment	→	**Empowerment**
Professional Control	→	**Self-Advocate Control**
Fixing Weakness	→	**Developing Strength**
Service	→	**Support**
Limiting Activity	→	**Facilitating Activity**
Discrimination	→	**Equal Rights**

Our understanding of disability has changed and continues to change in response to increasing understanding and recognition of the rights of persons with disabilities. We are moving away from seeing disability as a matter of charity to seeing disability as an issue of ensuring human rights and equality for everyone. People are recognizing that persons with disabilities are entitled to the same basic human rights that others enjoy. Persons with disabilities are part of the community.

Universal design, education for all, equal opportunity and anti-discrimination laws are all examples of this new approach to disability.

3. Human Rights and Disability Rights

(a) What are Human Rights?

Human rights are entitlements held by *all* people. They are **universal,** which means that they apply equally to everyone around the world. The *Universal Declaration of Human Rights,* made by the countries of the United Nations in 1948, states that *all* human beings are born free and equal in dignity and rights and that *everyone* is entitled to all rights and freedoms, *without distinction of any kind*.

Human rights help us to respect each other and live with each other. In other words, they are not only rights to be requested or demanded but rights to be respected and be responsible for. The rights that apply to you also apply to others.

Human rights can be divided into four kinds of rights:

- **Social rights:**

Social rights improve the well-being and standard of living of all members of society. They give people security as they live together in families, schools, and communities. Some examples from United Nations human rights treaties include:

- the right to the highest attainable standard of physical and mental health
- the right to adequate housing, food and sanitation
- the right to inclusive and accessible education

- **Economic rights:**

Economic rights deal with income-generating activities or income supports that allow people to have the necessities of life. Some examples from United Nations human rights treaties include:

- the right to own property
- the right to social security including social insurance
- the right to earn a living from work that is freely chosen
- the right to equal pay for equal work
- the right to access technical and vocational training programs

- **Cultural rights:**

Cultural rights deal with protecting, developing and enjoying one's cultural identity. Some examples from United Nations human rights treaties include:

- the right to participate in mainstream culture, arts, recreation, leisure and sport
- the right to create unique disability culture
- the right to cultural materials in accessible formats
- the right to access places of cultural performances

- **Civil and Political rights:**

Civil and political rights allow people to have equal citizenship. Some examples from United Nations human rights treaties include:

- the right to life, liberty and security of person
- the right to freedom of opinion
- the right to protection from torture and violence
- the right to vote and run for political office

Human rights are **indivisible** and **interdependent.** That means that no one type of right is more important than another. For people to be free from fear and want, they must be able to enjoy *all* of their rights - economic, social and cultural rights as well as civil and political rights.

(b) What are Disability Rights?

"Disabled persons frequently live in deplorable conditions, owing to the presence of physical and social barriers, which prevent their integration and full participation in the community. Millions of children and adults worldwide are segregated and deprived of their rights and are, in effect, living on the margins. This is unacceptable."

Mary Robinson, UN High Commissioner for Human Rights (1997-2002)

"Discrimination takes many forms. At times, it is embedded in laws and in practices. Yet more often, discrimination is less visible. It manifests itself in attitudes and in the belief that persons with disabilities are unable to learn and to work, or to take part in political decision-making that affects them. Or that persons with disabilities need charity to survive rather than rights. Discrimination also appears in the form of an inaccessible environment which prevents persons with disabilities from participating freely and independently in everyday activities." (UN High Commissioner on Human Rights Addresses World Congress of WFD, July 18, 2011) - http://www.usicd.org/index.cfm/news_un-high-commissioner-world-congress-of-wfd

Navanethem Pillay, UN High Commissioner for Human Rights (2008-)

'Disability rights' are not a separate or a new category of human rights. Disability rights include the full range of human rights (civil, cultural, economic, political and social) applied to situations faced by persons with disabilities.

Up until now, human rights have rarely been implemented in ways that reflect the experiences of persons with disabilities. It is hoped that with the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD), this situation will be improved. The CRPD clearly states that persons with disabilities are entitled to enjoy the *full* range of human rights, without discrimination.

(c) UN *Convention on the Rights of Persons with Disabilities* (CRPD)

The United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) was adopted by the U.N. General Assembly in 2006 and came into force in May, 2008. Once a country ratifies the CRPD, it has a legal duty to do what it says.

Persons with disabilities, disability organizations and their allies played an active role in deciding what would be included in the CRPD
The CRPD does not create new rights for persons with disabilities. Instead, it explains what existing civil, cultural, economic, political and social rights mean in situations faced by persons with disabilities. The rights covered by the CRPD are outlined in the text box on this page.

It is important to know whether your country has signed and ratified the CRPD. If a country has only *signed* the CRPD, it does not have a legal duty to do what it says. But, by signing, the country takes on a moral duty to not take actions that go against the treaty. Signing also shows that the country is willing to consider the next step to ratify the CRPD. Once a country *ratifies* the CRPD, it has a legal duty to do what it says..

Articles 10 to 30 of the CRPD cover the rights guaranteed to persons with disabilities as follows:

Article 10 – 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

An updated list of the countries that have signed and ratified the CRPD can be found on the website of the United Nations Treaty Collection at this link: http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15-a&chapter=4&lang=en. Another place to find this information is on the United Nations Enable website at this link: http://www.un.org/disabilities/

(d) Other United Nations Human Rights Treaties:

DRPI has adopted the “twin-track approach” to advancing the rights of persons with disabilities. Track one involves using the CRPD; track two involves using the other important United Nations human rights treaties that protect and promote the rights of persons with disabilities. Both tracks are followed at the same time.

These other important treaties apply to all persons, including *all persons with disabilities*:

- ***International Covenant on Economic, Social and Cultural Rights* (1976) (ICESCR)**
  This treaty deals specifically with economic, social and cultural rights.

- ***International Covenant on Civil and Political Rights* (1976) (ICCPR)**
  This treaty deals specifically with civil and political rights.

- ***Convention against Torture and Other Cruel, Inhuman or Degrading Treatment of Punishment* (1984)(CAT)**
  Persons with disabilities and especially those who live in institutionalized settings, are particularly vulnerable to torture and other forms of cruel, inhuman or degrading treatment. This type of treatment is not allowed under the CAT.

This treaty applies to all women and girls, including *women and girls with disabilities*:

- ***Convention on the Elimination of All Forms of Discrimination Against Women* (1981) (CEDAW)**
  It covers all types of rights – civil, cultural, economic, political and social.

This treaty applies to all girls and boys, including *girls and boys with disabilities*:

- ***Convention of the Rights of the Child* (1990)(CRC)**
  It covers all types of rights – civil, cultural, economic, political and social.

This treaty applies to all members of racial groups and/or minorities, including *members of racial groups and minorities with disabilities*:

- ***International Convention on the Elimination of All Forms of Racial Discrimination* (1969) (CERD)**
  It applies to persons with disabilities who suffer discrimination because they are part of a racial group or minority.

This treaty applies to all migrant workers and their families, including *all migrant workers who have disabilities and their families*:

- ***International Convention on the Protection of the Rights of All Migrant Workers and their Families* (2003)(CRMW)**
  It deals with rights violations faced by persons with disabilities who are migrant workers or part of the family of a migrant worker.

As with the CRPD, it is important to know whether your country has ratified these treaties. If your country has ratified any of these treaties, it is legally required to do what the treaties say.

Updated lists of the countries that have signed and ratified each of these treaties can be found on the website of the United Nations Treaty Collection at this link: http://treaties.un.org/Pages/Treaties.aspx?id=4&subid=A&lang=en

(e) General Human Rights Principles:

In addition to guaranteeing specific rights like "the right to health", the CRPD and other human rights treaties also include general principles that can be used to address many areas of rights. The general principles provide guidance about how each right in the treaty can be understood and ensured.

Here are the general human rights principles stated in the CRPD and other United Nations human rights treaties that are important to persons with disabilities:

DIGNITY

Dignity refers to the inherent worth of every person. Human rights are about protecting and promoting the self-respect of all person. Everyone should feel respected in their community and their society and in their everyday activities.

> **example:** Mirela was in a fire and has scars that cover her head and upper body. She has had difficulty finding a job and she is very poor. Because of the respect her friends and colleagues have for her, she is not forced to live in an institution or beg for money. Instead, she is invited to join a group of women who have a business raising chickens and selling their eggs. In this way, she is able to make the money she requires to meet her basic needs, and she has a sense of dignity.

AUTONOMY

Autonomy is the right of a person to make his or her own choices independently or with support. Autonomy means that the person is placed at the centre of all decisions affecting him or her.

> **example:** Robert has speech that is difficult to understand. When he goes to the community clinic, the doctor or his family or friends makes sure that Robert has someone with him who Robert trusts and who can assist Robert to communicate. With that support, Robert can ask the doctor questions and make decisions about his treatment.

PARTICIPATION, INCLUSION & ACCESSIBILITY

Inclusion is the right of all persons to participate fully and effectively. It involves making sure that society is organized to be accessible and is without physical or social barriers. This includes access to transportation; elections; clean water; sanitation; technology; appropriate sources of communication and media to ensure information. It also means that there have to be non-discriminatory attitudes and facilitation or accommodation to limit the impact of disability.

> **example:** Priyanga, who is blind, is welcome to attend the same school and classes as her brothers and sisters who are not blind. The school and the teacher think it is important for all children to have a chance to learn and so they try to accommodate her not being able to see by having Braille books and tactile learning tools.

NON-DISCRIMINATION & EQUALITY

Rights are guaranteed to everyone. It is discrimination for people to be denied their rights based on disability, race, sex, language, religion, political or other opinion, national or social origin, property, birth or age.

Discrimination happens when favouritism is shown to one group of people over another. It may be based on prejudice and is unfair. Laws, policies, programs, actions or failures to act that result in denying persons with disabilities the ability to exercise their human rights, is discrimination.

Everyone has the right to enjoy human rights equally. Rights, responsibilities and opportunities do not depend on whether someone is born with or without a disability. This does not mean that persons with disabilities will be treated exactly the *same* as persons without disabilities. Instead, society must be sure that persons with disabilities have what they need to exercise their rights fully – sometimes what a person with a disability needs to exercise his or her rights equally will be the same as what is needed by a person without a disability and sometimes it will be different.

examples:

Non-discrimination: Anna, a woman with an intellectual disability, is able to marry and have children. The laws of her country allow her to exercise these rights even though she has an impairment. Also, Anna knows that if her husband beats her, the police must act to protect her. They cannot ignore the abuse because she has a disability.

Equality: Nak, a man who is deaf, and his friend Dusit, who does not have a disability, are both able to get enough information about the candidates who are running for election to be able to exercise their right to vote. Both Nak and Dusit travel to a gathering where the candidates are speaking by using the same public bus. Since both sign language interpretation and a loudspeaker have been arranged by the event organizers, both Nak and Dusit can understand what the candidates are saying.

RESPECT FOR DIFFERENCE:

Respect for difference involves recognizing and accepting persons with disabilities as part of human diversity. Difference is not a reason to deny someone his or her rights and dignity. The responsibility to change does not fall on the individual but on the community and the government and society who must recognize diversity and find ways to be inclusive of the difference that disability represents.

example: Eghosa has a disability that requires him to walk with a cane. In order to remain mobile and self-sufficient, the buses in his community have to be accessible. The bus driver on Eghosa's regular route recognizes his needs and allows him time to walk from where he waits to the bus. The driver also allows Eghosa the extra few seconds it takes to reach his seat before starting to move the bus. Instead of worrying about losing time on his route, the driver thinks about the individual needs of his passengers.

All of the general human rights principles apply equally to men, women, boys and girls.

Disability rights monitors will use these general human rights principles when collecting information about the human rights situation of persons with disabilities in their countries.

1.3 Monitoring the Rights of Persons with Disabilities

1. What is Monitoring?

In technical terms, monitoring is “the active collection, verification, and immediate use of information to address human rights problems. Human rights monitoring includes gathering information about situations, observing events, visiting sites, and holding discussions with government authorities to obtain information and to pursue remedies”.

In other words, “monitoring” means finding out what is going on in people’s lives by:

- finding facts
- asking questions
- collecting a lot of information in one place to show what is happening
- finding ways to measure if anything is changing (using indicators)
- measuring progress toward justice for persons with disabilities
- tracking information

DRPI’s approach is to look at issues that matter to persons with disabilities and that impact their human rights. We want to develop the best possible evidence to support the move towards persons with disabilities achieving their rights. Below is a list of the main ways in which that *DRPI* tracks or monitors disability rights.

(a) Tracking (monitoring) Individual Experiences

- Through interviews or focus groups, stories are collected about when persons with disabilities have faced barriers and challenges. People are asked to tell their own story about when they have been left out, treated badly or prevented from participating because of their disability. These stories give us information about the real human rights situation faced by persons disabilities.

- Sometimes, persons with disabilities do not think it will make a difference to report the mistreatment or exclusion they experience. Sometimes people may fear that they will face more abuse if they tell about these things. The reality is that documenting and reporting individual cases of mistreatment and abuse that happens both out in society and within the family and other private settings, is important because it raises awareness and can lead to changing those conditions. The information may also uncover what is really going on and make it difficult for governments to claim that rights are being respected when they are not.

(b) Tracking (monitoring) Systems (laws, policies, programs and services)

- Laws and policies are reviewed and measured against United Nations standards to see whether they meet a country's obligations "to respect, protect and promote" human rights. Since laws and policies can appear to protect human rights but be used in ways that create inequality and violate the human rights of persons with disabilities, the ways in which laws operate is carefully reviewed and recorded.

- Legal cases and decisions are sometimes just as important as the written laws and regulations of a country when promoting human rights. A law can say one thing but be interpreted by courts and tribunals in a different way, making a big difference in the exercise of rights by individuals and groups.

- Government programs, services and practices often have a large impact on the daily lives of persons with disabilities. Documenting programs, services and practices that violate human rights – either directly or indirectly – provides evidence for the need to make changes.

(c) Tracking (monitoring) Attitudes

- Societal attitudes and public opinion have a big impact on the exercise of rights by persons with disabilities. One way of finding out about attitudes is to look at the media, which both reflects and plays an important role in influencing public opinion. Media plays a large part in how people around the world think about persons with disabilities and about disability issues generally.

- Monitoring social attitudes involves looking at and finding patterns in the way that disability is described and covered in print, broadcast and internet-based media to uncover social attitudes about disability and persons with disabilities. This information is then used to better understand individual rights experiences and systemic measures (laws, policies, programs and services) and determine what changes could be made to combat negative stereotypes and prejudice.

2. What makes *DRPI's* approach to monitoring unique?

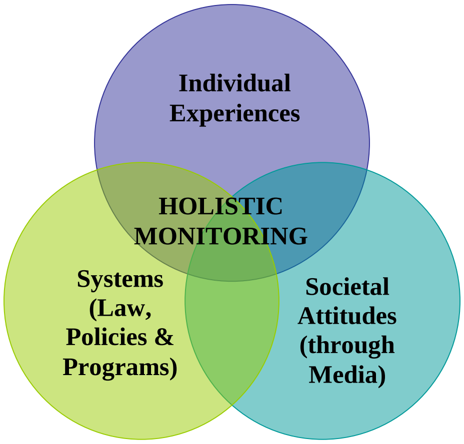
There are a number of ways that *Disability Rights Promotion International*'s approach to monitoring the rights of persons with disabilities is unique. The following aspects of the *DRPI* approach are important to highlight:

- It uses a *holistic approach* (that is, it tracks disability rights in more than one way and brings the information together)
- It puts *persons with disabilities in the lead* in monitoring
- It considers *human rights principles* when assessing the specific rights
- It recognizes that *disability rights monitoring has to be an ongoing, long term process*

(a) Using a Holistic Approach

Each of the ways of monitoring or tracking disability rights – individual experiences, systems and societal attitudes - gives us important information about the rights situation faced by persons with disabilities. Monitoring in any one of those three areas alone is not enough to give us a complete picture. A holistic approach that monitors the three areas independently and then pulls together all of the findings provides a better understanding of the reality facing persons with disabilities. It also provides a way of knowing how various issues relate to one another. A holistic approach recognizes that the discrimination and isolation of persons with disabilities is complicated, widespread and often ignored

The three ways of tracking disability rights gives us an idea of the nature and scope of a global disability rights monitoring project by recognizing that there are many different areas to examine. We collect information at the local, national and regional level to come to a global understanding of what is happening to persons with disabilities around the world.



To improve the human rights record for persons with disabilities is a complex task that involves a global picture that comes from persons with disabilities themselves, but must also be recognized and addressed by governments, in universities, by the public and in the general community.

(b) Ensuring Persons with Disabilities are in the Lead

When research is conducted *on* persons with disabilities there is little or no representation or involvement in planning, administration or implementation stages by persons with disabilities themselves. "Nothing about us without us" is more than a slogan for *DRPI* – it is the primary driving force and end goal in any monitoring. The right to take a lead role in monitoring that is about the disability community or about persons with disabilities is a fundamental feature of the CRPD. The structure, organization and design of *DRPI* monitoring projects is grounded in, and based on, partnerships and the involvement of disabled people's organizations (DPOs) and persons with disabilities. *DRPI* started that way and every step and stage of its development is based on that engagement. This ensures that decision-making rests with persons with disabilities in an ongoing and sustainable way.

(c) Using General Human Rights Principles in *DRPI* Monitoring

DRPI uses five general human rights principles found in the CRPD and discussed earlier, to provide guidance about how each right should be understood and applied.

These five general human rights principles are:

- Dignity
- Autonomy
- Participation, Inclusion and Accessibility
- Non-discrimination and Equality
- Respect for Difference

Rather than simply recording what services are available for persons with disabilities in a given country, or what a government has promised to persons with disabilities, these five principles provide a clear way of measuring whether rights are being respected and put in place in a meaningful way.

These principles allow monitors to not only record that a service is being provided but to go further to see the *way in which* it is being provided. For example, not just recording whether a person has some form of housing or food but looking further to see whether the person can choose the type of housing and food that they want (respecting autonomy) and whether the house has a roof that does not leak and the food is healthy (respecting dignity).

The general human rights principles also provide a global measure to compare and contrast what is happening in different countries and regions of the world.

(d) Recognizing Disability Rights Monitoring as an Ongoing Process

A goal of monitoring is to be sustainable so that the population of persons with disabilities and disabled people's organizations are able to gather evidence-based information about disability rights in an on-going process.

Monitoring is not a one-time audit, but an ongoing process of collecting information; adding to it and discovering if changes are taking place. To be effective, monitoring must continue over time. The first time that monitoring information is collected provides a starting point for identifying changes that need to be made to improve the enjoyment of all rights by all persons with disabilities.

It is only by monitoring again, after some time has passed, that it is possible to find out whether the situation has improved or become worse. Is the situation better than 5 years ago? Is it heading in the right direction? Do people feel they are less discriminated against? Are the laws and policies being implemented as promised? Is the disrespect of people's dignity being addressed? Is new technology being designed that supports the exercise of rights? Are the outcomes of changes making people's lives better? Are services being designed in ways that respect dignity, autonomy, equality?

People who experience discrimination have to answer these questions and analyze their own situation. They are the experts on their lives. As people become empowered to view themselves as rights-holders, it becomes obvious that it is important it to continue to monitor, track and seek penalties for abuses and social change.

Monitoring needs broad engagement. It is a long road to track disability rights and to make positive changes. But each step of the way is positive and can be built upon for the next phase or gaining rights.

DRPI's monitoring projects are designed to be sustainable so that persons with disabilities and disabled people's organizations are able to gather, on an on-going basis, evidence-based information about disability rights. Costs are kept low and monitoring capacity is built and fostered so that monitoring activities, led by persons with disabilities and their organizations, are able to continue into the future.

Module 2 – Individual Experiences Monitoring in Practice

This module focuses on monitoring the individual experiences of persons with disabilities including how to conduct interviews, how to organize and coordinate interviews and how to analyze and report on the information collected.

2.1 Individual Experiences Monitoring in Practice

Objectives:
By the end of this module, participants will:

- Understand the responsibilities of Monitors and other people involved in monitoring individual experiences.
- Know how to conduct a monitoring interview, including obtaining the informed consent of the Interviewee.
- Understand the qualities and skills of a good Monitor.
- Know how to make sure monitoring information is kept confidential.

1. Before the Interview

I. People involved in Monitoring:

Information about the life experiences of persons with disabilities is collected through interviews by **Monitors**. Monitors are also persons with disabilities. Two Monitors conduct each interview together.

The persons with disabilities who are interviewed are called **Interviewees**. One **Site Coordinator** works in each area where interviews take place. Site Coordinators work closely with the Monitors and the Project Coordinator to make sure that the interviews run smoothly including:

- assisting Monitors to schedule interviews,
- arranging disability-related adaptations,
- collecting information from the Monitors after the interviews and
- helping Monitors to solve any problems that may arise.

Site Coordinator duties are looked at in more detail later in this module.

Every country where monitoring takes place has a **Project Coordinator**. The Project Coordinator has overall responsibility for all of the monitoring activities. He or she:

- hires the Monitors and Site Coordinators,
- oversees their training,
- works closely with the Site Coordinators to make sure that monitoring moves forward in all the places where interviews take place,
- helps the Site Coordinators to solve any problems that arise,
- coordinates the analysis of the interviews,
- participates in writing the monitoring report and raises awareness about the monitoring project and data collected.

II. Getting ready for the Monitoring Interview

Here are a number of steps Monitors take to prepare for the interview:

(a) Know about the monitoring site.

The Project Coordinator, Site Coordinators and Monitors together will prepare a brief report containing **background information about each monitoring site** including:

- size of the area
- total population
- description of organizations of persons with disabilities
- major cities – names, population
- major religions
- languages spoken
- major ethnic groups
- standard of living, poverty and unemployment
- major causes of impairments in the area (for example, polio, war, and mines, toxic chemicals, etc.)
- percentage of the total population of persons with disabilities in the area who:
  * have specific impairments or types of disability (mobility, blind/low vision, deaf/hard of hearing, intellectual, psycho-social, others)
  * are men or women
  * fall within these age groups (18-25), (26-40), 41-55), (56-70) and (over age 70)
- type of terrain (for example, mountains, plains, etc.) (affecting transportation)
- cultural practices that will affect interviews

This background information will give Monitors and Site Coordinators an overview of the areas where they are working, and will help Site Coordinators and the Project

Coordinator decide who will be interviewed. It will also be used in the final monitoring report.

(b) Choose an appropriate location for the interview.

The location should be:

- ***Accessible* -** The location should be easy to reach by transport and be fully accessible to both the Interviewee and the monitoring team.
- ***Safe*** - The location should be secure from outside distractions. Interviews should not take place in a location where a lot of people will be able to see the Interviewee participating. This is one way of ensuring that the interview is confidential and the person being interviewed feels comfortable. The interview location should not raise suspicion among people who see the participants in the middle of a discussion.
- ***Calm*** - The location should have limited noise and distractions so that the interview will not be interrupted.
- ***Private*** - The interview should take place in private without family members or other people present. The Interviewee might not want to talk about traumatic experiences with other people present (for example, a family member, caretaker or other person). In some cases, it could be that family member, caretaker or other person who is responsible for a human rights violation (for example: abuse, withholding food or restricting movement). If the interview takes place in the Interviewee's home, make sure that there is privacy. No one should be able to overhear the conversation.

Some possible locations to consider include:

- quiet place in a public park
- place of worship
- private office
- quiet place in a community centre
- quiet tea or coffee shop

(c) Address Language Issues

It is best for the interview to be conducted in the language the Interviewee wants to use. This will make the Interviewee more comfortable and will allow Monitors to collect more detailed information. Wherever possible, the *Interview Guide* found in **Appendix A** will be translated into all of the languages in which interviews might take place. In all cases, the *Information Sheet* found in **Appendix C** and the *Free and Informed Consent Form* found in **Appendix D** will be translated and available in the language of the Interviewee.

Monitors should only conduct interviews when they speak the same language as the person being interviewed. This is one of the reasons why it is important to have Monitors come from the communities in which the interviews are taking place.

In the case where a Monitor or Interviewee is deaf, the interviews can go ahead using sign language interpretation or real time captioning.

Where an Interviewee has a communication disability, it may be possible to conduct an interview with the assistance of a communication facilitator and/or communication aid, depending on the particular situation of the Interviewee.

(d) Be sure that any disability-related adaptations required by Monitors or the Interviewee are in place.

Adaptations for Monitors
Monitors should consider whether they require any adaptations to participate fully in the interview and arrange for these in advance (for example, scheduling a support worker to assist, having the interview questions in the correct format such as Braille, using a sign language interpreter, etc.)

Adaptations for Interviewees
When scheduling the interview, Interviewees will be asked if there are any adaptations they require in order to participate fully (e.g., use of a sign language interpreter, materials in Braille, etc.). The Monitors and Site Coordinator will work together to arrange these adaptations.

(e) Recognize differences that may affect the interview including cultural norms, gender, age and status.

Differences between the Monitors and the Interviewee can make doing the interview more difficult. These differences may be related to things that come up in the interview. They may include attitudes about gender, age differences, and roles that people hold in their communities (for example, elder, chief, healer, professor) or appropriate topics of conversation. Even culturally specific ideas about the meaning or appropriateness of physical interaction (eye contact, personal space) can lead to misunderstandings. Find out about any differences before the interview and be sensitive to them during the interview.

(f) Wear the appropriate clothing for the interview.

Wear clothes that will allow everyone to feel comfortable and confident, including the Interviewee. In some cultures, it may be important to dress more formally for some Interviewees than for others. Consider cultural rules on this matter. In other cases, dressing too formally may make people feel uncomfortable. So the good judgment of the Monitor is important

(g) Know and feel comfortable with the *Interview Guide*.

It is important for Monitors to know the *Interview Guide* very well so that they are comfortable moving between topics and questions. It is absolutely necessary for Monitors to review the *Interview Guide* at least once before *every* interview. [See Appendix A]

(h) Gather all of the equipment and forms needed for the interview.

See the **Checklist of Equipment and Forms** in **Appendix G** for a full list of what each pair of monitors will need for their interviews.

(i) Make sure the audio recorder is working properly.

Practice using the audio recorder before the interview. This will help Monitors to appear professional and avoid confusion during the interview. For example, practice changing the cassette tape, moving between digital file folders or turning the recorder on and off. Bring extra cassette tapes (where necessary) and extra batteries to be sure that there are enough for the entire interview.

III. Qualities and Skills of a Good Monitor

Here are some of the qualities and skills of a good Monitor:

• Communication	• Objectivity
- Good Questioner	• Commitment
- Good Listener	• Honesty
• Personal Interaction	• Social and Political Awareness
• Precision	• Confidence
• Sensitivity / Empathy	• Essential Knowledge / Information
• Flexibility	

Communication

(a) Being a Good Questioner when interviewing means:

- Asking questions in a way that is respectful and easy for the Interviewee to understand. Using familiar everyday language that will be understood.
- Avoiding asking questions too fast or questions that are confusing.
- Avoiding asking questions in a way that will suggest the answer to the Interviewee. For example, instead of asking, “Were you discriminated against?” ask the Interviewee, “How were you treated by the school officials?”.
- Allowing time for the Interviewee to think about their answer to the question. A moment of silence is fine. Since the Interviewee has not heard the questions before, Monitors should give Interviewees time to think about their answers. Also, some people take time to open up.
- Balancing the need to let the Interviewee tell their story with the need to gather particular details for analysis purposes. The free-flow of conversation is more important than sticking to the order of questions in the *Interview Guide*.
- Not pushing the Interviewee beyond what he or she wishes to discuss. Remember that it is not about getting the interview at any cost. If someone does not want to answer a particular question, move on to another question unless the Interviewee states that they want to terminate the interview altogether.

IMPORTANT TIP: *Conducting interviews in pairs will make this easier to be sure that the Monitors collect all the information they need. While one Monitor asks the questions, the second Monitor can take notes and identify any issues to follow-up.*

(b) Being a Good Listener when interviewing means**:**

- Being able to listen carefully to what the Interviewee is saying.
- Avoid repeating questions the Interviewee has already answered. Pay close attention to the Interviewee so that he or she is not put in the position of having to say, "As I've told you before...". If, during the course of the interview, Monitors realize that there is information that they did not completely understand or that they would like the Interviewee to repeat, tactfully ask them a question like, "Am I correct that you said [repeat back what you remember hearing here]?" This prompts the Interviewee to clarify their comments.
- Being patient with repetitive statements that you may not think are in a logical order.

  Let the Interviewee tell his or her story in his or her own way. Otherwise, he or she may be reluctant to talk about sensitive issues – people need time to tell their stories and they need to tell them in the way they think about them. But, if the Monitors find they cannot follow the details of the story, it is appropriate to ask the Interviewee to narrate the story in a chronological order. This may help the Interviewee to structure the story and include important details.

IMPORTANT TIP: *Avoid finishing the sentences of Interviewees even if this is the usual way of talking in your culture or language. By finishing the Interviewee's sentence, Monitors will be getting their own experiences and not the Interviewee's experience.*

Personal Interaction when interviewing means:

- Knowing how to relate to Interviewees including showing respect for their knowledge, experiences and feelings, showing an interest in the Interviewee as an individual who is worthy of respect and concern and being respectful in the way Monitors dress for the interview.
- Being aware and receptive to nonverbal communication. Be aware that posture and how one sits in relation to the Interviewee can affect how comfortable the Interviewee feels. For example, in a confined space, leaning forward may appear threatening but, under other circumstances, not doing so may be seen as a lack of interest. Some Interviewees may prefer to sit closer to the Monitors; others may be very protective of their personal space or shy away from being touched. Observe the body language of the Interviewee to gain a sense of what is most appropriate in the situation.

IMPORTANT TIP: *Monitors should be very careful about communicating through body language, facial expressions or other means, that they do not believe or disagree with what is being said, even if that is the case.*

Precision and Probing when interviewing means**:**

Being observant and accurately recording the information received. Asking the right questions and probing to getting the information needed by probing or inquiring further whenever necessary.

- Probing means making sure that you find out all the information you need. Tips on how to probe for more information are found later in this module.
- Guiding the interview and redirecting whenever necessary to keep the Interviewee focused on the information they are giving. Avoiding falling into situations where the Interviewee begins to attempt to "interview" the Monitors. Where necessary, bring the Interviewee back to the purpose of the interview.
- Clarifying **generalization:** Interviewees might begin to talk about "persons with disabilities in general", rather than their own personal experiences. If this happens, there are several strategies Monitors can use to bring the Interviewee back on topic:
    - Ask the Interviewee if he or she is part of the group they are generalizing about. This moves the conversation from the "we" (or "they") to the "I".
    - Ask increasingly specific questions. This will often get the Interviewee to tell his or her own story and to give more details about the story they are telling.

Sensitivity/Empathy when interviewing means:

- Paying attention to how the Interviewee experiences the interview and responding in a caring way. Their story is important to them and they may find it difficult to tell.
- Being sensitive of subjects that are cultural taboos. For example, in certain places and cultures, it is forbidden to speak about sexual abuse. Talking about these types of abuses can be even more difficult for the Interviewee than talking about other issues.
- Developing and maintaining a feeling of acceptance and trust with the Interviewee.

Flexibility when interviewing means**:**

Being able to improvise in the interview and take initiative when necessary to make it easy and comfortable for the Interviewee to tell their story

Objectivity when interviewing means:

Observing things as they are and not judging the interviewee according to personal views or expectations. Not expressing personal opinions when interviewing.

Commitment when interviewing means:

Being dedicated to protecting and promoting human rights and to performing the tasks of a Monitor.

Social and Political Awareness in interviewing means:

Being aware of things like local traditions and customs as well as being aware of political structures and possible tensions.

Confidence in an interview means:

Being able to assert themselves in their role as Monitor where necessary, for example, by redirecting the Interviewee to the question asked.

2. Using the DRPI Interview Guide

I. Background to the Interview Guide

The *Interview Guide* used by Monitors is included as **Appendix A.**

The *Interview Guide* includes mainly open-ended and semi-structured questions. It has been designed to help Monitors find out information about the human rights experiences of the Interviewee. Information can be collected about all types of rights (civil, cultural, economic, political and social) and in relation to the general human rights principles (dignity; autonomy; participation, inclusion & accessibility; non-discrimination & equality; respect for difference). The *Interview Guide* is designed to give persons with disabilities an opportunity to tell their own story and to identify the rights issues that are most important to them.

II. Steps of the Monitoring Interview

This section reviews the steps of the monitoring interview following the order of the *Interview Guide* [Appendix A].

A. Beginning the Interview:

- **Introductions:**

Monitors begin the interview by greeting the Interviewee, thanking them for agreeing to be interviewed and introducing everyone who is with them (for example, Monitors, support worker, interpreter and anyone else attending the interview).

As few people as possible should be with the Interviewee and Monitors during the interview. For example, support workers who are not directly assisting with the interview should wait in a location near enough to respond to a signal for assistance but far enough away to not overhear the interview.

IMPORTANT TIP: *Remember that the Interviewee's friends and family members should not be present for the interview. In cases where members of the Interviewee's family ask Monitors why they are doing the interview, Monitors can give them a copy of the Information Sheet (Appendix C) which provides background information about the project. If family members or friends have more questions, Monitors can ask them to contact the Site Coordinator or Project Coordinator whose names and contact information is on the Information Sheet.*

Monitors should remember to:

- **Greet the Interviewee in a friendly way.** (Smile, shake hands, etc., according to local customs). The first few minutes of the interview are very important because they set the tone and hopefully put the Interviewee at ease.

- **Introduce themselves** providing their names and give a little of their own background. For example, Monitors might want to tell the Interviewee about the town they come from, the disability organization they work with, etc.

- Monitors also **introduce any interpreters, support workers or other people who are with them**, clearly explaining each person's role.

- Introduce **all of the equipment** the Monitors have brought with them (for example, audio recorder, notebook, etc.).

- **Ask the Interviewee if he or she is comfortable.**

- **Request written, free and informed consent:**

  Next, the Monitors ask the Interviewee whether he or she agrees or "consents" to participate in the monitoring interview. This is a very important step in the interview process. Many times, persons with disabilities have had research "done on them", without their consent. Human rights monitoring involves working *with* persons with disabilities, not *on* persons with disabilities.

  Note that in *DRPI* projects, we are not interviewing children (that is people under the age of 18). We are also not interviewing people who cannot give their own consent or who cannot agree themselves that they want to be interviewed.

  If an Interviewee refuses to grant his or her consent to be interviewed in writing, the interview cannot proceed.

  An Interviewee's decision to participate in the monitoring interview must be "free", "informed" and "in writing".

FREE

To be a “free” consent, the Interviewee must not feel forced to participate in the interview. He or she must be free to choose whether or not to take part and feel confident that they will not experience any negative consequences if they decide not to participate.

Also, Interviewees must be informed that even if they decide to participate, they will be able to stop participating at any time during the interview.

Monitors must make sure that they do not influence Interviewees with their authority or their own feelings of how important the interviews are. Respect the needs and views of the Interviewee. If someone does not wish to participate, that is fine; there will be other people who will want to be interviewed.

INFORMED

To be an “informed” consent, the Interviewee must understand all aspects of the monitoring project including:

- what will happen during the interview;
- how the information provided by the Interviewee will be kept confidential;
- how the information will be used;
- possible consequences of participation – Interviewees must be informed of any potential risks involved in providing information but, at the same time, these risks should not be overemphasized.
- if there are any situations where the Monitors are required by law to report things said during the interview (*only if the Project Coordinator tells the Monitors that this is something that applies in their country*).

IMPORTANT TIP: *All of the issues dealing with “free” and “informed” consent are covered in detail in the Information Sheet found in Appendix C.*

Every person who might be interviewed should be given a copy of the *Information Sheet* in his or her language and in a format that is accessible to them (for example,12pt font, large print, Braille, etc.). If a potential Interviewee cannot read the *Information Sheet*, Monitors must read the document aloud to them. In all cases, the Monitors will review the *Information Sheet* with the potential Interviewee, making sure that everything is understood and answering any questions. A copy of the *Information Sheet* will be left with the Interviewee.

WRITTEN

Finally, the Interviewee must provide written proof that his or her consent to participate is free and informed by signing or officially marking the *Free and Informed Consent Form* found in **Appendix D**. Verbal consent is not enough. If an Interviewee refuses to provide written consent to be interviewed, the interview cannot proceed.

Monitors take 2 copies of the *Free and Informed Consent Form* with them to each interview. Both copies will be signed. One copy is kept by the Interviewee and one is kept by the Monitors and given to the Site Coordinator following the interview.

Request Written Permission to Audio Record the Interview

In order to make sure that there is a complete and accurate record of the information provided by the Interviewee, the Monitors will make an audio recording of the interview.

Monitors must ask the Interviewee for permission to tape or digitally record the interview. When asking for permission, the Monitors should emphasize that all written and audio records of the interview will be kept confidential.

In cases where a hearing person is interviewing a person who uses sign language, the audio recorder will record both the hearing person's voice and the voice of the sign language interpreter. In cases where both the Monitors and Interviewee use sign language, two interpreters will be used, and each of their voices will be audio recorded. If real-time captioning is used, the digital transcript of the interview can supplement the audio recording.

If the Interviewee consents to have the interview taped or digitally recorded, he or she must sign and date the *Free and Informed Consent Form* (in **Appendix D**) on the line indicated.

Recall that Monitors take 2 copies of the *Free and Informed Consent Form* with them to each interview. Both copies will be signed. The Interviewee keeps one and one is kept by the Monitors and given to the Site Coordinator following the interview.

The Monitors can begin audio recording the interview once the Interviewee has given this signed consent.

- **Write the Interviewee’s Name on the *Identification Sheet***

The Interviewee’s name is ***not*** recorded in the audio recording of the interview or in the *Interview Notes*. This protects the privacy of the Interviewee. The audio recorder is stopped when this information is received.

The Interviewee’s name is only written on a *separate* document called the *Identification Sheet* where it is assigned an “Interview Code”.

The Interview Code is composed as follows:

(i) 2 letters for the **region** where the interview is taking place
example: Africa - AF
Asia-Pacific – AP
Europe – EU
Latin America - LA
North America – NA

(ii) 2 letters for the **country**
example: Rwanda – RW
South Africa – SA
Uganda – UG
Argentina – AR
Chile – CH

(iii) 2 letters for the **monitoring site**
example: Kigali – KG
East Region – ER
West Region – WR

(iv) 1 letter for the **pair of Monitors** conducting the interview
example: when Jean and Maria are Monitors working in a pair - A
when Sujit and Nur are Monitors working in a pair - B
when Jean and Esteban are Monitors working in a pair - C

(v) 2 digit number for the particular interview conducted by the monitoring pair, in sequence.
example: first interview done by Jean and Maria – 01
eleventh interview done by Jean and Maria - 11

Using the above examples, the code for the fourth interview conducted by the Monitors Jean and Maria working in the East Region of Rwanda, Africa would be: AF-RW-ER-A-04.

IMPORTANT TIP: *The Interview Code is recorded on each page of the Interview Notes. If a cassette tape is used to audio record the interview, Monitors write the Interview Code on the tape. If the interview is recorded using a digital recorder, the Interview Code is used in the digital file name. The Interviewee's name is not recorded on either the cassette tape or the digital file name for the interview. At both the beginning and end of the audio recording, one of the Monitors should state the Interview Code for that interview, by stating: "This is the beginning/end of interview AF-RW-ER-A-04".*

A sample *Identification Sheet* is included as **Appendix E**.

Only the Monitors, Site Coordinator and Project Coordinator will ever see the *Identification Sheet* and know the names of the people who have been interviewed.

The *Identification Sheet* must always be kept separate from the *Interview Notes* and any tape or digital recordings of the interview. It will remain with the Project Coordinator and will not be used or even looked at when the interview is being analyzed.

B. Experiences faced by the Interviewee:

In order to put the Interviewee at ease and to encourage him or her to speak about the rights issues that he or she feels are most important to them, Monitors begin by asking broad questions about the Interviewee's life and his or her daily experiences (called "open-ended" questions)

Here are the three open-ended questions in the *Interview Guide*:

(a) Please tell me a little about your life during the past five years. What things do you do? Where do you go? Who do you meet?

(b) What are the things in your life that are most satisfying?

(c) What are the most difficult barriers or challenges that you face in your life?

IDENTIFYING 1st EXPERIENCE:

Having found out something about the person being interviewed and their lives, it is now the time to explore some particular events in the individual Interviewee's life in some detail.

To do that, the Monitors ask the Interviewee to speak about a particular time when their rights have been violated.

The question in the *Interview Guide* does not use the words "human rights" since some Interviewees might not know what "human rights" are. Instead, other words have been used to describe human rights.

In order to make sure that the information collected is current, it is important that the issues or experiences raised *happened* **within the last 5 years**. Monitoring is about the present situation of people so we want to get stories that have happened recently.

Here is the question in the *Interview Guide*:

1.1 Do you recall a particular time or event <u>in the last five years</u> when you were left out or treated badly or prevented from participating because of your disability?

BACKGROUND INFORMATION ABOUT 1st EXPERIENCE:

After identifying the experience or issue, Monitors ask questions to find out more details. The goal is to get as much information as possible about the experience that the Interviewee has raised and wants to talk about.

Like a journalist investigating a story, Monitors want to find out Who? What? Where? When? and How? The questions asked are:

1.2 WHAT happened? WHERE and HOW did it happen?

1.3 Is this still happening or did it just happen once?

1.4 Are there other details that you want to share with us about what happened, when and how in this experience?

When asking these questions, it is very important to probe, dig or explore for as much information as possible about the experience. See Section 2.1(3)(a) below for further information about probing.

RELATING 1st EXPERIENCE TO THE EXERCISE OF AUTONOMY, DIGNITY, PARTICIPATION, INCLUSION AND ACCESSIBILITY, NON-DISCRIMINATION AND EQUALITY AND RESPECT FOR DIFFERENCE – THAT IS, RELATING THE EXPERIENCE TO THE HUMAN RIGHTS PRINCIPLES:

Next, the Monitors ask questions that attempt to link the experience raised by the Interviewee to the general human rights principles identified in Module 1 (dignity; autonomy; participation, inclusion & accessibility; non-discrimination & equality; respect for difference). Remember that these are general principles set out in the *Convention on the Rights of Persons with Disabilities and other United Nations human rights instruments.*

Here are examples of some of the questions about human rights principles asked in the *Interview Guide*:

[Dignity]

1.5 HOW did this experience make you feel and WHY? (For example, did you feel respected/not respected, ignored/cared for, worthy/ unworthy?)

1.6 WHAT made you feel that way?

1.7 What do you think made people treat you that way?

[Autonomy]

1.8 Did you feel that you had a choice about what happened to you?

WHY? or WHY NOT?

1.9 If you had a choice, would it have made a difference to what happened? In what way?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO CHOICE AND MAKING A DECISION YOURSELF (AUTONOMY) ASK:

(a) Did you want to make a different decision or did you want to do something else? WHAT was the different decision or what did you want to do?

(b) Did you have enough information to make that decision?

If not, what prevented you from having enough information?

(c) Did you feel pressured to act the way you did? WHO/WHAT was pressuring you? HOW did it make you feel?

Refer to the complete version of the *Interview Guide*, found in Appendix A for a full list of the questions related to the general human rights principles. (See questions: 1.5 to 1.15; 2.5 to 2.15 and 3.5 to 3.15)

The questions in the *Interview Guide* have been developed to draw out information related to the human rights principles without naming the principle being discussed. When asking the questions, the Monitors should not name the principle. For example, Monitors will *not* say: "The following questions deal with the general principle of 'Dignity.'" Instead, Monitors will simply move directly to the questions under each principle, for example: "How did this experience make you feel and why?" We have put in the principles as guideposts for the Monitors.
Note that when asking these questions, it is very important to *probe* for as much information as possible. See Section 2.1(3)(a) below for further information about probing.

REPORTING HISTORY

Now the Monitors want to know something about whether the Interviewee told anyone what happened to him or her. So the Monitors find out whether or not the Interviewee reported the experience to anyone. If the experience was not reported, the Monitors ask why not? If it was reported, the Monitors ask what, if any, action was taken by the person or organization it was reported to?

The 'reporting history' questions are asked to see whether persons with disabilities have a way to get help in situations when their human rights are violated. Did they feel they had anyone who could assist them? The questions are *not* asked in order to make a judgment about the Interviewee's decision to report, or not to report, a particular experience. It is understood that there are many reasons why an Interviewee may choose not to report an issue.

For example, sometimes there is no authority responsible for the issue; other times, the Interviewee may not have known about people who could help them; or, perhaps the Interviewee did not feel safe reporting the experience because he or she feared that something bad would happen to him or her.

If the Interviewee seems uncomfortable with the reporting history questions, the Monitors should use their own words to explain to the Interviewee why these questions are being asked.

Here are the reporting history questions in the *Interview Guide*:

1.16 Did you report the experience to anyone?
☐ yes ☐ no

- ***If you REPORTED the experience, what kind of person/ organization did you report it to?***
  ☐ government official / social worker
  ☐ police officer
  ☐ religious leader
  ☐ human rights commission
  ☐ disability organization (DPO)
  ☐ other: ____________________________
  (specify)
  - ***how did that person react?***
  - ***what action was taken?***

- ***If you did NOT REPORT the experience to anyone:***
  - WHY did you not report it?

POSSIBLE SOLUTIONS, WAYS TO AVOID FUTURE VIOLATIONS:

Monitors also ask Interviewees for their opinion about the actions they think should be taken to improve the situation they experienced and/or to prevent that type of rights violation from taking place again, in the future.

These questions are asked because:
- the Interviewee is often in the best position to identify the solution to the problem; and
- this type of information might be useful to local disability organizations and policy makers when they are trying to avoid future violations of human rights

When asking for this information, Monitors must be sure that that they do not make the Interviewee believe that suggested solutions will be acted upon by those doing the study. The information collected will be used by disability organizations to call for changes, but there is no guarantee that people in power will listen or that changes will happen quickly.

Here is the possible solutions question in the *Interview Guide*:

1.17 In your opinion, what action[s] should be taken to improve [or prevent] the experience in the future?

FINAL COMMENTS ABOUT THE EXPERIENCE:

Finally, the Monitors ask the Interviewee if he or she has any further information to add about the issue.

Here is the question in the *Interview Guide*:

> ***1.18 Is there anything else that you would like to tell us about that experience?***

IDENTIFYING & GETTING INFORMATION ABOUT 2nd EXPERIENCE:

Next, where time permits, the Monitors ask about a 2nd experience. The Interviewee is asked:

> ***2.1 Do you recall another particular time or event in the last five years when you were left out or treated badly or prevented from participating because of your disability?***

Note that it is important not to rush the telling of the first experience that the Interviewee wants to talk about just to get to a 2nd or 3rd experience. But, it is helpful if the Monitors have time to collect information on more than one experience.

The Monitors then cover the questions from (b) to (f) above, about that 2nd experience. For a full list of the questions related to the 2nd Experience, see questions 2.1 to 2.18 in the *Interview Guide* found in Appendix A.

IDENTIFYING & GETTING INFORMATION ABOUT 3rd EXPERIENCE:

Next, if the Monitors still have time, they will ask about a 3rd experience. Questions (b) to (f) above are asked about that experience.

For a full list of the questions related to the 3 rd Experience, see questions 3.1 to 3.18 in the *Interview Guide* found in Appendix A.

IMPORTANT TIP: *We have included the same questions three (3) times in the interview guide so that the Monitor does not have to flip back and forth as they move from the 1st experience to the 2nd experience to the 3rd experience.*

C. Follow-up & Verification Information:

After gathering the details regarding one or more experiences, Monitors ask the Interviewee if there are one or more people who could be contacted to provide further details regarding the issues that have been raised – that is, whether there are any other people who know about the experience(s) the Interviewee has told the Monitor about.

Monitors write the names of these people on the *Identification Sheet* and ask the Interviewee whether he or she consents to having someone on the monitoring team contact these people. Contacting these people without the Interviewee’s consent would violate the Interviewee’s privacy. Many times there will be no one who knows of the experience that the Interviewee has faced so there will be no need to record any information here.

If the Interviewee wants to give you the name of a person who saw what happened, it is helpful to find out the name and contact numbers of that person. If consent to contact one or more people is given by the Interviewee, the Monitors should write their contact details - for example, telephone number; email address; regular mail address, etc. on the *Identification Sheet* which is always kept confidential.

Here are the questions in the *Interview Guide*:

> ***Is there anyone you would like us to could contact who saw what happened to you or who you would want to provide us with more information about the experiences you have raised?***
>
> ***FOR 1st EXPERIENCE:***
> ▪ ***What is their name? [write name on Identification Sheet]***
> ▪ **Can we contact this person? ☐ YES ☐ NO**
> **- If yes, what is the best way for us to contact him or her?**
> **[MONITOR: write details on *Identification Sheet*]**
>
> ***FOR 2nd EXPERIENCE:***
> ▪ ***What is their name? [write name on Identification Sheet]***
> ▪ **Can we contact this person? ☐ YES ☐ NO**
> **- If yes, what is the best way for us to contact him or her?**
> **[MONITOR: write details on *Identification Sheet*]**

D. Collecting Background Information about the Interviewee:

Next, the Monitors collect background information about the Interviewee. Here, it is very important for the Monitors to ask all of the questions in the Interview Guide one by one. This information is important to get a more complete picture of the living conditions of the persons with disabilities interviewed. For example, if Monitors do not record this information it will be impossible to understand whether certain types of discrimination are related to individual characteristics such as age, sex, type of impairment, etc.

Here are examples of some of the questions asked in this part of the *Interview Guide*:

Now, if you don't mind, we would like to ask you a few questions about yourself.

4.1 What is your sex?

4.2 In what year were you born?

4.3 How would you describe your disability? [choose as many as apply]
☐ mobility
☐ sensory – if so, ☐ blind ☐ low vision ☐ deaf ☐ hard of hearing
☐ intellectual
☐ psychiatric
☐ other ___________________________
(ask Interviewee to describe)

4.4 How long have you had your disability?
☐ since birth
☐ since ________ (ask Interviewee to state the year)

For a full list of the questions about the Interviewee's Background, see questions 4.1 to 4.14 in the *Interview Guide* found in Appendix A.

E. Ending the Interview & Finding Other People to Interview

After collecting the Interviewee's background information, the Monitors ask:

> ***"Do you have anything else that you would like to add?"***

Be sure to give the Interviewee time to think and respond.
Next, the Monitors ask:

> ***"Do you have any final questions for us?"***

The Monitors answer any questions that are raised.

Finding Other People to Interview

Monitors always ask the Interviewee if they know any other person with a disability in their community who might be interested in participating in an interview. This is important because the Site Coordinator and the Project Coordinator will use these names when they decide who will be interviewed. They may not use all the names collected but they will use some so the more names they have, the better.

Here are the questions in the *Interview Guide*:

> ***Do you know someone with a disability who lives in your community who we could interview for this study?***
>
> ***What is his or her name?***
>
> ***What type of disability does he or she have?***
>
> ***Is he or she a man or a woman?***
>
> ***How old is he or she?***
>
> ***How can we contact him or her?***

This information is written on the *Identification Sheet*.

[There is no guarantee that the person who is referred to the Monitors by the Interviewee will be interviewed. Monitors will pass the suggestions on to the Site Coordinator who will consider whether, given what is known about the potential Interviewee (sex, type of disability), he or she is the type of person that is underrepresented in the group that has been interviewed so far. More information about how this decision is made is found in section 2.2 (2)(a), below.]

Concluding the Interview:

Finally, the Monitors briefly review the following with the Interviewee:

- what will happen with the information the Interviewee has provided
- how the information will be kept confidential
- the purpose of the project
- important timeframes (for example, when the report from the interviews will be ready)

Monitors make sure the Interviewee knows that the information he or she has provided will make a valuable contribution to improving the lives of persons with disabilities in their region, their country, and internationally,

Monitors should be careful not to raise unreasonable expectations on the part of the Interviewee. They should make sure to let the interviewee know that there will not be any particular follow up to the specific situations they have brought up in the interviews but the very fact that this work is going on is an indication of the progress that is being made. Do not promise rewards or results.

Remember to leave the *Information Sheet* with the Interviewee so that they have the contact details for the Site Coordinator, Project Coordinator and the disability organization running the project. Monitors can add their personal contact details to the *Information Sheet* if they wish.

Monitors should be sure to **thank the Interviewee** for his or her time.

IMPORTANT TIP: *After the interview, Monitors should not begin a personal conversation with the Interviewee. There may be many things that Monitors would like to continue to discuss but it is better to leave those for another day. There may be confusion about what is to be kept confidential if a conversation continues.*

F. Completing *Interview Notes* & Transferring Data

There are a number of important things that have to be done by the Monitors after the interview. They need to be completed as soon as possible.

Following the interview, Monitors have to:

- **Secure the audio recording and mark it with the correct Interview Code** (see *Identification Sheet*)**.**
- **Listen to the audio recording of the interview.** If part of the audio recording is not clear, Monitors should explain what is missing (if they remember) in the *Interview Notes* (see **Appendix F**). This should be done as soon as possible after the

interview. The fresher the interview is in the Monitors' minds, the easier it will be to fill in the blanks or make comments.

- **Complete the *Interview Notes* including the following observations:**

  - overall impression of the interview (for example, Interviewee seemed
  - nervous or anxious over certain questions, the atmosphere was comfortable, etc.).
  - details about the location of the interview (for example, whether it was held indoors or outdoors, type of building where it was held, type of room, who else was around, and any other information that the Monitors think is important).
  - information about who was present at the interview (number of Monitors, and interpreters (if there were any).
  - details about any challenges faced or interruptions that occurred during the interview (for example, airplane flew overhead making it difficult to hear, lost electrical power so could not see, etc.) at what stage in the interview they occurred and what steps were taken to address them – what things made the interview go smoothly and what made it more difficult
  - things made the interview go smoothly and what made it more difficult
  - any concerns about the truthfulness and/or accuracy of anything the Interviewee said - explain why the Monitors have these concerns (for example, answers were very inconsistent, answers seemed rehearsed, etc.)

- **Be certain that one of the Monitors has signed and dated the *Free and Informed Consent Form*.**

- **Provide the Site Coordinator with the following documents:**
  - audio recording of the interview – labeled with the Interview Code
  - completed *Interview Notes*
  - completed *Identification Sheet*
  - 1 copy of the signed *Free and Informed Consent Form*

In order to protect the confidentiality of the information, no copies should be made of any of the written or audio interview records.

The Site Coordinators and Project Coordinator will make sure that the written and audio records are stored in locked cabinets in secure locations. Where records are stored in electronic format (for example, digital audio recordings), the computer systems and access to files will also be secured.

3. Interviewing Skills & Issues

(a) Probing for More Information

Probing involves asking follow-up questions when:

- a response is not fully understood,
- answers are vague, ambiguous, confusing or unclear
- more specific or in-depth information is needed.

When using monitoring tools like the *Interview Guide*, probes or ways of digging for more information cannot be planned in advance. It is not possible to know what issues the Interviewee might raise and how Monitors might need to probe or question further to learn more. But, it is helpful to be aware of the possible need to probe and some general ways to do so.

Here are some examples of probing questions:

- Could you please tell me more about…?
- I just want to make sure I really understood you. What was it exactly that …?
- I’m not certain what you mean by… Could you give me some examples?
- You mentioned… What stands out in your mind about that?
- This is what I thought I heard…Did I understand you correctly?
- How does it make you feel? What makes you feel that way?
- You just told me about… I’d also like to know about…
- Can I take you back to something you said earlier?..
- When you said…, what gave you that impression?
- What makes you say that?

Questions beginning with “what” or “how” are good probing questions because they ask for more detail.

IMPORTANT TIP: *Avoid questions that begin with “why”. They may make the Interviewee feel defensive. Instead of “why”, start the question with “what”.*

The questions in the *Interview Guide* have been designed to avoid “yes” and “no” responses, but it will also be important to probe for depth and ask more questions to get more details. Probing is especially important at the beginning of the interview since this lets the Interviewee know that you want to know the whole story and not just a summary. It sets the tone. If an Interviewee realizes that every brief response to an open-ended question is going to be followed by a set of extra direct questions, he or she may begin to give more details without the Monitors having to prompt.

IMPORTANT TIP: *The quality of the final monitoring report depends to a great extent on the quality and richness of the data collected through personal interviews. Probing to get more complete answers to the questions or clarify the meaning of a particular statement is a very important technique for Monitors to develop.*

This information about Probing is also found in **Appendix H.** Monitors can have it with them when they do their interviews.

(b) Working with People with Different Types of Disabilities

Monitors will be working with people with many types of disabilities or impairments. In some cases, even people with disabilities themselves have not had a chance to work with people with impairments that are different than their own. In this section, Participants have a chance to get to know about disabilities other than their own.

The guiding principle is that all people should be treated with dignity and respect. People will have their own preferences regarding how they want to be treated. The general tips provided below are meant as suggestions only. The best advice is: "When in doubt, ask the person what they want."

General Tips for Communicating with Persons with Disabilities

- Where shaking hands is the custom, it is appropriate to offer to shake hands when introduced to a person with a disability. People with limited hand use or who wear an artificial limb can also shake hands in many cases. There may be other ways of greeting someone and this will be particular to the culture.
- When speaking with a person with a disability, talk directly to that person, not through his or her companion or support person. This applies whether the person has a mobility impairment, an intellectual impairment, is blind or is deaf and uses an interpreter.
- Use a normal speaking tone and style. If someone needs you to speak in a louder voice, they will ask you to do so.
- Treat adults as adults. Address people who have disabilities by their first names only when extending the same familiarity to all others.
- If offering assistance, wait until the offer is accepted. Then listen to or ask for instructions.
- Do not be afraid to ask questions when unsure of what to do. It is you who is uncomfortable, not the person with the disability. For example, if you are not sure how a person communicates, or what they want, the best thing to do is ask.
- Listen to the person with the disability. Do not make assumptions about what that person can or cannot do. Remember that persons with disabilities, like all people, are experts about themselves. They know what they like, what they do not like and what they can and cannot do.

- Do not focus on the details of a person’s disability or impairment. Questions asked during interviews should deal with the circumstances of the Interviewee’s life, *not* the details of his or her impairment.
- Respect all assistive devices (i.e., canes, wheelchairs, crutches, communication boards, service dogs, etc.) as personal property. Unless given specific permission, do not move, play with, or use them.
- Treat persons with disabilities with the same common courtesies you extend to others.

(c) Dealing with Inconsistencies

Getting accurate information is very important in the process of monitoring. If Monitors get a sense that what an Interviewee is saying is not true or accurate, they should ask more probing questions. If there still seems to be an inconsistency in the story, Monitors should continue with the interview as normal, however, after the interview, Monitors should take the following steps:

- discuss the concerns with their monitoring partner
- write their concerns in the *Interview Notes*, explaining their reasons
- discuss their concerns with the Site Coordinator. He or she will let the Monitors know what to do about these doubts. There may be ways of checking the story told or that particular interview may not be used as part of the overall data.

When making a decision whether the Interviewee is telling the truth, Monitors can consider these general observations about credibility:

- Many Monitors consider a person to be credible if he or she is forceful and clear. However, the Interviewee may not be forceful or clear because he or she is powerless or has been traumatized. Also, the culture of some countries or regions may not permit the Interviewee to communicate directly or even to look at the Monitors while talking.

- Confusion or inaccuracy about dates does not necessarily mean that the Interviewee’s statements are not truthful. The Monitors need to be patient with an Interviewee who is not very clear about time sequences. Some Interviewees may not refer regularly to the calendar in their daily lives. They may need to be assisted by tying the events to holidays or other dates that are well-known.
- Finally, take into account local and cultural patterns of speech. For example, exaggeration may be a common trait in certain areas. An interview coming from that area may report that “thousands died”. In this case, it would be important to ask follow-up questions to understand whether the Interviewee only meant to emphasize that “many”, although perhaps not “thousands of”, people died.

(d) Responding to Emotions:

Talking about human rights abuses may be healing for the Interviewee but it can sometimes reopen wounds and cause psychological or even physical stress. For example, telling the story of abuse may lead a person to feel that the abuse is happening again. Monitors should give the Interviewee time to cry or vent their anxiety and assure them that it is okay to do so. Helpful ways to respond include:

- Offering to take a short break from the interview and then to come back and finish the interview
- Changing the subject and coming back to that subject at a later time in the interview

When returning to the topic, remind the Interviewee that they can pause or stop the interview at any time.

Monitors will have a list of supports available in the community, such as trauma counseling and support networks that Interviewees can choose to contact after the interview.

(e) Dealing with Interruptions

It is important for Monitors to be aware of their surroundings during the interview. For example, if it becomes very noisy and this is disturbing the interview, stop the interview, take a break, and begin again when the environment has become quieter or, move to a quieter location.

If distractions occur, be sure that everyone involved with the interview understands what is going on. For example, if an Interviewee is deaf and is not facing the source of noise, he or she may not realize that there is noise that is disturbing the interview. In that case, the Monitors should let the Interviewee know where and what the distraction is and how they plan to deal with it.

(f) Ensuring the safety of Monitors, Site Coordinators and Interviewees

Monitors and **Site Coordinators** could occasionally (it is rare) face physical or emotional dangers when performing their jobs. Here are some steps to keep Monitors and Site Coordinators safe:

- If anyone feels unsafe or threatened when working in the field, for example, if Monitors find that the place where they have arranged to meet an Interviewee is dangerous, they should get themselves and the Interviewee (if he or she consents) away from the danger as soon as possible.
- Avoid traveling alone if there is a risk of common crime, getting lost or getting arrested.

- Make sure someone (either the Site Coordinator or a responsible family member) knows where the Monitors are going and when they plan to return. Have a plan of action in place in case you do not return as scheduled.

There may be cases when **Interviewees** face physical and emotional threats because of their participation in the interview process. This is not common but Monitors and Site Coordinators want to be aware of this possibility and take steps to secure the safety of Interviewee:

- If doing an interview will put the Interviewee in danger, the interview must not continue.
- When requesting that the Interviewee provide consent, Monitors need to review any possible negative consequences of participating in the interview and allow the Interviewee to make his or her own free and informed decision about whether he or she wants to participate.
- At the end of the interview, Monitors will let Interviewees know that if the Interviewee finds that there are bad or unpleasant consequences to them because of their participation in the interviews, they should contact the disability organization running the project using the contact information provided on the *Information Sheet*.

(g) Keeping the Monitoring Information Confidential and Private

The Monitors assure the person before interviewing them that the information they share as well as their personal information (name, contact information) will be kept confidential. It is important that this promise be kept.

Here are some ways to make sure that the Monitors protect the privacy and confidentiality of the information given in the interviews:

- Choosing a location for the interview that is safe and private.

- Ensuring that no identifying information about the Interviewee (for example, names and contact information of Interviewees and people who can give more information about the situations raised) is included on the audio recording of the interview or in the *Interview Notes*. Identifying information will *only* be written on the *Identification Sheet* and *Consent Form*. Site Coordinators will review the interview records to make sure that personal information is kept separate from all other reports of the interview.

- Labeling the audio recordings (tape cassettes or digital files) and *Interview Notes* from the interview with the alphanumeric Interview Code assigned to the interview.

- Giving *all* interview records (*Consent Form*, audio recording, *Identification Sheet*, *Interview Notes*) to their Site Coordinator as soon as possible after each interview. As soon as possible, Site Coordinators will then transfer *all* interview records to the Project Coordinator. When Monitors, Site Coordinators and the Project Coordinator have the interview records in their possession, they are responsible for keeping them in a secure, locked location. Note that *Identification Sheet*s and *Consent Form*s should be kept in a different secure location from the audio recordings and *Interview Notes*. Where records are stored in electronic format (for example, digital audio recordings), access to the computer where the files are stored will also be secured.

- Never referring or talking about statements made by one Interviewee when interviewing another Interviewee.

- Not discussing the information shared by Interviewees with anyone other than their monitoring partner and the Site Coordinator (this means Monitors should *not* talk about Interviewees' experiences with family members friends or anyone else).

2.2 Organizing & Coordinating Individual Experiences Interviews in the Field

The previous unit looked at how to conduct individual experiences monitoring interviews. Before those interviews take place, a number of planning and coordination issues have to be addressed.

Objectives:

By the end of this unit, participants will:

- Know how to organize and coordinate an individual experiences monitoring project.

Here is a checklist of things to do to organize and coordinate monitoring interviews:

Before the Interviews take place:
(This is the job of the disability organizations running the project and the Project Coordinator with help from the Site Coordinators)

☐ choose the places where the interviews will take place (monitoring sites)

☐ gather background information about each of the monitoring sites

☐ get government permission (if you need it in your country)

☐ gather the forms and equipment needed (see Checklist in Appendix G for details)

☐ adapt monitoring tools (Interview Guide & Information Sheet) and methods for cultural, social and economic differences

☐ translate monitoring tools and training materials into local languages as necessary

☐ recruit site coordinators and monitors

☐ train site coordinators and monitors

☐ decide what diversity characteristics will be used to choose the people to be interviewed (the interview sample) and set up the targets in the Matrix Tables (see Appendix I)

☐ identify the first 5 or 6 people to approach as potential interviewees

During the Interviews:

(This is the job of the Site Coordinator with help from the Monitors and the Project Coordinator)

☐ identify good places to conduct interviews

☐ contact potential interviewees and assign interviews to pairs of monitors (see Checklist in Appendix J for the steps to follow)

☐ decide who will be interviewed next by using the Matrix Tables in Appendix I to help balance the sample – will it be:
(a) someone who was recommended by an interviewee?
OR
(b) someone who has particular diversity characteristics that are not held by any of the people who have been recommended by interviewees?
- here, will have to conduct outreach with community organizations that can help to identify someone with those diversity characteristics – for example, if you need to locate a woman with a physical impairment, you could ask local organizations of person with disabilities, women's groups, community-based rehabilitation groups, etc.)

☐ consult with the monitors regularly to make sure that the interviews are moving along without problems

☐ collect monitoring records (audio and written) from monitors regularly and keep them secure

☐ check audio recordings and notes from interviews to make sure that good quality information is being collected – give monitors feedback where necessary

1. How to Get Started?

Organizing and coordinating individual experiences interviews is important and takes time. Effective monitoring depends on careful planning. This section provides information on what needs to be done to organize and coordinate the interviews. The Project Coordinator, Site Coordinator, Monitors and disability organization(s) supporting the monitoring project all have a role to play in making the information collection a success

Here are some important questions to address:

(a) Where will the interviews take place?

It is not possible to interview every person with a disability in any country so, it will be necessary to decide whom to interview. For example, the interviews could take place with persons with disabilities living in a certain:

- neighbourhood (for example, a shantytown) OR
- city (for example, Bangkok in Thailand) OR
- state (for example, Tamil Nadu State in India) OR
- province (for example, Western Cape Province in South Africa)

Each different area where interviews will be held is called a **monitoring site**. In most countries, *DRPI* suggests that three monitoring sites are chosen in order to interview more people with different lifestyles and living environments. DRPI recommends that it is best to have one urban area, one rural area and one town or village taking into account the diversity of circumstances discussed below.

The areas that are chosen for monitoring sites will influence the conclusions that can be made in the report. For example, if three cities are chosen as monitoring sites, there will not be any information about the situation of people living in the countryside. When choosing sites, consider the circumstances of the country and decide **which monitoring sites will give the most complete picture.** Some examples of possible differences in circumstances to consider include:

- people who live in **urban** areas (cities) and people who live in **rural** areas (countryside) or people who live in small towns
- people from **diverse ethnic groups** and the locations where they live
- people who **speak different languages** and the locations where they live

- people who are **rich,** people who are **poor,** people **in between rich and poor** and whether there are different geographic areas where different income groups live

- people with different **types of impairment** or **causes of impairment** – where certain types or causes of impairment are more common in a certain areas (for example, physical disabilities caused by landmines in post-conflict areas)

The time and money available for monitoring will also affect where the interviews will take place. Some practical things to consider here include:

- how **easy it is to travel in the area**? (for example, how good is the transportation to and from that area and within it? are there places to stay? is travel more difficult at different times of the year – climate, holidays?)

- is there **support from local organizations of persons with disabilities**? – does the area have organizations of persons with disabilities who will assist with recruiting the Site Coordinator, Monitors and Interviewees?

Decisions about the monitoring sites are usually made by the disability organization(s) supporting the project and the Project Coordinator.

(b) Do you need permission from the government?

In some countries, governments require groups to get official permission before conducting monitoring interviews. If this is necessary in your country or in a region, the procedure required by the government must be followed. It is the responsibility of the Project Coordinator to find out what is required by the government.

In cases where official permission is required, it is important to be sure that the government understands that the monitoring will take place independently and without government involvement. Government officials will receive the final monitoring report but they will not be able to know who was interviewed or see transcripts of the interviews. The Project Coordinator investigates this issue.

(c) What research tools and methods will be used? Will changes have to be made to suit the country?

Monitoring will take place around the world, in areas with different cultures and social and economic conditions. The monitoring tools and methods will take differences into account while also making sure that information collected in different parts of the world can still be compared.

Monitoring Tools: The *DRPI Interview Guide* (Appendix A) and other Monitoring Tools (for example: *Information Sheet* (Appendix C) and *Free and Informed Consent Form* (Appendix D) are used by Monitors when conducting interviews. While most of these tools can apply in all cultures, some things will need to be adapted. For example, the section of the *Interview Guide* where the Interviewee is asked questions about the schools that he or she went to and the type of house he or she lives in will need to have options that reflect local customs and situations. Appendix B sets out the areas where local changes may have to be made to the Interview *Guide.*

Wherever possible, the *Interview Guide* should be translated into the language that will be used during the interview. In all cases, the *Information Sheet* and the *Free and Informed Consent Form* have to be translated into the language used by the Interviewee.

Monitoring Methods: Cultural norms will be taken into account in scheduling and carrying out interviews (for example, if it is not appropriate for a woman to be interviewed by a man; or if it is a religious holiday for some). Strategies will be developed to address them in the field (for example, ensure that there are pairs of female Monitors who could conduct interviews with women).

The Project Coordinator and the disability organization(s) hosting the monitoring project will be responsible for the adaptation of monitoring tools and methods for cultural, social and economic differences. When the training takes place, there will be an opportunity to for the Monitors and Site Coordinators to create a strategy for the interviews.

(d) Who will be the Monitors and Site Coordinators?

Site Coordinators: Each monitoring site has at least one Site Coordinator who is a person with a disability. It is best if the Site Coordinators live, or have lived for some time, in the monitoring site where they will work. Then, the Site Coordinators will know the local languages, customs and transportations systems. Site Coordinators do not need to have previous experience in this type of position but, they should be people who are organized, reliable, personable and able to identify and solve problems.

The Project Coordinator and disability organization(s) supporting the project work together to recruit the Site Coordinators.

Monitors: Like the Site Coordinators, it is best if Monitors live or have lived for some period of time in the monitoring site where they will be doing interviews. The number of Monitors that are needed for each Monitoring site can vary depending on:

- the number of interviews to take place in the site;
- the timeframe for the project, and
- how often the Monitors are available.

Within a team of country Monitors, there should be a balance in terms of gender, age, ethnicity and type of disability. Monitors do not need to have previous experience conducting monitoring interviews since they will have an opportunity to learn how to do interviews and to use the tools and methods. But, it is helpful if the people chosen have the qualities and skills of a good Monitor that were discussed earlier, in section 2.1(1)(c).

The Project Coordinator, Site Coordinators and disability organization(s) supporting the project work together to recruit the Monitors.

As soon as Monitors and Site Coordinators have been selected, they should be asked to identify any disability-related supports or adaptations that they will need to do their jobs so that these can be provided.

(e) What information and equipment will be needed for the interviews?

See the **Checklist of Equipment and Forms** in **Appendix G** for a full list of what each pair of Monitors will need for their interviews.

IMPORTANT TIP: *Since there are several different forms used during the interviews, some monitoring teams have found it helpful if the forms are copied on 3 different colours of paper: 1. forms that are kept by the Monitors and used at each interview (that is, the Interview Guide and a copy of the Information Sheet) are copied on 1 colour of paper (example, white); 2. forms that are kept by the Interviewee (a copy of the Information Sheet, a copy of the signed Free and Informed Consent Form) are copied on a 2nd colour of paper (example, pink); 3. forms that are given to the Site Coordinator after the interview (that is, 2nd copy of the Free and Informed Consent Form, the Identification Sheet and the Interview Notes) are copied on a 3rd colour of paper (example, yellow).*

Monitors also need the **brief report** with **background information about each monitoring site** in section 2.1(1)(b) above. This background information will give Monitors and Site Coordinators an overview of the areas where they are working and will also be used in the final monitoring report. Developing this report is the responsibility of the Project Coordinator who will work with the Site Coordinator and Monitors to make sure the information is correct and complete.

Because monitoring interviews can raise issues that are stressful for some Interviewees and Monitors, it is important to know about places where Monitors and Interviewees could get counselling services following the interview if they need it.

The Project Coordinator needs to develop a list of resources setting out **contact details for counseling services** available at each monitoring site. The Project Coordinator can use the knowledge of the Site Coordinator and the Monitors in preparing the list. The list will be given to all Monitors and be available to Interviewees.

In a few countries, but not all, there are mandatory reporting requirements in the law for abusive, neglectful or self-destructive behaviour. Such situations might include child abuse or neglect, neglect or abuse of elderly people or persons with disabilities, or people who might be suicidal. In countries where there are mandatory reporting laws the laws must be followed and Monitors will have to tell potential Interviewees about the specific kinds of information that they, as monitors, would be legally required to report to the authorities. The monitors would tell the interviewees this information when they are asking for informed consent. The Interviewee will then be able to decide whether or not to talk about that type of information during the interview. The Project Coordinator will be responsible for finding out if there are any mandatory reporting requirements in the country and for giving Site Coordinators and Monitors the details about these requirements during the training.

2. How to Coordinate Data Collection?

Both the Site Coordinator and Project Coordinator play key roles in coordinating the interviews. Overall responsibility lies with the Project Coordinator while the Site Coordinators play a key role on a day-to-day basis. This section explains how the interviews are coordinated.

(a) Who will be interviewed?

What is "sampling" and who is in the "sample"?

The process of deciding who to interview is called "**sampling**" and the particular people who are interviewed (who will all be persons with disabilities) are members of the "**sample**".

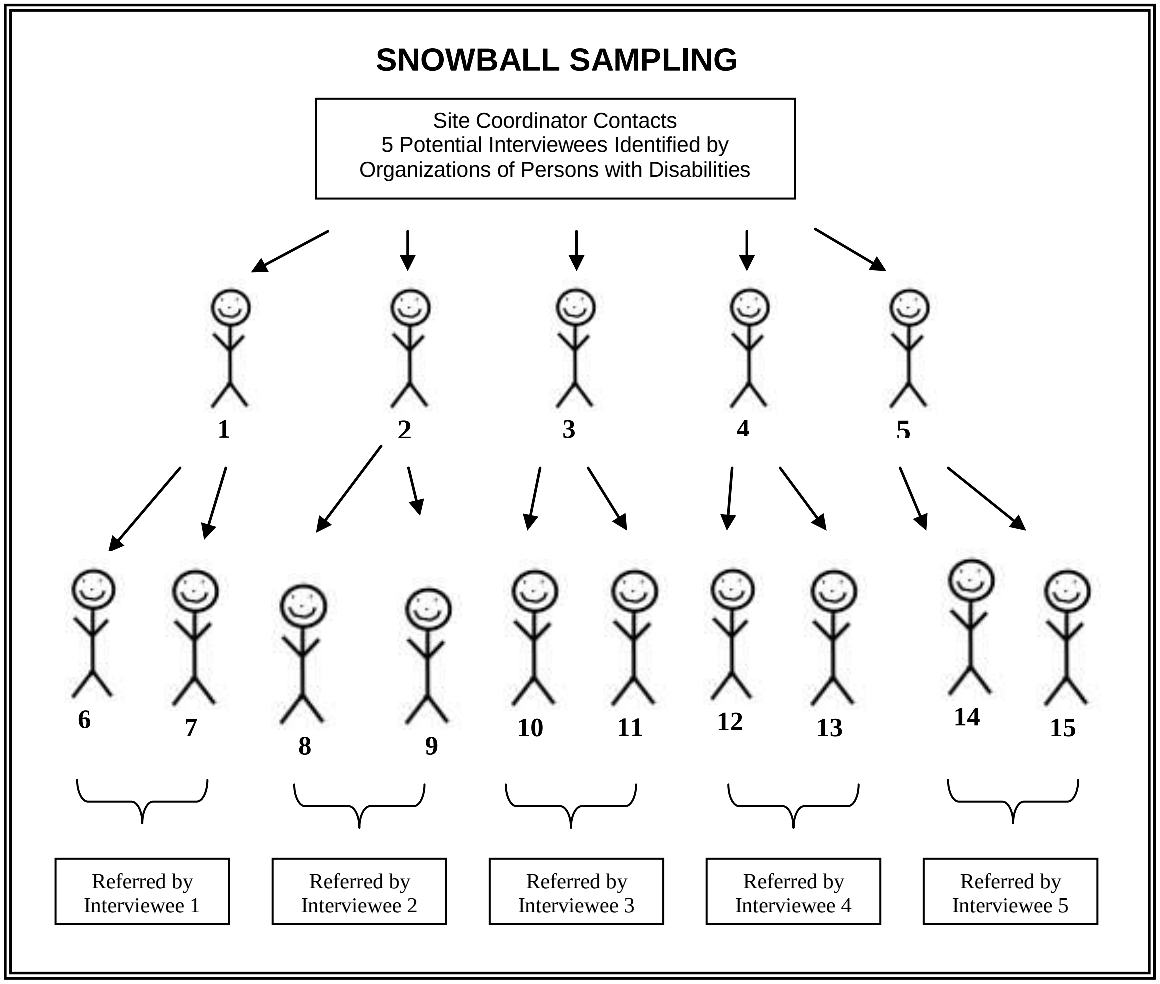
Snowball sampling?

One way of deciding whom to interview (gathering a sample) is through a method called **snowball sampling**. This technique involves beginning with a small group of people to interview (a small ball of snow) and then increasing the size of the group of people to interview by asking people who have been interviewed to suggest other people to be interviewed (rolling a snow ball along the ground makes it pick up more snow and get bigger).


Here is a picture of a person rolling a snowball.

At the beginning, in each monitoring site, a small group of people (5 or 6), who have different types of impairments, are interviewed. At the end of each interview, Monitors ask the Interviewee if he or she can suggest someone else to be interviewed. The Monitors record this person’s name, background and contact information on the *Identification Sheet* that they give to the Site Coordinator. The next people interviewed are chosen from these suggestions that come from all the monitors.

Snowball sampling is often used to reach groups of people who are marginalized or excluded from mainstream society. It broadens the sample of people interviewed beyond the boundaries of people with disabilities who are already involved in the disability organizations. As the snowball increases it includes more people from different income, ethnic, religious and types of disability groupings. This means that the study overall will be more likely to reflect the diversity of the whole population of people with disabilities.


SNOWBALL SAMPLING

How to make sure that the sample is balanced?
One way to ensure diversity of the sample is to choose a variety of monitoring sites. Then, within each of the monitoring sites, relevant characteristics measuring diversity are considered. The process of balancing the representation of these different diversity characteristics is called “**balancing**” the sample.

Ways to Balance the Sample:

(i) **Define the characteristics used to ensure the diversity of the sample in each monitoring site.**

In *DRPI* projects, the characteristics used to ensure diversity of the sample in each monitoring site have been: type of disability, sex and age group (only age 18 and over) and socio-economic status (the Site Coordinator and Project Coordinator will have to determine what factors would best indicate socio-economic status – some examples could include type of housing, level of income or degree of education).

The Site Coordinator and Project Coordinator will work together to determine the targets for each category of Interviewee based on the information collected for the background report on the monitoring site regarding the percentage of the total population of persons with disabilities in the area who have specific impairments or types of disability; who are men or women; who live in different areas, who have different socio-economic characteristics and who fall within particular age groups. Those targets are added to the Matrix Tables used by the Site Coordinator and Project Coordinator (see Appendix I) and discussed further below.

(ii) **Consider the diversity characteristics when selecting people to be interviewed.**

When selecting which of the people who have been suggested by the Interviewees to interview, Site Coordinators will use the diversity characteristics discussed above. In this way, they make sure that broad ranges of people are included in the sample. The **Matrix Tables** in Appendix I can be used to assist. The Project Coordinator has the final responsibility for making sure that the overall sample is diverse and representative and will talk to the Site Coordinators regularly to make sure this is happening.

Some groups of persons with disabilities are harder to find than others because they are more socially isolated. It is important to remember that the quality of the monitoring information collected will depend on making sure that members of these isolated groups are also included in the sample. This would include people who are living *rough* (on the streets); who are in refugee areas; who are living in families where they are isolated in their homes and so on.

As the interview sample grows, Site Coordinators may find that none of the people who have been suggested by Interviewees have the diversity characteristics needed to balance the sample. When this happens, Site Coordinators can return to local organizations of persons with disabilities for recommendations of people to interview who meet those characteristics and the Project Coordinator will also assist. It may take extra time and effort to locate Interviewees who represent the full array of persons with disabilities so this should be taken into consideration when planning the project timeline.

(b) How are the interviews set up?

Here are some ideas for the Site Coordinator about contacting people to ask them if they want to be interviewed:

- Explain briefly about the purpose of the interviews using the *Information Sheet* as a reference and see whether the person is interested in being interviewed (remember that the Monitors will still have to go through the formal process of obtaining informed consent before beginning the interview).
- Schedule the time and place for the interview and assign the interview to a pair of Monitors. Monitors can only do 2 interviews in a day so plan on that as your goal.
- Keep track of the letter assigned to each pair of Monitors for the Interview Code (for example, “A” for Jean and Maria; “B” for Sujit and Nur; “C” for Jean and Esteban and be sure that the Monitors know which letter to use).
- Organize any disability-related adaptations required by the Interviewee.
- Organize how to cover the cost of transportation to/from interview location for both the Monitors and the Interviewee
- Keep records of all money given out for adaptations and transportation (collecting receipts where possible).
- Be sure that Monitors have all the necessary equipment and forms for the interview. (see Checklist in Appendix H)

A Checklist to assist with Setting Up Monitoring Interviews is found in Appendix J.

(c) Are the interviews moving along?

Site Coordinators will want to take steps to make sure that the interviews run smoothly in their monitoring sites. Here are some steps to take to make that happen:

- Talk with Monitors regularly to:
  - make sure that they are completing interviews on time
  - find out about challenges Monitors are facing (for example, problems with equipment , transportation, documents, etc.) and help find solutions
  - make sure that Monitors are able to deal with any emotional stress of interviewing (note that Monitors can use the same counseling services recommended to Interviewees)
  - make sure the Monitors are keeping the interview information confidential

- Where possible, while the interviews are taking place, hold 1 or 2 meetings of all the Monitors in the monitoring site to discuss common problems and questions. Regular discussions with monitoring partners, other Monitors working in the monitoring site and the Site Coordinator will help Monitors to withstand the demands of doing the interviews and improve their ability to gather good quality information.
- Keep a record of the interviews each Monitor conducts (including: Monitor name, date, name of monitoring partner, interview code)
- Be in regular contact with the Project Coordinator. Whenever there are issues that the Site Coordinator cannot address him/herself, contact the Project Coordinator. It is a good idea for the Project Coordinator to try and visit the monitoring site at least once during the period in which the interviews are taking place and to meet with all the Monitors
- After all of the interviews at a monitoring site have been completed, transfer all records that have been used to coordinate the interviews (matrix tables, record of expenses, etc.) to the Project Coordinator

(d) Is good quality information being collected?

Site Coordinators play an important role in making sure that the information collected in the monitoring interviews is detailed and clear. It is very important that Site Coordinators take these steps to be sure the data is as good as it can be:

- Check the *Identification Sheet*, *Interview Notes* and *Consent Form* to make sure they are accurate and complete.
- Listen to a sample of the audio recordings of the interviews to ensure that:
  (a) the recordings are good quality (make sure you can hear the voices clearly).
  (b) detailed information is being collected (make sure that the answers given by Interviewees are not just one sentence long; Monitors are probing for more information, that is, asking follow-up questions about Who? What? Where? When? Why? - to get the full story from the person being interviewed.)
- If there are any problems with the quality of the information being collected, follow-up with Monitors to correct the problem for future interviews.

Module 3 - Systemic Monitoring (Laws, Policies & Programs)

This module focuses on monitoring the systems (that is, laws, policies and programs) that governments have put in place to enable the rights of persons with disabilities. It provides a way to collect information about laws, policies and programs and to analyze and write reports using this information.

By the end of this module, participants will:

- Know how to prepare for a systemic monitoring project.
- Understand how to use the DRPI template to collect and analyze information about laws, policies and programs from a human rights perspective.
- Know how to compile the information and write a report on systemic monitoring data.
- Understand the qualities and skills of a systemic Monitor.

3.1 Systemic Monitoring in Practice

Laws, policies and government programs play an important role in ensuring that persons with disabilities are able to exercise their rights. Systemic monitoring involves looking at whether the legal and policy frameworks of a country meet a country's human rights commitments and whether they meet international principles of human rights. Looking at this information shows whether a country's legislation and policy tolerates or actively prohibits discrimination against persons with disabilities. The information tells the story of what the government is doing or not doing to promote the rights of persons with disabilities.

People involved in Systemic Monitoring

The people who collect and analyse the information about laws, policies and programs, like those who do individual experience monitoring, are called **Monitors**. Monitoring government policies, programs and laws (systems) can be accomplished by one person alone. However, if there is a team of people who can work together to gather and analyse the information, the results are generally better.

Having people who are familiar with collecting this type of data, such as professors and students from local universities or representatives of national human rights institutions as part of the monitoring teams may be helpful. Often these people have experience in accessing data about laws, policies, programs and services and also they have expertise about the legal system that they can share with colleagues from organizations of persons with disabilities. In all cases, it is important to make sure that a majority of the Monitors are persons with disabilities. Many people with disabilities also have legal and policy training and are familiar with policies and programs so they make very good monitors in this type of monitoring.

The Project Coordinator will work with the disability organization(s) supporting the monitoring project to decide how many Monitors should be involved and who the Monitors will be.

1. Getting Ready for Systemic Monitoring

This next section looks at what Monitors need to do before starting to collect systemic information in their country:

(a) What is the country's general human rights situation?

It is useful to have some background information on the human rights situation of a country that is being monitored. What types of material will help Monitors to get a good picture of the human rights situation in that country?

- reports
- key studies
- newspaper articles and
- other relevant material on the country's human rights situation

This information can be collected and read both before and while systemic monitoring is taking place. It can be found in government, university and NGO documentation centres, through national, regional and international human rights organizations, as well as on the Internet. These materials are a place to begin collecting systemic information and are important sources of data.

(b) What is the scope of the investigation?

In most DRPI projects, Monitors will look at all areas of human rights. But, it is possible to use the DRPI Template to look only at specific topics. In addition, Monitors can limit their examination to certain population groups or jurisdictions: national, regional or local.
In this way, the questions that can be asked may be broad such as:

- How do existing laws and policies in the country address the human rights of people with disabilities?
  (all rights, all persons with disabilities, all jurisdictions)

- How do existing laws and policies protect and promote *the right to education* for *children with disabilities*?
  (specific right (education); specific population group (children with disabilities, all jurisdictions)

Or they can be more narrowly defined such as:

- Are existing laws and policies effective in *protecting and promoti*ng th*e right to education of children with disabilities* in *rural areas*?
  (specific right (education), specific population group (children with disabilities), specific jurisdiction (rural areas).

Two criteria to ensure rights:

1) Must enact national law and policy
2) Must allocate budget for implementation of national law at the local level

(c) What are the legal sources in a country?

Systemic monitoring information comes from a number of different legal sources:

Constitutions:
Where there is a constitution in a country, it is an important legal source. Written constitutions may provide statements protecting the human rights of people. An example is the *Chapter 2- Bill of Rights* of the *Constitution of the Republic of South Africa, 1996*.

Legislation:
Legislation includes statutes and codes and acts and by-laws passed by governments. Legislation is legally binding but can be changed.

Case Law:
Case law is the reported decisions of courts and other legal tribunals that interpret and apply the law.

Policies:
Policies outline government strategies or directions about various legal and social issues. They have an influence as guiding statements and may or may be legally binding.

Programs:
Programs are the measures that governments take to implement legislation and policies. Programs are ways in which human rights are put in place.

Legal Systems:
It is helpful for Monitors to understand the type of legal system that is in place in the country where they are monitoring. Having this knowledge will help Monitors to know which sources of law (described above) are most important (hold most weight) in their country when it comes to systemic measures to protect rights.

Currently there are three major legal systems in the world: **civil law**, **common law** and **religious law**. Below, is a brief and simplified overview of each of these systems. But, Monitors should know that many countries have developed variations of these systems

Civil law is found in many countries around the world. In this type of law, listings of laws (codification) in constitutions and legislation are recognized as most important. Case law is of secondary importance. Judges are given the authority to interpret legislation but their decisions are not binding on future cases dealing with the same issues.

Common law is a system of law whose sources are the decisions in cases by judges. Common law systems usually also involve a legislature that passes new statutes. A main difference between the common law and civil law systems is that judges operating under the common law must respect the decisions that previous judges have made on similar issues (this is, they are “bound by precedent”). Civil law judges do not have this restriction.

Religious law refers to a system that uses a religious system or document as a source of law and the basis for the country’s legal system. The most common example is Islamic Sharia law based on the *Qur’an* and *Sunnah*. Depending on the country, religious sources may apply only to particular areas of regulation (for example, family law) or could be used along with statutes passed by a legislature.

Monitors will want to examine all types of government and judicial action (constitutions, legislation, case law and policies) that are important in their legal system in order to build a *comprehensive view* of the systemic measures in place to ensure the rights of persons with disabilities.

(d) What is my network of contacts?

Even the most knowledgeable monitoring team will find it useful to develop a network of contacts. These contacts will:

- help gather and analyze information
- advise the Monitors about recent relevant developments
- increase the visibility of the monitoring project across sectors
- assist with widespread dissemination of monitoring results .

It is helpful to start building this network as early as possible. Possible contacts can include:

- human rights organizations
- other nongovernmental organizations,
- government officials,
- academics and researchers working in the area
- lawyers
- journalists
- other people working in the area I

MPORTANT TIP: *It is a good idea and very useful to conduct focus groups of knowledgeable people in disability organizations to identify an initial list of laws, policies, programs and case laws as the basis for the template.*

2. Using the DRPI Template for Systemic Monitoring

Background to the Template

The *DRPI Law and Policy Template* is the tool used by Systemic Monitors to both *collect information* about and *assess* government actions to protect, promote and fulfill the human rights of persons with disabilities.

The DRPI Template:

- is structured around the *Convention on the Rights of Persons with Disabilities (CRPD) but also cross-references ot*her international and regional human rights instruments that protect the rights of persons with disabilities.

- It covers all types of rights (civil, cultural, economic, political and social).

- It specifically focuses on monitoring the rights of person with disabilities in domestic law and policy.

Here is an example of a page from the *DRPI Template*:

DRPI Law and Policy Monitoring Template

International & Regional Human Rights Standards (Convention/ Art.) (1)	Question (2)	Definitions and Items Considered in Analysis (3)	Description & Record of Relevant Laws/Policies Relied Upon in Analysis: (4)	Other Sources Used in the Analysis (e.g. statistics, national budgets, information from key informants): (5)	Integrated Analysis of laws and policies on the books and other sources against human rights standards and principles: (6)
Accessibility **CRPD, art 9.1, 9.2 abcde** **IACEDPD, art 3.1abc** **ACHR-PSS, art 18c** **SR 5** **(CCPR, art 12.1)** **(ECHR-P4, art 2)** **(ACHR, art 22)** **(CERD, art 5e)**	17. Do the laws or government policies guarantee **to persons with disabilities access to** the physical environment, transportation, information and communications, both in rural and urban areas?	According to the UN Disability Convention, measures to promote the right of access shall include: **[check which of the following requirements are considered in the analysis]** ☐ developing minimal national standards and guidelines for accessibility and monitoring their implementation; ☐ providing signage in Braille, easy-to-read-and-understand forms and other forms of live assistance (e.g. guides, readers and sign language interpreters) in services and facilities open to the public; ☐-providing training for stakeholders on accessibility issues facing persons with disabilities.			**Conduct an integrated analysis to identify inconsistencies with standards in human rights treaties considered in column 1.** **Include a discussion about how well the country meets each of the 5 general human rights principles in the specific area of rights under consideration:** ▪ Dignity ▪ Autonomy ▪ Participation, Inclusion & Accessibility ▪ Non-discrimination & Equality ▪ Respect for Difference **With all the information you found provide a response to the question in column 2 by assigning stars in the report card:** *** non-compliance** **** needs significant improvement** ***** generally compliant or needs only slight adjustment**

3. A Step-by-step guide on how to use the DRPI Law and Policy Template to Collect and Analyze systemic monitoring information

This section reviews how to use the DRPI Law and Policy Template to collect and analyze systemic monitoring information. It explains how the Template is organized, what information it provides and what information should be gathered, recorded and analyzed by Systemic Monitors.

The DRPI project adopts a twin-track approach recognizing the importance of the CRPD in advancing the rights of persons with disabilities while also recognizing the importance of other human rights treaties as tools for change. Putting references to a number of international and regional human rights treaties into the Template, allows the Template to be used to monitor compliance with the CRPD *as well as* other human rights instruments that apply to persons with disabilities.

Monitors should be aware of what treaties have been ratified and that are legally binding on the country being monitored. [see Module 2 where this was also discussed]. Remember that Monitors can find information on the ratification of international human rights instruments online at the link: http://treaties.un.org/Pages/Treaties.aspx?id=4&subid=A&lang=en.

(a) Review Information about the Right being Considered (Template Columns 1,2 & 3):

First, Monitors learn about the right that is being considered:

Column (1) International & Regional Human Rights Standards (Convention/Article) identifies the articles and sections of the international and regional human rights treaties, including the CRPD, related to the right that is covered by the questions asked in column 2. An explanation of the abbreviations used for a number of human rights instruments is found at the beginning of the Template guide.

Monitors do not need to enter anything in Column (1).

Monitors begin the process of monitoring by reading provisions in the human rights treaties that apply to the question in column 2.

Column (2) Question poses a question based on what the country has to do for persons with disabilities under the human rights treaties found in Column 1. Question 0 is the most general question of the template and cannot be answered until all of the information from Questions 1-38 has been collected and analyzed.

IMPORTANT TIP: *Question 0 is a general, overall evaluative question that cannot be answered until all of the information from Questions 1-38 has been collected and analyzed. Don't try to answer it until you have completed all the questions.*

Column (3) Definitions and Items Considered in the analysis sets out relevant definitions taken from the text of the CRPD and also includes a list of considerations to guide the Monitors' analysis. These considerations are useful in interpreting and clarifying the meaning of the questions included in Column 2. Monitors can make a decision about whether or not to take these considerations into account when they are collecting and analyzing the information.

IMPORTANT TIP: *Whenever a list of considerations for analysis is included in Column 3, Monitors must indicate with check marks in Column 3 which of the considerations they took into account.*

Example

Convention/ Art. (1)	**Question (2)**	Definitions and Items Considered in the analysis: (3)
Inclusion in Society **CRPD, art 19** **SR 4, 5 & 9** **IACEDPD, art 13.1b & 1c** **ACHR-PSS, art 18c** **(ECHR-P4, art2)** **(CERD, art 5f)** **(CCPR, art 25c)**	**25. Does any law or policy of the State protect the right of persons with disabilities to live independently and be included in the community?**	In relation to this right, the UN Disability Convention requires States to take appropriate measures to: **[check which of the following requirements are considered in the analysis]:** ☐ protect the right of persons with disabilities to determine how, where, and with whom they live, on an equal basis with others, and ensure that they are not forced to live in a particular living arrangement; ☐ ensure access for persons with disabilities to a range of in-home and other community support services, including personal assistance, necessary to support living and inclusion in the community; rof seitilicaf eht dna secivres ytinummoc taht erusne ☐ na no elbaliava edam era noitalupop lareneg eht era dna seitilibasid htiw snosrep ot sisab lauqe .sdeen rieht ot evisnopser

(b) Collect & Analyze Systemic Monitoring Data (Template Columns 4, 5 and 6):

Column (4) Description & Record of Relevant Laws/Policies Relied Upon in Analysis: Systemic Monitors collect sources of systemic data that are relevant to their country's legal system as well as the question being considered by the Monitor. For example, Monitors will be looking for whether or not there is a written constitution, legislation, case law, policies and programs.

It is very important that Systemic Monitors provide accurate and full references to all of the legal sources that they use. In this way, it will be easier for Systemic Monitors who follow up the work and add to it at a later time to identify changes that have been made to legal and policy frameworks. It is also important to provide direct quotations of relevant passages in laws, policies and programs since the specific wording used can make a difference in the way that laws, policies and programs are interpreted.

IMPORTANT TIP: *Monitors have found it helpful to create separate computer files for each of the Template questions and include the relevant legal and policy sources in those files. This is a good idea as a way of keeping such a large amount of information organized*.

Monitors need to make sure that their research is extensive and exhaustive and includes general legislation and policies as well as disability-specific legislation and policies. Monitors can use library resources as well as Internet searches. If Monitors do not have previous experience collecting legal and policy information in their country, it would be helpful to ask knowledgeable informants (possible examples include human rights lawyers, professors, policy analysts, leaders in the disability community) to be sure that all of the relevant material is collected.

IMPORTANT TIP: *To keep organized, monitors have found it helpful to organize the information first in separate files for each Template (see tip above) and then divide into the following categories: constitution; legislation; case law; policies; programs.*

Here is an example of the types of information that could be collected in Column 4 in order to answer Question 25. The example is from Canada and is not complete.

Column (5) Other Sources Used in Analysis: Here, Monitors look to see whether persons with disabilities are able to realize their rights in practice. Sometimes, a law, policy or program can look as though it will help to enable rights when it is on paper but ends up not having a positive impact in realizing rights. Perhaps it has not been enforced or resources have not been allocated to support enforcement of the law, policy or program.

Example

Convention/ Art. (1)	Question (2)	Definitions & Requirements of the Question (3)	Description & Citation of Relevant Laws/Policies Relied Upon in Analysis (4)
Inclusion in Society **CRPD, art19** **SR 4, 5 & 9** **IACEDPD, art 13.1b & 1c** **ACHR-PSS, art 18c** **(ECHR-P4, art2)** **(CERD, art 5f)** **(CCPR, art 25c)**	25. Does any law or policy of the State protect the right of persons with disabilities to **live independently** and be **included in the community**?	☑ protect the right of persons with disabilities to determine how, where, and with whom they live, on an equal basis with others, and ensure that they are not forced to live in a particular living arrangement;	**CONSTITUTION:** ***Canadian Charter of Human Rights and Freedoms,* s.7** right to life, liberty, security of the person → liberty includes the right to choose one's own living arrangement. **LEGISLATION:** ***Canadian Human Rights Act*,** (R.S.1985, c. H-6) (current as of [DATE]), **s.6** denial of commercial premises or residential accommodations on grounds of disability is prohibited → this permits persons with disabilities to choose to occupy commercial or residential spaces freely **CASE LAW:** ***Gray (Litigation Guardian of) v. Ontario*** [2006] O.J. No.266 (Ont. Sup. Ct.) **-** Residents of Rideau Regional Centre (the "RRC") who suffered from mental disabilities were to be moved to another facility without consent Insufficient evidence to conclude that the Plaintiff has shown that a greater public interest would be served, if the interim injunction was granted. →This case illustrates that the right to choose one's own living arrangement is susceptible to infringement where the greater public interest outweighs the individual interest.

Monitors turn to other sources to gather information for this investigation. Some possible sources are:

- **national and local statistics**
- **national budgets**,
- **policy or research reports**,
- **key informant interviews** (with, for example human rights lawyers, journalists, NGO representatives) **,**
- data from the **individual experiences monitoring interviews**

Drawing on these various sources, Monitors gather information to create a more comprehensive picture.

Column (6) Integrated Analysis of laws and policies on the books and other sources:

Here, monitors conduct an integrated analysis to identify inconsistencies with standards in human rights treaties considered in column 1. This analysis should include a discussion about how well the country meets the 5 general human rights principles in relation to the specific area of rights under consideration. The five human rights principles are:

- Dignity
- Autonomy
- Participation, Inclusion & Accessibility
- Non-discrimination & Equality
- Respect for Difference

With all the information they found monitors should then provide a response to the question in column 2 by assigning stars in a report card:

*** non-compliance**

**** needs significant improvement**

***** generally compliant or needs only slight adjustment**

The general human rights principles were discussed in Module 1. Here are they are again:

DIGNITY:

Dignity refers to the inherent worth of every person. Human rights are about protecting and promoting the self-respect of all people.

AUTONOMY:

Autonomy is the right of a person to make his or her own choices independently. Autonomy means that the person is placed at the centre of all decisions affecting him or her.

PARTICIPATION, INCLUSION & ACCESSIBILITY:

Inclusion is the right of all persons to participate fully and effectively. It involves making sure that society is organized to be accessible and is without physical or social barriers.

NON-DISCRIMINATION & EQUALITY:

Rights are guaranteed to everyone. It is discrimination for people to be denied their rights based on disability, race, sex, language, religion, political or other opinion, national or social origin, property, birth or age.

Discrimination happens when favouritism is shown to one group of people over another. It may be based on prejudice and is unfair. If there is a law, policy, program, action or failure to act that results in denying persons with disabilities the ability to exercise their human rights, that is discrimination. Everyone has the right to enjoy human rights equally. Rights, responsibilities and opportunities do not depend on whether someone is born with or without a disability. This does not mean that persons with disabilities will be treated exactly the same as persons without disabilities. Instead, society must be sure that persons with disabilities have what they need to exercise their rights fully – sometimes what a person with a disability needs to exercise his or her rights equally will be the same as what is needed by a person without a disability and sometimes it will be different.

RESPECT FOR DIFFERENCE:

Respect for difference involves recognizing and accepting persons with disabilities as part of human diversity. Difference is not a reason to deny someone their rights and dignity. The responsibility to change does not fall on the individual but on the community and the government. Society must recognize diversity and find ways to be inclusive of the difference that disability represents.

Here is an example of the analyses carried out in Column (6):

EXAMPLE:

Education example from India:

- The hostels and residential schools established specially for the education of visual impaired and speech and hearing impaired children in the name of special facilities and training, have become worse than prisons, due to severe lack of funds and finances as well resources,. The State Budget had reached One Lakh Crore Rupees and the Chief Minister of the State proudly proclaims that 46 Thousand Crores from the above Budget are available as part of the 5-Year Plan from the Central Government (Source: www.aponline.gov.in). If the 3% reservation protected for people with disabilities in the People with Disabilities Act, 1995 were to be implemented, then at least 3000 Crore Rupees of the State Budget and 1600 Crore Rupees from the Plan Budget, that is 4600 Crore Rupees in total should be allocated for the welfare of people with disabilities in this state through several development programs. The reality is that barely 3% of this amount of 4600 Crores, that is 150 Crores, is just about allocated for the programs for persons with disabilities. The Persons with Disabilities Act also stipulates that 3% of the Budgets allocated for each of the Departments should be set aside for taking up the concerned programs for persons with disabilities but to date, this has not been implemented at all.
- At present both the Central and State Governments can spend the allocated funds at the rate of One Rupee per person with disability. That is why many voluntary organizations are encouraged to get funds from outside the country to work with persons with disabilities.
- In addition to all this, the State Government has increased the amount given to people with disabilities as disability pension from 200 to 500 Rupees, with the financial and administrative support of the Ministry of Rural Development, to be disbursed also through the functionaries of the same Department. The State Government is also planning to increase the money given for scholarships for children with disabilities who are studying in schools and colleges, equal to the amount given to students from lower castes and aborigines, which is unprecedented.

Example:

Transportation example from Canada:

In Canada there are laws and regulations protecting people with disabilities' rights to personal mobility and transportation, both at federal and provincial levels (e.g. the Intercity Bus Code of Practice, issued in 1998 by the Canada Transportation Agency and the Accessibility Standards for Costumer Services, Ontario)

In the city of Toronto, Ontario, the mainstream transportation systems (buses, streetcars and the subway) continue to be inaccessible to many users with disabilities. To compensate, the city runs a special transportation service for people with disabilities (Wheel-trans) that provides door-to-door transportation on an individualized basis to persons with disabilities. However, users of Wheel-trans, interviewed during the individual monitoring study in Toronto, voiced a number of complaints about the ways in which the service operates. Here are some of the reports collected:

"With wheel-trans you can't control. Today my return ride is almost at 5:30. I didn't really need to leave at 5:30 but I have to stick around and wait. Even though I may be sitting here until 6 I cannot cancel it because if I do it I'll be kicked off of Wheel-trans for a month… So in situations like that I don't have a choice" (18-06-2008-interview16)

"I've been in Toronto for 15 years and I still cannot go east and west through the downtown core on regular TTC service because streetcars are not wheelchair accessible in any way, shape or form. They've got more accessible buses but if I could take the regular TTC I wouldn't have to rely on wheel-trans at all to go to work and to go home" (DTA16-28-08-2008)

Human Rights Principles Analysis:

Although Wheel-Trans provides some access to transportation for persons with disabilities, it operates on grounds that are inconsistent with human rights principles of inclusion, autonomy, dignity and non-discrimination. Indeed, it is a segregated service, over which users have little or no control at all, and because of limitations in the number of buses available and the long rides offered, it often creates significant barriers to social and economic participation of its users on equal terms with others.

3.2 Writing a Systemic Monitoring Report

Reporting is important in making the findings of a study widely available. A report also makes it possible to measure how things change over time and if there is progress towards a society in which more people can exercise their rights. After all the systemic data has been compiled, organized, and analyzed – that is, when the template has been completed - the next step is for the monitoring team to produce a report.

To ensure that information can be compared among countries and over time, DRPI suggests the following way to format the systemic monitoring reports:

➢ **Introduction**

This section should provide an answer to the following questions:

- **Why is the report being writtern?**
- **Who** conducted the research?
- **What** is covered in the report?
- Any other **background information** that could be important to the reader

➢ **Start by providing an overview of the general legal provisions governing persons with disabilities in the country**

Providing a general picture of the situation in the beginning of a report gives readers an idea of the topics that will be discussed in the report.

EXAMPLE

1. CONSTITUTIONAL POSITION

What is the constitutional position on disability in India? While the Indian Constitution prohibits discrimination per se, it does not explicitly prohibit discrimination on grounds of disability. However, a seven judge constitutional bench of the Supreme Court of India in *Indra Sawhney vs. Union of India* held that the "spirit of Articles 14 [right to equality] 15(1) [right against discrimination] and 16 [right against discrimination in public employment]" allowed for discrimination and affirmative actions for persons with disabilities. As a result of this decision, the Constitution may be read as explicitly prohibiting discrimination against persons with disabilities.

(from D.R.P.I. India – Systemic Monitoring Report)

➢ **Address one human right at a time**

Be clear and concise. Present the analysis of the human right that is being discussed in this section of the report. Ensure clarity by providing and quoting from the various sources used.

Identify:

- the trends
- the gaps
- the positive developments, if there are any.

Once this is complete, move to the next human right and present the analysis.

EXAMPLE

RIGHT TO EDUCATION

The rights of children with disabilities are addressed primarily, if not exclusively, through the medium of universal education, Article 21A of the Constitution of India. Drawing on this the enunciation of the zero rejection policy by the Sarva Shiksha Abhiyan (SSA), and the special strategies in this programme to draw children with disabilities into the mainstream of education, are significant (Ministry of Human Resource Development). The SSA goal of the Universalization of Elementary Education (UEE) necessarily meant that children with disabilities be included. One of SSA's missions, therefore, is to ensure that every child with a disability is provided quality education in a learning environment best suited to his or her needs. SSA maintains an emphasis on including children with special needs in mainstream schooling whenever possible by providing pre-integration programmes when needed, as well as adequate in-school support.

However, an alternate report on the Education of Disabled Children and Youth (National Centre for Promotion of Employment for Disabled People) enumerates the failures of SSA to deliver these educational opportunities to children with special needs, and criticizes the "lack of clear vision at the policy level to meet the education needs of children with different impairments."

(from D.R.P.I. India – Systemic Monitoring Report)

➢ **Write a conclusion for the report**

In this section of the report the monitoring team summarizes their findings by answering the **«what does all this mean»**? In writing the conclusion, the monitoring team looks back at the initial purpose of the report and answers the issues or questions that were raised there. Include a clear summary of the main points and outline the findings of the research.

➢ **Make recommendations that come from the findings of the study**

The purpose of monitoring is to promote social change and improve the lives of persons with disabilities. Making recommendations based on the findings is an important contribution to that process.

In writing this section remember that:

- **Recommendations should come directly from the conclusions**
- Recommendations should state **what is to be done at legislative and policy level to improve the human rights situation of persons with disabilities**
- Recommendations should state **who is responsible for implementing the changes recommended**
- Recommendations should state **how and when changes need to happen**

3.3 Qualities and Skills of Systemic Monitors

Here are some of the many of the qualities and skills of a good systemic Monitor:

Objectivity
Observing things as they are and not judging them according to personal views or expectations. Not expressing personal opinions when reporting.

Commitment
Being dedicated to protecting and promoting human rights and to performing the tasks of a Monitor.

Social and political awareness
Being aware of political and legal structures and possible tensions.

Broad Knowledge / Information
Having knowledge of human rights and disability rights, along with the requirements of the DRPI Template.

Thoroughness
Being extensive and exhaustive in the search.

Accuracy and Precision
Providing precise information and well-documented reports, avoiding vague references and general descriptions.

Being Willing to Connect:
Demonstrate the willingness to connect with other who have knowledge

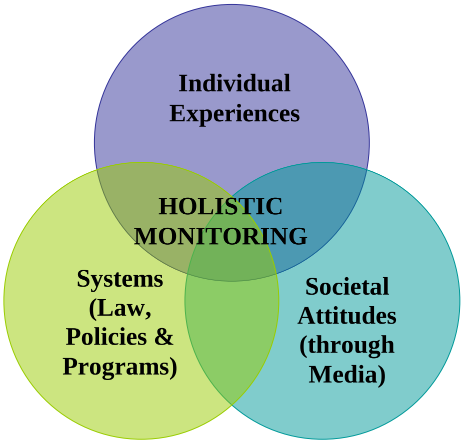
Words to Remember:

> "The challenges we have to confront in the promotion of the human rights of people with disabilities is to make it appear as what they are, in common sense. When we talk with governments, politicians or academics about human rights and persons with disabilities they think we are talking about something from outer space. The principles of human rights are common sense. All of us want to be treated on an equal level with others and all of us want to be treated with inherent dignity."

Lauro Purcil of the Philippines,July 9th, 2011
DRPI Asia-Pacific Regional Training, Thailand

Module 4 –
Putting the Pieces Together: Creating a Holistic Report

This module looks at the way DRPI brings together the three types of monitoring information to build a comprehensive, holistic picture of the rights of people with disabilities. The three types of monitoring, and sources of the holistic report, include individual experiences interviews, the DRPI law and policy template and societal attitudes (media) monitoring to make a comprehensive or 'holistic' picture of the rights of people with disabilities.

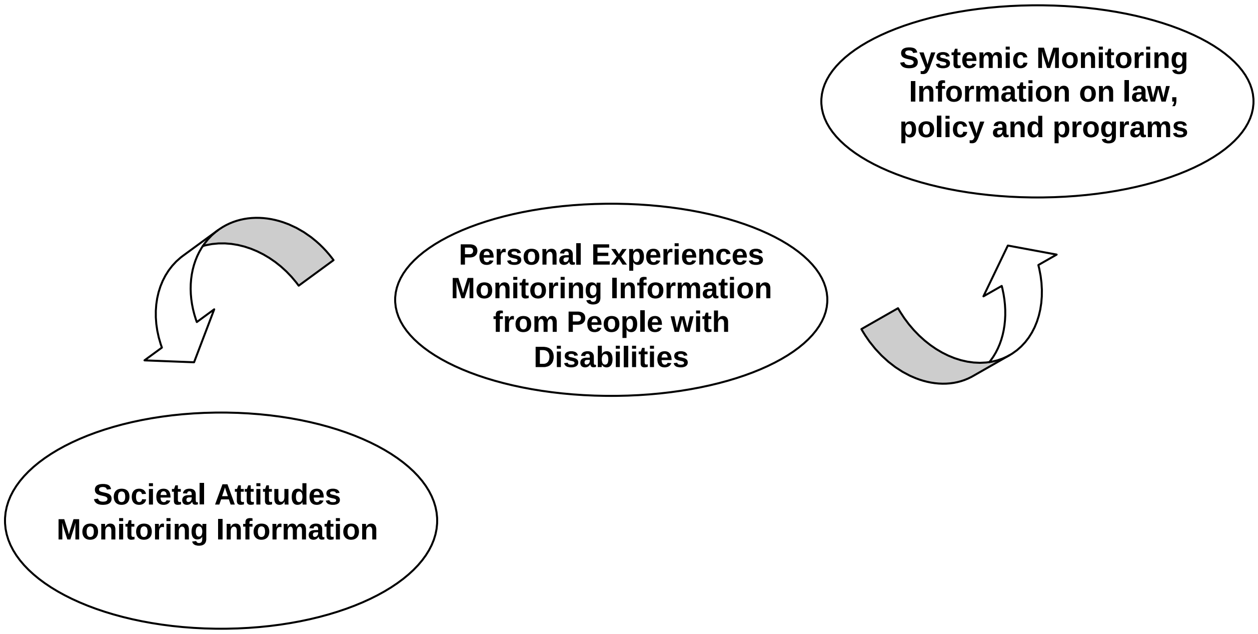


4.1 Introduction to Holistic Reporting

A holistic monitoring report presents a comprehensive picture of the human rights of persons with disabilities living in a particular country. It involves pulling together individual interviews with information from one or two of the other monitoring areas - systemic or societal attitudes monitoring. This makes it possible to understand how rights guaranteed to persons with disabilities on the books become rights in their everyday lives.

DRPI's approach to holistic monitoring makes the lived experiences of persons with disabilities central to tracking/monitoring rights. Personal stories are important in identifying the gap between laws, policies and programs on the books and how those impact people's lives. They also provide an important way to understand the impact of societal attitudes on the exercise of rights.

The experiences of persons with disabilities are at the centre of the holistic report and bring together information from systemic monitoring and societal attitudes monitoring



What does the holistic monitoring report provide?

- Filling the gaps between individual and systemic monitoring
    - What are the promises?
    - What is the reality?
    - How is it possible to change so that the reality and the promises are the same?

- It gives voice to the way persons with disabilities live and the way in which they are able to enjoy their rights

- It links rights that governments and policy makers say people have and the everyday experiences of persons with disabilities

- It examines the impact that societal attitudes towards disability (reflected in media reporting) has on the exercise of rights

- It provides the information needed to start the conversation between government representatives and members of the disability community to develop laws, common policies and programs that are responsive to the human rights violations faced by persons with disabilities

- It emphasizes fact-based monitoring vs. impressionistic monitoring

4.2 Writing a Holistic Monitoring Report

1. Getting Ready to Write the Report:

Here are steps in preparing a report on ‘holistic’ monitoring:

- Pull together the information from different monitoring focus areas (individual experiences, systemic, societal attitudes) to be integrated in the analysis
- Review and discuss any challenges faced by the monitoring report teams that might affect the quality of the information collected.
- Collect the contact numbers and e-mails of people who might be useful to the monitors preparing the final report

There are several steps in bringing the information from difference sources (persons with disabilities, laws/policies/programs and media) together into one report. The diagram below shows these steps.

DIAGRAM: Multi-step Approach to Holistic Reporting

STEP 1
Identify the 'hot issues'

STEP 2
See how the 'hot issues' relate to the rights guarantees set out in human rights treaties

STEP 3
Identify the questions about systemic issues and societal attitudes hidden or embedded in the individual stories

STEP 4
Find the patterns of the denial of rights

STEP 5
Find the gaps in the protection and practice of disability rights

2. Holistic Reporting – Step-by-Step:

Step 1 - Identify the 'hot issues' – that is, the issues from the individual experiences interviews that were the most important.

Here are some examples of "hot issues" raised by persons with disabilities who were interviewed in DRPI monitoring projects:

- Not allowed to choose or access needed aids and devices
- Denied education and subsequently a job because of limited education
- Can't move around because of lack of transportation
- Lack of access to good health care or health care at all
- Living in poverty
- Unable to get things that brothers and sisters have

DRPI's holistic approach makes the human rights situation experienced by persons with disabilities in their daily lives the starting point for analysis. The first step in the holistic process is to identify the *'hot issues'*. These issues come from the analysis of personal stories collected by individual experiences Monitors (see Module 2). They are the barriers that were talked about most often by those interviewed. They were identified as key reasons why people felt they were not experiencing their rights. A 'hot issue' usually covers a range of personal stories, not only one story. These stories tell us about ways that a 'hot' issue is experienced by people in their daily lives.

Here is an example of one woman's story. This story would not be so very different from the many stories that would be collected in the individual experiences monitoring. You can see that even in a short segment like this many issues are raised.

> *"This is my personal, life experience, as I am blind, and the blindness is actually the consequence of long term diabetes. Beside all these problems imposed by the blindness as such, it is also closely related to all complications and things connected with the same, basic disease - such as giving insulin, hypoglycemic comas, glycemic variations, and in fact everything that affects me to function normally in everyday life. I think that my life is to a great extent affected by my disease, and by the disease I mean diabetes - not the blindness. I will in particular highlight some basic things of which I am deprived of, first of all because I am a diabetic, and second because I am blind diabetic and that is that I have injured dignity, and that since I became blind, I am no longer welcome in the daily hospital for diabetics, where people without visual impairment go. Another thing is availability, possibility to be independent to control my basic disease, and that is the blood glucose meter with speech module, increased number of strips,*

> *needles and everything else, concerning that beside visual impairment there are other complications. Then, insensibility to provide an assistant, some kind of support, given that I live alone and that the worst period of my life is during the night, when I struggle for it and when the possibility to wake up is 50:50 %. When I don't feel well, will I wake up or not? And all those small things, such as pen-injectors (applicators) which are not adapted in any segment for blind persons. Sometimes I stab myself and realize that I don't have insulin in the pen-injectors anymore, so I have to start all over again, and those are just some small thing which I wouldn't even mention if there were no other things previously mentioned. I will say in this context that I think that in this part of my life all mentioned segments are violated – dignity, independence, participation in life, and that I am discriminated against diabetics who don't have such complications I am facing. Now I have been that no one wants to offer me a life insurance, no way. With regards to this, I will say that we rely too much on the law which provides the right for orthopedic and other aids, i.e. on the regulation which is based on the law, but which does not perform any categorization on the base of real and individual needs of every person. There is no such approach to get what you really need instead of what you don't need. The regulation states that you have the right on that, so take it, because you are eligible, it doesn't matter whether you actually need it or not, while the things you need more – things which will improve the quality of your life are not available for you". (Croatia)*

Key issues covered by this story are *the ability to access health services and the impact on personal safety and security.* These issues become a 'hot issue' if they repeatedly come up within many people's interviews. When this repetition or "hot" issue is identified, it tells us that this is a prevalent area in which the rights of people are being denied.

Issues raised by this particular story with systemic implications are:

1. A need for health services that are necessary for persons with disabilities because of their disability, including proper early detection and intervention, as well as services aimed at decreasing and preventing further disability, including disabilities of children and older persons.
2. A need to provide these health services as near as possible to the communities where persons with disabilities live, including rural areas.
3. A need to ensure that health care workers provide the same quality services for people with disabilities as for others based on free and informed consent.
4. A need to ensure that people are not going to bed at night frightened that they won't live until the morning because they don't have medical care
5. A need to raise awareness about human rights, dignity, independence and needs of persons with disabilities through training as well as through the promotion of ethical standards in public and private health sector.

6. A need to prohibit discrimination against persons with disabilities in providing health and life insurance that will be enacted in a fair and reasonable manner.
7. A need to prevent discriminatory denial of health care services on the basis of a particular disability or multiple disabilities.

For the rest of this module on creating a holistic report, we will use this one story as a ‘hot issue’. However, we would like to reiterate that, in reality, a ‘hot issue’ is made of several stories that bring together a range of perspectives and contexts as they come out of personal experiences.

Step 2 – See how the ‘hot issues’ relate to the rights guarantees set out in human rights treaties

Once the ‘hot issues’ are identified, the next step is to identify the rights provided in international human rights treaties that are connected to the ‘hot issue’ and understand what these rights provisions mean and what they include. The individual stories show us the broader denial of rights as well as the barriers faced by those who tell their stories.

The team compiling the report can start with the provisions in the CRPD but should also consider the relevant provisions in other international and regional human rights treaties that apply to persons with disabilities.

[Note that Column 1 of the DRPI Law and Policy template includes references to the articles in the CRPD and other regional and international human rights conventions that relate to different subjects. This can assist monitors in identifying the relevant human rights guarantees].

This step makes it possible to link the personal experiences gathered through interviews with the information collected by systemic monitoring report teams. Using the DRPI Law and Policy template (see Module 3) as well as the review of media reports by societal attitudes monitoring report teams, a fuller picture emerges.

Using our example, monitors want to identify the provisions set out in the CRPD and other international human rights treaties that provide rights guarantees in relation to the ‘hot issues’ discussed in the story – namely the right to access health services as well as the right to safety and security.

> **CRPD - Article 25 - Health**
> *Member States recognize the right of the persons with disabilities to exercise the highest standards of health without discrimination on the basis of disability. Member states shall also undertake all necessary measures in order to provide persons with disabilities access to the health services, which take into account their gender or rehabilitation. Member states will in particular ensure that people with disabilities have the same range, quality and standard of free services provided to all others, including those in the*

area of sexual and reproductive health and health programs covering the entire population.

International Covenant on Social, Economic and Cultural Rights (ICESCR) - Article 12
"The enjoyment of the highest attainable standard of health". Right to health is the right to enjoy goods, services and conditions necessary for the realization of the highest attainable level of health

World Health Organization – definition of health
" A state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity"

UN Special Rapporteur on Health
Right not to be discrimination against generally includes protection against discrimination in health care and underlying determinants of health and includes special attention to Vulnerable Groups

Convention on the Elimination of Discrimination Against Women (CEDAW) - Articles 12 and 24 *have general recommendations on women and health*

Step 3 – Identify the questions about systemic issues and societal attitudes hidden or embedded in the individual stories

The next step is to decide what questions need to be answered so that we can identify whether the individual story reflects a broader pattern of discrimination including identified barriers as well as the denial of rights and services. This involves pulling together and analyzing the information collected in the different focus areas (individual experiences, systemic, societal attitudes).

First, decide on a broad, *overall question* that needs to be answered. Then, identify *specific questions* that can be answered in each of three types of monitoring focus areas.

Here is an example of an overall question and follow-up specific questions. These questions could be used to explore the issue of accessing appropriate medical care in a non-discriminatory environment that also ensures personal safety, security, dignity and choice.

Overall question:

Do persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability?

Specific questions – Related to Monitoring Focus Areas:

Individual Experiences:

- What did persons with disabilities say about their ability to access health services?
- What situations do persons with disabilities face when they access health services that are normally available for the general population? What are their experiences when they look for services adapted to their disabilities?

Systemic:

- Are there laws, policies and programs that support the right of persons with disabilities to appropriate health services?
- What perspectives do these laws, policies and programs suggest? Are there provisions that ensure access of persons with disabilities to health services available for the general population without discrimination?

Societal Attitudes:

- Does media reporting about disability and persons with disabilities address the right of persons with disabilities to access appropriate health services?
- Does the media present stories about people with disabilities that makes it clear that access to disability-adapted health services is an entitlement?

Step 4 – Find the patterns of the denial of rights: Organize the monitoring information available around the 'hot issues':

Once the monitoring questions are developed, the next step is to identify the information from the individual experiences interviews, DRPI Law and Policy Template, as well as media monitoring that relate to the 'hot issues'. This requires coordination of the various pieces. It is useful, at this stage, to have regular communication between the monitoring report teams who have been involved in collecting and analyzing these different sources of information. The team compiling the holistic report should make sure that they:

- Work with the "individual experiences" monitoring report team to find the information from interviews that relates to 'hot issues' that have been identified.

- Work with the "systemic" and "societal attitudes" monitoring report teams to find information from the DRPI Law and Policy Template as well as from the review of media reports that relates to the 'hot issues'

- Carefully save all of the information in a secure location. Be sure to create a backup copy of the information.

- Review the challenges that were faced by the individual experiences, systemic and societal attitudes monitoring report teams that might affect the quality of the information collected.

In the example, monitors move on to identify information from the DRPI Law and Policy Template that address the ‘hot issue’ raised by the personal story we are using as an example.

Monitoring information related to the ‘hot issue’ access to health services and the implications for personal safety and security (from Croatia).

> **CONSTITUTION of Croatia, Article 14:** Prohibits discrimination against persons with disabilities in all areas of social life. It proscribes: “*Everyone in the Republic of Croatia shall enjoy rights and freedoms, regardless of race, colour, gender, language, religion, political or other belief, national or social origin, property, birth, education, social status or other characteristics”*.
>
> *It is an open-ended non-discrimination clause. That means it covers a prohibition to discriminate on the ground of disability in all areas of social life although disability as a ground for discrimination is not expressly mentioned in the clause. According to Art. 57 (2) of the Constitution, the State shall devote special care to the protection of disabled persons and their integration into social life.*
>
> *Croatia’s programmatic activities are guided by the Croatian Government National Strategic Development Framework 2006-2013.*
>
> *THE CROATIAN LAW ABOUT HEALTH*
> *The Mandatory Health Insurance Act (Official Gazette No 85/06, 105/06, 118/06) provides persons with disabilities the same range, quality and standard of free health care. There are services designated and designed for persons with disabilities – such as a polyclinic for rehabilitation of hearing and speaking.*

Step 5 – Find the gaps in the protection and practice of disability rights: Put together and analyze the monitoring information from the different focus areas:

The last step is to put all the pieces of the puzzle together – that is, the team does an integrated analysis of the information.

Taking each ‘hot issue’ at a time, the team compiles the report looking at:

- How persons with disabilities understand or frame the ‘hot issue’ when they talk about it in the individual experiences interviews – what does it mean to them?
- What specific rights guarantees in international and regional human rights instruments are engaged by this ‘hot issue’?

- How are the general human rights principles (dignity; autonomy; participation, inclusion & accessibility; non-discrimination & equality; respect for difference) respected or denied in the experiences related to these ‘hot issues’?
- Are current laws, policies and programs in the country that are supposed to protect, promote and fulfill that right?
- Do these laws, policies and programs work in practice?
- Do the laws, policies and programs advance the human rights principles?
- Do societal attitudes about the ‘hot issue’, as reflected in the media monitoring information, affect the enjoyment of this right by persons with disabilities?

Through this analysis, the Monitoring Report Team can identify both best practices and gaps in the way that people are exercising and enjoying their rights.

The example below looks at how monitoring information can identify and analyze ‘hot issues’ such as access to health care services. This specific monitoring information was collected in Croatia.

How are human rights principles reflected in personal stories?

In our example, the woman who tells her story links her experiences with the principles of autonomy, dignity, and participation and accessibility. Because of the lack of diabetes services adapted to her disability, she is unable to make choices to manage her disease and live a life she can control.

> *“…Then, insensibility to provide an assistant, some kind of support, given that I live alone and that the worst period of my life is during the night, when I struggle for it and when the possibility to wake up is 50:50 %. When I don’t feel well, will I wake up or not? …I will say in this context that I think that in this part of my life all mentioned segments are violated – dignity, independence, participation in life, and that I am discriminated against by diabetics who don’t have such complications I am facing.”*

Are the human rights principles advanced in practice?

In practice, the programs designed to facilitate equal access to health care are not responsive to the needs of people with various types of disabilities. As a consequence, a lot of people depending on these services live in isolation and often have to depend on others.

Fitting the pieces together

This is a good example of how a “hot issue” identifies that there are systemic issues hidden within the personal stories of the people interviewed through our individual experience monitoring. It is through their personal stories that we learn that there is something in the law, policy or practice that acts as a barrier to being able to exercise one’s rights.

If we just heard the individual story, it is possible to think that it is an isolated example. If we only reviewed the laws, policies and programs, we might think that there was adequate opportunity to exercise rights. When we put the two together, it is evident that there are important barriers that must be addressed but cannot be tackled by an individual alone. That is the power of good monitoring and of writing a solid and valid holistic report.

What does the holistic monitoring report provide? – Filling the gaps

Comprehensive reporting on the human rights situation of people with disabilities makes an important contribution to understanding their lives and daily situations. It identifies gaps within promises made by governments, service providers and others as well as providing greater understanding of what life in everyday circumstances is like for people with disabilities. It identifies the difference between policy and practice, promise and reality. To get a clear understanding of where human rights are effective and practiced, monitoring needs to look at the holistic picture. The voice of people with disabilities is key to understanding the realization of rights.

The monitoring report gives voice to the way persons with disabilities live and the way in which they are able to enjoy their rights. It links rights that governments and policy makers say people have with the everyday experiences of persons with disabilities. It examines the impact that social attitudes, as reflected by the media, have on the exercise and realization of rights. It provides the information needed to start the conversation between government representatives and members of the disability community to develop laws, policies and programs that are responsive to the human rights violations faced by persons with disabilities.

EXERCISE: Assume the personal story below happened in your country. Use it to practice the holistic monitoring approach.

"I would like to continue with my story and have to emphasize the issue of persons with multiple disabilities. I think that even the Convention does not pay enough attention to this issue, and the legislation in Serbia also has failed to adequately address the issue of people with multiple disabilities. Practical problems are really numerous, not only in health, but in education and everyday life as well. I for example have a problem of blindness and damage to a hand, and I am a diabetic for years as well. And then the problems multiply, since there is an issue how to solve them in practice. Here is an example: when I wanted to come to this seminar, there were couple of options – to go with different people, with assistants… but at the end I was almost forced to decide to go with my wife, because she is the only one who can give me the insulin. The assistant who helps me in Belgrade doesn't know how to do that, he has not learned. For that reasons I have decided to go with my wife, although she has reduced immobility. When I find out three years ago that I have to receive insulin, I posed a question - can I, as a blind person and with the hand impairments learn to give myself insulin and measure blood glucose level? The aids intended for blind persons have not been helpful to me, so I had to rely on the others – spouse or other persons who are familiar with giving insulin or measuring blood glucose level. There was simply no way in my situation, or I could not find the way to solve the problem. I even posed a question, since I had to receive the insulin, whether to leave the job in the Organization of Blind, as that was a new situation and new problem. After some thinking, I have decided to stay and work, because my wife was giving me the insulin in the mornings and evenings, and personal assistants helped me in going to work and in resolving of other life important issues. What is also important, and what is connected with the personal assistance is that Serbia has recently adopted law on social protection where such service is foreseen; however it is necessary to adopt some by-laws to specify such service and such right. The problem is that it is not completely clear who and how will provide the funds for the organization and functioning of such service. It was also not regulated who will have the right to personal assistance, whether it should be provided only for people with physical disabilities, blind persons… and what will be the content of the service, what is happening with people with multiple disabilities and many other issues related to personal assistance which are not resolved. In practice, the state has provide very little personal assistance, there are some in Belgrade, and some

are provided through projects by organizations of persons with disabilities, but those project last for short period of time – six months, nine months and after that the personal assistance is no longer available. Such kind of support for people with the most severe types of disabilities and combined disabilities *is necessary, but in practice it has not been provided. Regardless of this law on social security and law on anti-discrimination, which recognizes the right for inclusion, I know that when we, in the Organization of Blind organize some event, for example literary evening, or have organized going to the theatre, I ask some why they didn't appear, their answer is simple – I didn't have personal assistant. The same goes for persons with physical disabilities."*

The following issues from the story should be addressed:

Identified issues:
- Marriage privacy
- Access to personal Assistance/devices
- Inclusion

Here's what you have covered in this module:

- How to create a holistic report
- How to identify the gaps between individual and systemic monitoring
- How to write a holistic monitoring report
- How to identify "hot issues" and relate them to international rights treaties and legislation
- How to create overall and specific lines of questioning to determine areas in which rights are being denied as well gaps in rights protection

After completing this module, you now have the tools to create a holistic report based upon what you've uncovered throughout the personal interviews you've conducted. Creating a solid and thorough report will be critical in addressing systemic barriers for people with disabilities and will help advance the realization of protected rights.

Module 5 - Using Monitoring Information to Achieve Social Justice for Persons with Disabilities

Monitoring is building a body of knowledge rather than a one-time audit.

Tracking or monitoring rights does not end with collecting information, analyzing it and writing reports. Many different groups can use human rights monitoring information to achieve the goal of improving the lives of persons with disabilities:

- organizations of persons with disabilities (DPOs)
- other organizations interested in promoting the rights of persons with disabilities
- governments
- national human rights institutions
- private organizations and businesses
- media

This module focuses on how *organizations of persons with disabilities (DPOs)* can use monitoring information to create positive change in their countries, communities and around the world. Article 33 of the CRPD requires that "persons with disabilities and their representative organizations be involved and participate fully in the monitoring process." "Nothing about us, without us" is more than a slogan.

5.1 Taking Action at the Country & Community Level:

Because the goal of monitoring is to bring improvements to the daily lives of persons with disabilities, strategies to achieve these changes should begin at the community and country level with attempts to influence people to make changes that will impact whether persons with disabilities enjoy their rights (e.g. influencing governments, employers, owners of private businesses, educators, etc.).

Here are some ways that DPOs can take action in their own countries and communities:

Taking Action at the Country and Community Level
    1) Lobby for changes in laws, policies and programs
    2) Bringing a legal claim
    3) Raising awareness through public education and action

Taking Action Internationally
    1) Convention on the Rights of Persons with Disabilities
        a) Status Reporting Process
        b) Writing a parallel report
        c) Supporting an
    2) Taking Action Under Other Human Rights Treaties

1. Lobbying for Changes in Laws, Policies and Programs:

Information that is collected through monitoring highlights the changes that should be made in a country's laws, policies and programs to improve how well those laws, policies and programs protect, promote and fulfill the rights of persons with disabilities – for example:

- getting rid of (repealing) any existing laws, policies and programs that violate human rights
- changing the wording (amending) or interpretation of existing laws, policies and programs to make them protect, promote and fulfill human rights better
- creating new laws, policies and programs to fill the gaps

By providing facts that show the problems with existing laws, and programs, monitoring information can persuade people that change is needed. By also providing concrete examples of ways in which governments are doing a good job of ensuring rights, monitoring can provide the basis for practices that are learned from and shared.

Monitoring reports can be sent to government officials and meetings can be held to discuss solutions that can bring particular human rights issues into the political spotlight. This is called "lobbying" or "advocacy".

Article 33(1) of the CRPD requires that each country that has ratified the convention designate one or more focal points within government (for example, a particular office or department) to be responsible for issues that relate to the rights of persons with disabilities. Meeting with people working in these offices or departments is a good place for DPOs to start when trying to convince governments to make changes.

Article 33(3) of the CRPD also requires that "persons with disabilities and their representative organizations be involved in the monitoring process". This means that disability organizations have a way to demand a seat at the table when issues affecting the rights of person with disabilities are being discussed.

EXAMPLE:

A report from DRPI's monitoring project in Kenya contains a chapter with evidence-based recommendations to changes to the laws, policies and programs of that country. Here are some of its recommendations:

> **"Mainstreaming disability rights in public service:**
> The lack of a constitutional provision that directs government bodies to mainstream disability issues needs to be addressed.
> a) The government should mainstream disability issues by incorporating information about the human rights of disabled people in all training curricula for its officers. This would allow individual officers to be responsive to reports of human rights violations by disabled people.
> b) The government should incorporate disability in its national development strategy.
> **Legislation:**
> c) The *Persons with Disability Act 2003* (PDA) needs to be amended so that it is no longer anchored on the *Standard Rules of Equalization of Opportunities for Persons with Disabilities* but on current international and regional human rights conventions.
> As well, the penalties in the act should be more severe in order to prevent disability discrimination."

Making these recommendations in the monitoring report is very important. But, it is also important to take the next step and make sure that government officials and others who have the power to influence changes in laws, policies and programs (for example, media representatives, members of various political parties, labour unions, etc.) receive the report and have the recommendations explained to them.

2. Bringing a Legal Claim:

Through careful monitoring, situations may be exposed in which the government or private persons are violating the rights of one or more persons with disabilities. Sometimes in such a case it will be possible to bring a legal action to address the violation(s), penalize those who are responsible and get compensation.

Each country will have different agencies that hear complaints about human rights violations. This will depend on the legal and political system in the country. Some examples of possible agencies include:

- **courts of law**

- **national human rights institutions, national disability rights institutions** or **other independent national bodies with the power to hear claims about violations of disability rights** (CRPD, Article 33(2) requires governments to create "A framework to promote, protect and monitor implementation of the CRPD, including one or more independent procedures".

- **other administrative tribunals** with the power to make decisions about human rights violations in particular areas of life (for example, a tribunal making decisions about employment and the workplace).

3. Raising Awareness through Public Education and Action:

Monitoring information can also be used to raise awareness about current human rights abuses, dispel myths and negative attitudes toward persons with disabilities and gather public support to prevent further violations. Many rights violations faced by persons with disabilities stem from negative attitudes in society. Possible public education and action can include, for example:

- public forums and information sessions
- letter writing campaigns to government and other officials who can influence change;
- public demonstrations and protests;
- postings on websites, listservs, blogs and social networks;
- letters and press releases to the news media.

The aim of these activities is to reach as many people as possible. To be effective, any public campaign should involve the communication tools that are commonly used in your community and country (e.g. radio, television, newspapers, internet, word of mouth, Facebook, Twitter, etc.). It is important to be sure that information is accessible (e.g. using various formats – print, Braille, electronic; ensuring sign language interpretation; choosing locations for events that are fully accessible, etc.).

The way the monitoring data will be used depends on the DPO's agenda for change and the decisions it makes about the most effective way to reach that goal.

5.2 Taking Action Internationally

The goal of taking action at the international (United Nations) level is to influence the behaviour of governments, organizations and other people to make change happen at the country and community levels. Statements made by committees and officials of the United Nations bring violations of human rights happening in a country to the attention of people around the world and help to pressure governments and local organizations in that country to make changes.

1. Taking Action under the *Convention on the Rights of Persons with Disabilities* (CRPD):

The provisions of the CRPD include some ways that persons with disabilities and their organizations can take action at the international level.

Committee on the Rights of Persons with Disabilities:

Article 34 of the CRPD creates a committee of independent experts with the responsibility to oversee whether countries that have ratified the CRPD are meeting their obligations under the Convention. This group is called the Committee on the Rights of Persons with Disabilities. It has 18 members who are nominated and elected by the countries that have ratified the CRPD. Members are on the Committee for a term of 4 years and can be re-elected only once. The full Committee meets twice a year at the United Nations Headquarters in Geneva, Switzerland.

The webpage for the Committee on the Rights of Persons with Disabilities is found at: http://www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx.

This webpage is hosted by the UN Office of the High Commissioner for Human rights (OHCHR). It includes information about which countries have ratified the CRPD and its optional protocol, the current membership and work of the Committee, reports submitted to the Committee and other related publications, stories and events.

There are two (2) main ways that the Committee on the Rights of Persons with Disabilities monitors whether countries are meeting their obligations under the CRPD:

- Periodic State (Country) Reporting Process (CRPD, Articles 35 & 36)
- Individual and Group Communications (Complaints) Process (Optional Protocol to the CRPD)

DPOs can take action at the international level by participating in both of these processes:

(a) State (Country) Reporting Process

Countries that have ratified the CRPD are required to provide comprehensive reports to the Committee on the Rights of Persons with Disabilities explaining the steps they have taken to make sure that persons with disabilities in their country are enjoying the human rights guaranteed by the Convention [see CRPD, Article 35]. These reports are called "**State Reports**".

A country's first State Report must be submitted within 2 years of that country's ratification. After the first State Report, the country must submit subsequent State Reports at least every 4 years. [again a formatting problem]

The CRPD, Article 35(4) reminds governments about their duty "to closely consult with and actively involve" organizations of persons with disabilities when preparing their State Reports. DPOs can choose whether or not they think it will be useful to participate in any consultation process that is established.

(b) Writing a Parallel Report

Whether or not DPOs choose to participate in government consultations on the State Report, they can play an important role in the state reporting process by submitting **"Parallel Reports"** (also known as "Shadow" or "Alternate" Reports) about how well the country has met its obligations. The Committee will use the additional information included in Parallel Reports to question and challenge claims made by the country. Parallel Reports provide another way for the Committee to get a full picture of whether the country is fulfilling its obligations under the CRPD and other Conventions. It is possible for a DPO to both participate in government consultations on the State Report and also submit a Parallel Report directly to the Committee.

At this time, the Committee on the Rights of Persons with Disabilities has not published any formal Guidelines for Parallel Reports submitted by DPOs and other NGOs. This means that there are no set restrictions on content and format.

The Committee on the Rights of Persons with Disabilities has published *Guidelines for State Reports on the CRPD*. The Guidelines can be found at the link:

http://www.ohchr.org/Documents/HRBodies/CRPD/CRPD-C-2-3.pdf

Here is a suggested Outline for a Parallel Report:

Suggested Outline for a Parallel Report
(for reports under the CRPD or other human rights treaties)

1. Table of Contents

2. Executive Summary:

- Highlight:
  - briefly summarize 4 or 5 ‘hot issues’ (key issues of concern)
  - recommendations

- (optional) suggest questions that the Committee could ask the representatives of the country either before the country meets with the Committee in-person (for example, as part of the ‘List of Issues’) or during the in-person meeting (that is, during the ‘constructive dialogue’) [see below for explanations of ‘List of Issues’ and ‘constructive dialogue’]

3. Background:

- Brief background information about the DPO(s) submitting the report

- Explain how the information in the report was collected and analyzed: (WHO? WHAT? WHEN? WHERE?)

4. Key Issues of Concern: (this is the most detailed part of the report)

- Report on 4 or 5 ‘hot issues’ (key issues of concern) about the human rights situation of persons with disabilities in the country that come from monitoring information

When Reporting on each ‘Hot Issue’:

- be as comprehensive as possible but keep in mind that if a report is too long, the members of the Committee will not have time to read it
- note the specific article(s) of the human rights treaty (e.g. CRPD or other human rights treaty) that are being violated
- refer to information to support the statements made (e.g. quotes from individual experiences monitoring interviews and information collected using the DRPI systemic template)
- comment on the information about the ‘hot issue’ contained in the State Report:
  - correct any inaccuracies in the information provided by the State (refer to paragraph numbers in the State Report rather than page numbers)
  - if the State Report does not include important information about the hot issue, add the missing information so that the Committee has the full story

5. Key Recommendations:

- provide specific recommendations
  - concrete and specific
  - listed in order of priority
  - include timeframe for implementation
  - suggest ways that DPOs can be actively engaged in implementation

- (optional) suggest questions that the Committee could ask the representatives of the country either before the country appears before the Committee (for example, as part of the ‘List of Issues’) or during the country’s appearance (that is, during the ‘constructive dialogue’)

6. REFERENCES

* detailed references – providing Internet links wherever possible

Other key points to keep in mind when writing a Parallel Report:

- **Tone:** Parallel Reports are best written using a neutral and objective tone. They should clearly point out problems and propose solutions.
- **Timeline:** Parallel Reports should be submitted as soon as possible after the country submits the State Report, but when that is not possible, it is still useful to submit a report when it is ready
- **Language:** Parallel Reports have to be submitted in one of the official languages of the United Nations (English*, French, Spanish (Castilian), Arabic, Russian or Chinese (Mandarin)).*
- **Working with Other DPOs:** There is no limit on the number of Parallel Reports that can be submitted for each country. However, a report that has been compiled by more organizations may hold more weight. The Committee may find it easier to manage fewer reports.

For more information about Parallel Reports, see:

- DRPI publication: *Claiming Disability Rights: Some Suggestions for Action* found at: http://drpi.research.yorku.ca/
- OHCHR publication, *Working with the United Nations Human Rights Programme: A Handbook for Civil Society* (Chapter IV) found at: http://www.ohchr.org/EN/AboutUs/CivilSociety/Documents/Handbook_en.pdf
- International Disability Alliance publication, *Guidance Document: Effective Use of International Human Rights Monitoring Mechanisms to Protect the Rights of Persons with Disabilities* found at: http://www.internationaldisabilityalliance.org/resources/

What happens with State Reports and Parallel Reports?

Once the Committee receives a State Report, it sets the date during one of its twice-yearly **meetings** in Geneva when it will **consider the State Report** with representatives of the country. These meetings are sometimes called “**constructive dialogues**”. DPOs can attend these meetings as observers but cannot make submissions.

Before this meeting, the Committee reviews the State Report and any Parallel Reports received and sends the country a **“List of Issues**”, asking the country to clarify, complete and/or update the information that it provided in the State Report. The country must respond to the List of Issues in writing.

Finally, the Committee adopts and publishes its own report called “**Concluding Observations**”. This report identifies areas where the country should make changes to laws, policies or practice in order to meet its human rights obligations. Countries must make sure that the Concluding Observations are widely available to the public in their own countries [see CRPD, Article 36(4)] and they are also posted on the Committee website.

DPOs and their allies can use the information included in the Concluding Observations to pressure governments to make changes. It is important for DPOs to:

- tell international and country media about any criticisms made by the Committee
- mention the Committee’s conclusions and recommendations in any relevant legal action
- follow-up on the Committee’s recommendations through lobbying efforts in your home country.

Where to Find Documents Related to the CRPD State Reporting Process for a Particular Country on the OHCHR Website:

There are two different ways to find this information on the OHCHR website.

Option 1 – Webpage of the Committee:

[Note: It is more difficult to find information using this option, BUT information is posted here first):

1. Go to the webpage of the Committee on the Rights of Persons with Disabilities: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx
2. In the menu on the right-hand side of the page, under the subtitle "The Committee", click on the link "Sessions". This should bring you to the page at: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Sessions.aspx
3. Look for the name of the country you are interested in, in the chart on that page. Where the country is listed more than once, click on the most recent link (e.g. Tunisia is listed first for the 4th Session, 4-8 October, 2010 but is listed again for the 5th Session, 11-15 April, 2011. The most recent link, and the one you should click on, is the one for the 5th session). The most recent link will give you the most information. Once complete, these charts contain links to the following:
   - **Timetable:** Details about when the State Report will be considered by the Committee
   - **State Report & Core Document:** State Report in all available languages.
   - **List of Issues:** List of Issues sent by Committee and Response from Country
   - **Information from Other Sources:** Parallel Reports & other information received by the Committee
   - **Delegation Lists and Statements:** Country Delegates participating in the constructive dialogue with the Committee and any formal statements submitted by the country.
   - **Concluding Observations:** Concluding Observations issued by the Committee

Option 2 - Search Engine for Treaty Bodies Database:

[Note: It is easier to find information using this option BUT, the database does not include Parallel Reports from DPOs and there is a delay before the information is posted.]

1. Go to the OHCHR webpage on Human Rights Bodies: http://www.ohchr.org/EN/HRBodies/Pages/HumanRightsBodies.aspx
2. In the menu on the right-hand side of the page, under the subtitle "Treaty Bodies", click on the link "Treaty Body Document Search". This should bring you to the page at: http://tb.ohchr.org/default.aspx
3. Use the drop-down menus to choose:
   Convention – CRPD
   Country – find country you want to know about
   Type – choose the type of information you want to find (e.g. State Party Report, List of Issues, etc.)
4. Click on "Search". Look for the name of the country you are interested in the chart on that page. Where the country is listed more than once, click on the most recent link (e.g. Tunisia is listed first for the 4th Session, 4-8 October, 2010 but is listed again for the 5th Session, 11-15 April, 2011. The most recent link, and the one you should click on, is the one for the 5th session). The most recent link will give you the most information. Once complete, these charts contain links to the following:

- **Timetable:** Details about when the State Report will be considered through constructive dialogue
- **State Report & Core Document:** State Report in all available languages.
- **List of Issues:** List of Issues sent by Committee and Response from Country
- **Information from Other Sources:** Shadow Reports & other submissions received by the Committee
- **Delegation Lists and Statements:** Country Delegates participating in the constructive dialogue with the Committee and any formal statements submitted by the country.
- **Concluding Observations:** Concluding Observations published by the Committee in all available languages.

If the country is not listed, either it has not submitted its State Report yet OR the State Report has been submitted but it is not posted on the website yet.

(c) Supporting an Individual or Group Complaint:

A Model Complaint Form for communications is found on the UN OHCHR website at: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/IndividualComplaints.aspx

If a country has ratified the *Optional Protocol* to the CRPD, individuals and/or groups in that country can bring complaints to the Committee on the Rights of Persons with Disabilities, claiming that their rights under the Convention have been violated. These complaints are called "**communications**".

DPOs can use monitoring information to identify possible complaints to raise in this process and help individuals and groups to file claims. Remember that DPOs will need to have the consent of the person or group before filing a claim.

After considering the complaint, the Committee will issue a decision. If the Committee finds that there is a violation, it will recommend that the country take action to fix the situation. The recommended action can involve a money payment, changing legislative changes and/or other actions.

The country has a moral obligation to implement the Committee's decision but it is not possible for the Committee to *force* the country to do so. This means that it is important for DPOs to publicize any findings of a violation widely in their home country, using these international results to push for change at home. When writing Parallel Reports, DPOs should also provide information to the Committee on cases in which the country has not put into effect the Committee's decisions.

For more information on individual and group complaints see:

- *Fact sheet on the procedure for submitting communications to the Committee on the Rights of Persons with Disabilities under the Optional Protocol to the Convention* found at: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx
- *Guidelines for submission of communications to the Committee on the Rights of Persons with Disabilities under the Optional Protocol to the Convention* found at: *http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx*
- DRPI publication: *Claiming Disability Rights: Some Suggestions for Action* found at: http://drpi.research.yorku.ca/

Where to Find Decisions issued by the Committee on the OHCHR Website:

1. Go to the OHCHR webpage on Human Rights Bodies: http://www.ohchr.org/EN/HRBodies/Pages/HumanRightsBodies.aspx
2. In the menu on the right-hand side of the page, under the subtitle “Treaty Bodies”, click on the link “Treaty Body Document Search”. This should bring you to the page at: http://tb.ohchr.org/default.aspx
3. Use the drop-down menus to choose:
    Convention – CRPD ; Country – find country you want to know about
    Type – Jurisprudence
4. Click on “Search”.

2. Taking Action under other Core UN Human Rights Treaties:

The CRPD is a very important human rights treaty protecting and promoting the rights of persons with disabilities. However, in addition to the CRPD, there are 8 other core United Nations human rights treaties that also apply to persons with disabilities and provide more ways for DPOs to take action at the international level. DPOs are encouraged to adopt a “twin-track” approach to advancing the rights of persons with disabilities:

-track one involves using the CRPD;

-track two involves using the other important United Nations human rights treaties and bodies that protect and promote the rights of persons with disabilities.

Both tracks are followed at the same time.

Each of the 8 other core human rights treaties is monitored by a committee of experts similar to the Committee on the Rights of Persons with Disabilities. They all have state reporting procedures like that found in the CRPD and all but the *Convention on the Rights of the Child* have individual and group complaint procedures similar to the communication procedure under the CRPD Optional Protocol.

As part of the “twin-track” approach, it is important for DPOs to submit their own **Parallel Reports** under these treaties or work with NGOs and networks in their countries to ensure that a disability perspective is included in collective Parallel Reports. This will help to mainstream the consideration of key disability issues in the UN human rights system. For example, the Committee on the Elimination of Discrimination against Women will learn about the particular forms of discrimination faced by girls and women with disabilities. Taking action using the other 8 core treaties also provides a way for DPOs in countries that have not ratified the CRPD to ensure that disability rights concerns from their countries reach the UN level.

DPOs may also want to support the submission of **individual or group complaints** under these treaties. This is one option for DPOs in countries that have not ratified the Optional Protocol to the CRPD but have ratified complaints procedures in other treaties. It gives an entry point for these DPOs to have some voice.

The rules of procedure for state reporting and complaints vary under each human rights treaty so it is important to review and follow the rules set by the relevant expert committee. Unless the rules of the procedure for a human rights treaty outlines a particular format to be followed, the “Suggested Outline for a Parallel Reports” included above can be used for parallel reports under any human rights treaty.

The following chart provides information about the 9 core UN human rights treaties (including the CRPD): who is covered by the treaty; the name of the relevant expert monitoring committee; whether the treaty has a state reporting procedure; whether the treaty has a communications procedure and links to webpages where DPOs can find out more about rules and procedures.

Core United Nations Human Rights

TREATY	WHO IS COVERED	EXPERT MONITORING COMMITTEE	STATE REPORTING PROCEDURE ?	COMMUNICATIONS PROCEDURE?	WEBPAGE WITH MORE INFORMATION
Convention on the Rights of Persons with Disabilities (CRPD)	all persons with disabilities	Committee on the Rights of Persons with Disabilities (CRPD)	yes	yes	http://www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx
International Covenant on Economic, Social and Cultural Rights (CESCR)	all persons with disabilities	Committee on Economic, Social and Cultural Rights (CESCR)	yes	yes	http://www2.ohchr.org/english/bodies/cescr/index.htm
International Covenant on Civil and Political Rights (CCPR)	all persons with disabilities	Human Rights Committee (HRC)	yes	yes	http://www2.ohchr.org/english/bodies/hrc/index.htm
Convention against All Forms of Discrimination against Women (CEDAW)	girls and women with disabilities	Committee on the Elimination of Discrimination Against Women (CEDAW)	yes	yes	http://www2.ohchr.org/english/bodies/cedaw/index.htm
Convention on the Rights of the Child (CRC)	girls and boys with disabilities	Committee on the Rights of the Child (CRC)	yes	no	http://www2.ohchr.org/english/bodies/crc/index.htm
Convention on the Elimination of all Forms of Racial Discrimination (CERD)	all persons with disabilities	Committee on the Elimination of Racial Discrimination (CERD)	yes	yes	http://www2.ohchr.org/english/bodies/cerd/index.htm
Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)	all persons with disabilities	Committee against Torture (CAT)	yes	yes	http://www2.ohchr.org/english/bodies/cat/index.htm
Convention on the Protection of the Rights of All Migrant Workers and Members of their Families (CRMW)	persons with disabilities who are migrant workers and their families	Committee on Migrant Workers (CMW)	yes	yes	http://www2.ohchr.org/english/bodies/cat/index.htm
Convention for the Protection of All Persons from Enforced Disappearance (CED)	all persons with disabilities	Committee on Enforced Disappearances CED)	yes	yes	http://www.ohchr.org/EN/HRBodies/CED/Pages/CEDIndex.aspx

There are several other ways that DPOs can take action at the international level, using a “twin-track approach” including:

- Input into **General Comments and Recommendations** drafted by the Expert Committees monitoring human rights treaties (that is, the CRPD Committee and the Committees of the 8 other core human rights treaties)
- Participation in **Universal Periodic Review by the Human Rights Council**
- Contributing to Investigations under **United Nations Special Procedures**

For more information see:

- OHCHR publication: *Working with the United Nations Human Rights Programme: A Handbook for Civil Society* found at: http://www.ohchr.org/EN/AboutUs/CivilSociety/Documents/Handbook_en.pdf

Final Points about International Action:

Lobbying and advocacy are key to social change and social justice. The United Nations has put these processes in place to ensure that countries are progressing in implementing rights, addressing rights violations and moving towards social justice for persons with disabilities as well as others throughout the world. DPOs can make use all of these international processes – both under the CRPD and other human rights treaties and bodies - to effect change at the country and community levels – using the pressure of international opinion to influence change at home. To do this, it is important for DPOs

- To make sure that any statements or decisions by international monitoring bodies (e.g. expert committees, Human Rights Council, Special Rapporteurs and Independent Experts) are brought to the attention of country media, politicians (e.g. opposition parties) and other interested pressure groups.

- To work towards the universal ratification of the CRPD *and* its Optional Protocol so that these international processes can be used by disability rights activists in every country.

The exercise of rights of persons with disabilities happens at the local, national, regional and international levels of action. Ensuring that all persons with disabilities around the world are able to exercise their rights is an effort that crosses national boundaries. The solidarity of the movement for disability rights is vital to achieving that goal.

Moving Forward

1) Pull together into one movement rather than pillars of disability types
2) Join with other rights seekers (women, children, racial groups)
3) Get information on where your country is at and report processes
4) Monitor to gather facts... and monitor again

APPENDICES

Appendix A

[**NOTE:** This version of the Interview Guide will be adapted to meet the cultural, social and economic differences of the country where it is used. See Appendix B for possible adaptations.]

INTERVIEW GUIDE

for Monitoring the Individual Human Rights Experiences of Persons with Disabilities

A. Beginning the Interview

Introductions:

- **[Introduce everyone present (e.g. monitors, aide(s) and anyone else attending the interview)]**

- **[Explain the equipment you have with you.]**

Request Written, Free and Informed Consent to Participate in Interview:

- **[Review the *Information Sheet* with the interviewee.]**

- **[Ask the interviewee if she/he will consent to participate by signing the *Free and Informed Consent Form*.]**

- ***[If the interviewee does not want to sign the consent to participate line on the* Free and Informed Consent Form*, thank him/her for his/her time and END the interview. Do not proceed any further.]***

- **[If the interviewee signs the consent to participate line on the *Free and Informed Consent Form*, proceed with the next step]**

Request Written Permission to Audio Record the Interview:

- **[Ask the interviewee if she/he will consent to having her/his interview audio recorded by signing the *Free and Informed Consent Form*.]**

- **[If the interviewee does not want to sign the consent to record line, thank him/her for her/his time and END the interview. Do not proceed any further.]**

- **[If the interviewee signs the consent to record line on the *Free and Informed Consent Form*, proceed to the next step.]**

Write information on *Identification Sheet*:

- **[Write the interviewee's name on the *Identification Sheet*.]**

[BEGIN AUDIO RECORDING NOW]

[MONITOR: Say into the audio recorder, "This is the beginning of Interview (insert Interview Code here)]

B. Experiences faced by the Interviewee:

(a) Please tell me a little about your life during the past five (5) years. What things do you do? Where do you go? Who do you meet?

(b) What are the things in your life that are most satisfying?

(c) What are the most difficult barriers or challenges that you face in your life?

[1st EXPERIENCE]

1.1 Do you recall a particular time or event in the last five (5) years when you were left out or treated badly or prevented from participating because of your disability?

1.2 WHAT happened? WHERE and HOW did it happen?

1.3 Is this still happening or did it just happen once?

1.4 Are there other details that you want to share with us about this experience?

[Dignity]

1.5 HOW did this experience make you feel and WHY? (For example, did you feel respected/not respected, ignored/cared for, worthy/ unworthy?)

1.6 WHAT made you feel that way?

1.7 What do you think made people treat you that way?

[Autonomy]

1.8 Did you feel that you had a choice about what happened to you?

WHY? or WHY NOT?

1.9 If you had a choice, would it have made a difference to what happened? In what way?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO CHOICE AND MAKING A DECISION YOURSELF (AUTONOMY) ASK:

(a) Did you want to make a different decision or did you want to do something else?

WHAT was the different decision or what did you want to do?

(b) Did you have enough information to make that decision?

If not, what prevented you from having enough information?

(c) Did you feel pressured to act the way you did?

WHO/WHAT was pressuring you? HOW did it make you feel?

[Participation, Inclusion & Accessibility]

1.10 Did people in your community who knew or saw what happened to you do anything about it?

If yes, WHO?
[MONITOR: interviewee does not need to give someone's name here – can give general description of the person e.g. "neighbour", "sister", etc.]

WHAT did they do?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO PARTICIPATION, INCLUSION or ACCESSIBILITY ASK:

(a) Were you kept apart or left out?

(b) Did you need a service or some assistance so that you could participate?

If YES, what service(s) or assistance did you need?

Did you receive it?

If you did not receive it, HOW did that affect you?

[Non-Discrimination & Equality]

1.11 How do you think your disability affected what happened to you?

1.12 Do you think that persons without disabilities would be treated the same way you were?

WHY or WHY NOT?

HOW would they have been treated?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES of DISCRIMINATION or INEQUALITY ASK:

(a) Do you know anyone else who was treated in the way you were?

[Respect for Difference]

1.13 Were you treated the way you were because people thought you were different?

In what ways do people see you differently?

1.14 Do you think that a person without a disability would have been treated in a similar way?

If not, how do you think he/she would be treated?

1.15 Do you feel that people label you and then treat you differently because of the label?

If YES, what label do they use?

HOW does this label affect you?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO RESPECT FOR DIFFERENCE ASK:

(a) Would someone of a different ethnicity be treated that way?

WHY? or WHY NOT?

How are people from a different ethnicity treated in your community?

(b) Would a woman be treated that way?

WHY? or WHY NOT?

How are women in your community usually treated?

(c) Would a poor person be treated that way?

WHY? or WHY NOT?

How are poor people treated in your community?

1.16 Did you report the experience to anyone?
☐ yes ☐ no

- **If you REPORTED the experience, what kind of person/ organization did you report it to?**

☐ government official
☐ police officer
☐ army officer
☐ NGO employee
☐ religious leader
☐ cultural leader
☐ ombudsperson
☐ human rights commission
☐ disability organization (DPO)
☐ other: ______________________________
(explain)

NOTE: Parts of the Interview Guide that have been highlighted in yellow may be changed to suit particular local circumstances. See more information in Appendix B.

- **How did that person react?**

- **What action was taken?**

- **If you did NOT REPORT the experience to anyone:**
  - **WHY did you not report it?**

1.17 In your opinion, what action[s] should be taken to improve [or prevent] the experience in the future?

1.18 Is there anything else that you would like to tell us about that experience?

[MONITOR: HERE YOU WILL MOVE ON TO THE 2nd EXPERIENCE …]

2.1 Do you recall *another* particular time or event in the last five (5) years when you were left out or treated badly or prevented from participating because of your disability?

2.2 WHAT happened? WHERE and HOW did it happen?

2.3 Is this still happening or did it just happen once?

2.4 Are there other details that you want to share with us about this experience?

[Dignity]

2.5 HOW did this experience make you feel and WHY? (For example, did you feel respected/not respected, ignored/cared for, worthy/unworthy?)

2.6 WHAT made you feel that way?

2.7 What do you think made people treat you that way?

[Autonomy]

2.8 Did you feel that you had a choice about what happened to you?

WHY? or WHY NOT?

2.9 If you had a choice, would it have made a difference to what happened?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO CHOICE AND MAKING A DECISION YOURSELF (AUTONOMY) ASK:

(a) Did you want to make a different decision or did you want to do something else? WHAT was the different decision or did you want to do?

(b) Did you have enough information to make that decision?

If not, what prevented you from having enough information?

(c) Did you feel pressured to act the way you did? WHO/WHAT was pressuring you? HOW did it make you feel?

[Participation, Inclusion and Accessibility]

2.10 Did people in your community who knew or saw what happened to you do anything about it?

If yes, WHO?
[MONITOR: interviewee does not need to give someone's name here - can give general description of the person e.g. "neighbour","sister",etc.]

WHAT did they do?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO PARTICIPATION, INCLUSION or ACCESSIBILITY ASK:

(a) Were you kept apart or left out?

(b) Did you need a service or some assistance so that you could participate?

If YES, what service(s) or assistance did you need?

Did you receive it?

If you did not receive it, how did that affect you?

[Non-Discrimination & Equality]

2.11 How do you think your disability affected what happened to you?

2.12 Do you think that persons without disabilities would be treated the same way you were?

WHY or WHY NOT?

HOW would they have been treated?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES of DISCRIMINATION or INEQUALITY ASK:

(a) Do you know anyone else who was treated in the way you were?

[Respect for Difference]

2.13 Were you treated the way you were because people thought you were different?

If not, how do you think he/she would be treated?

2.14 Do you think that a person without a disability would have been treated in a similar way?

If not, how do you think he/she would be treated?

2.15 Do you feel that people label you and then treat you differently because of the label?

If YES, what label do they use?

HOW does this label affect you?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO RESPECT FOR DIFFERENCE ASK:

(a) Would someone of a different ethnicity be treated that way?

WHY? or WHY NOT?

How are people from a different ethnicity treated in your community?

(b) Would a woman be treated that way?

WHY? or WHY NOT?

How are women in your community usually treated?

(c) Would a poor person be treated that way?

WHY? or WHY NOT?

How are poor people treated in your community?

2.16 Did you report the experience to anyone?
☐ yes ☐ no

- **If you REPORTED the experience, what kind of person/ organization did you report it to?**

☐ government official
☐ police officer
☐ army officer
☐ NGO employee
☐ religious leader
☐ cultural leader
☐ ombudsperson
☐ human rights commission
☐ disability organization (DPO)
☐ other: ______________________________
(explain)

- **How did that person react?**

- **What action was taken?**

- **If you did NOT REPORT the experience to anyone:**
  - **WHY did you not report it?**

2.17 In your opinion, what action[s] should be taken to improve [or prevent] the experience in the future?

2.18 Is there anything else that you would like to tell us about that experience?

MONITOR: HERE YOU WILL MOVE ON TO THE 3rd EXPERIENCE …]

3.1 Do you recall *another* particular time or event <u>in the last five (5) years</u> when you were left out or treated badly or prevented from participating because of your disability?

3.2 WHAT happened? WHERE and HOW did it happen?

3.3 Is this still happening or did it just happen once?

3.4 Are there other details that you want to share with us about this experience?

[Dignity]

3.5 HOW did this experience make you feel and WHY? (For example, did you feel respected/not respected, ignored/cared for, worthy/unworthy?)

3.6 WHAT made you feel that way?

3.7 What do you think made people treat you that way?

[Autonomy]

3.8 Did you feel that you had a choice about what happened to you?

WHY? or WHY NOT?

3.9 If you had a choice, would it have made a difference to what happened?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO CHOICE AND MAKING A DECISION YOURSELF (AUTONOMY) ASK:

(a) Did you want to make a different decision or did you want to do something else?

WHAT was the different decision or did you want to do?

(b) Did you have enough information to make that decision?

If not, what prevented you from having enough information?

(c) Did you feel pressured to act the way you did?

WHO/WHAT was pressuring you? HOW did it make you feel?

[Participation, Inclusion and Accessibility]

3.10 Did people in your community who knew or saw what happened to you do anything about it?

If yes, WHO?
[MONITOR: interviewee does not need to give someone's name here – can give general description of the person e.g. "neighbour", "sister", etc.]

WHAT did they do?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO PARTICIPATION, INCLUSION or ACCESSIBLITY ASK:

(a) Were you kept apart or left out?

(b) Did you need a service or some assistance so that you could participate?

If YES, what service(s) or assistance did you need?

Did you receive it?

If you did not receive it, how did that affect you?

[Non-Discrimination & Equality]

3.11 How do you think your disability affected what happened to you?

3.12 Do you think that persons without disabilities would be treated the same way you were?

WHY or WHY NOT?

HOW would they have been treated?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES of DISCRIMINATION or INEQUALITY ASK:

(a) Do you know anyone else who was treated in the way you were?

[Respect for Difference]

3.13 Were you treated the way you were because people thought you were different?

In what ways do people see you differently?

3.14 Do you think that a person without a disability would have been treated in a similar way?

If not, how do you think he/she would be treated?

3.15 Do you feel that people label you and then treat you differently because of the label?

If YES, what label do they use?

HOW does this label affect you?

FOR EXPERIENCES WHERE THERE ARE CLEAR ISSUES RELATED TO RESPECT FOR DIFFERENCE ASK:

(a) Would someone of a different ethnicity be treated that way?

WHY? or WHY NOT?

How are people from a different ethnicity treated in your community?

(b) Would a woman be treated that way?

WHY? or WHY NOT?

How are women in your community usually treated?

(c) Would a poor person be treated that way?

WHY? or WHY NOT?

How are poor people treated in your community?

3.16 Did you report the experience to anyone?
☐ yes ☐ no

- **If you REPORTED the experience, what kind of person/ organization did you report it to?**
  ☐ government official
  ☐ police officer
  ☐ army officer
  ☐ NGO employee
  ☐ religious leader
  ☐ cultural leader
  ☐ ombudsperson
  ☐ human rights commission
  ☐ disability organization (DPO)
  ☐ other: ______________________________ (explain)

  - **How did that person react?**

  - **What action was taken?**

- **If you did NOT REPORT the experience to anyone:**
  - WHY did you not report it?

3.17 In your opinion, what action[s] should be taken to improve [or prevent] the experience in the future?

3.18 Is there anything else that you would like to tell us about that experience?

[TURN AUDIO RECORDER <u>OFF</u> NOW]

C. Follow-up & Verification Information:

Is there anyone we could contact who saw what happened to you or who could provide us with more information about the experiences you talked about?

FOR 1st EXPERIENCE:

- **What is their name? [write name on *Identification Sheet*]**
- **Can we contact this person? ☐ YES ☐ NO**
  - If yes, what is the best way for us to contact him or her?
  [MONITOR: write details on *Identification Sheet*]

FOR 2nd EXPERIENCE:

- **What is their name? [write name on *Identification Sheet*]**
- **Can we contact this person? ☐ YES ☐ NO**
  - If yes, what is the best way for us to contact him or her?
  [MONITOR: write details on *Identification Sheet*]

FOR 3rd EXPERIENCE:

- **What is their name? [write name on *Identification Sheet*]**
- **Can we contact this person? ☐ YES ☐ NO**
  - If yes, what is the best way for us to contact him or her?
  [MONITOR: write details on *Identification Sheet*]

[TURN AUDIO RECORDER BACK ON NOW]

D. Background Information:

Now, if you don't mind, we would like to ask you a few questions about yourself.

4.1 What is your sex?

4.2 In what year were you born?

4.3 How would you describe your disability? [choose as many as apply]
☐ mobility
☐ sensory – if so, ☐ blind ☐ low vision ☐ deaf ☐ hard of hearing
☐ intellectual
☐ psycho-social
☐ other ______________________________
(ask interviewee to describe)

4.4 How long have you had your disability?
☐ since birth
☐ since ________ (ask interviewee to state the year)

4.5 Did you go to school?
☐ yes ☐ no

- If YES, what kind of school?
[MONITOR: interviewee should identify as many as apply]
☐ primary school
☐ secondary school

☐ trade school
☐ college
☐ university

4.6 Is there a specific place where you live?
☐ yes ☐ no

If YES, do you
☐ own that place?
☐ lease that place?
☐ rent that place?
☐ live with someone who owns, leases or rents the place?

Is the place in a permanent building?
☐ yes ☐ no ____________________ (explain)

If YES, what is the building made of?
☐ concrete
☐ wood
☐ other: ____________________ (explain)

4.7 How far do you live from the City Centre?

4.8 Who lives with you?
[MONITOR: interviewee should identify as many as apply]
☐ no one
☐ spouse
☐ children [if yes, how many children ?]
☐ parent(s) [if yes, how many parents ?]
☐ other family member(s) [if yes, how many family members ?]
☐ friend(s) [if yes, how many friends ?]
☐ other ______________ (explain) [if yes, how many?] _________

4.9 How far is the closest police station to where you live?

4.10 What do people use to cook with in your neighbourhood?
[MONITOR: Interviewee should indicate as many as apply]
☐ electricity
☐ wood
☐ paraffin
☐ charcoal
☐ gas
☐ dust oven
☐ other: ____________________ (ask interviewee to specify)

4.11 How do you get the water that you use?

- ☐ **in the house**
- ☐ **central source nearby**
- ☐ **borehole**
- ☐ **collected from lake, river, stream or well**
- ☐ **other: ___________________(ask interviewee to specify)**

4.12 Do you have toilets in your house?

- ☐ **yes**
- ☐ **no, but centralized and accessible**
- ☐ **no, pit latrines**
- ☐ **other _________________________________**

(ask interviewee to specify)

4.13 What kind of sewage system do you use for your home?

- ☐ **open sewage system**
- ☐ **closed sewage system**
- ☐ **no sewage system**

4.14 How far is the nearest health centre from your house?

4.15 What type of care is offered by the health centre?

- ☐ **homeopathic**
- ☐ **traditional tribal medicine**
- ☐ **western medicine**
- ☐ **natural medicine**
- ☐ **other _________________________________**

(ask interviewee to specify)

4.16 Do you have a job?

- ☐ **yes**
- ☐ **no**

If yes, what is your job? ________________________ (specify)

Do you get paid?

- ☐ **yes**
- ☐ **no**

4.17 Do you belong to an organization of persons with disabilities?

- ☐ **yes**
- ☐ **no**

4.18 Would you say that the area where you live is accessible for persons with disabilities?

- ☐ **yes**
- ☐ **no**

4.19 What makes the area where you live accessible or not accessible?

E. Ending the Interview

- **Do you have anything else that you would like to add?**

- **Do you have any final questions for us about the study?**

[MONITOR: Answer these questions.]

[MONITOR: Review briefly what will happen with the information the interviewee has provided, the purpose of the project and the relevant time frames.]

[MONITOR: Say into the audio recorder: “This is the end of Interview (insert Interview Code here)”]

[STOP AUDIO RECORDING THE INTERVIEW NOW]

Identifying Another Person to Interview:

- **Do you know someone with a disability who lives in your community who we could interview for this study?**
- **What is his or her name?**
- **What type of disability does he or she have?**
- **Is he or she a man or a woman?**
- **How old is he or she?**
- **How can we contact him or her?**

[MONITOR: Write this information on the *Identification Sheet*.]

[MONITOR: Thank the interviewee very much for his/her time. Remember to leave the *Information Sheet* with the interviewee for his/her information.]

F. Completing Notes & Transferring Data

CHECKLIST:

☐ **<u>Cassette Audio Recorder</u>: Remove the USED cassette tape from the recorder and write the correct Interview Code (from *Identification Sheet*) on the cassette.**
<u>Digital Audio Recorder</u>: Secure the recording by turning OFF recorder immediately after the interview and downloading the interview file to a secure computer as soon as possible. Label the file with the correct Interview Code (from *Identification Sheet*)

☐ ***As soon as possible after the interview,* monitoring pairs should listen to the audio recording of the interview. If part of an audio recording is not clear, monitors should explain what is missing (if you remember) in the *Interview Notes*.**

☐ **The *Interview Notes* should also contain the following observations:**

- **Provide your overall impression of the interview (e.g. interviewee seemed nervous or anxious over certain questions, the atmosphere was comfortable, etc.).**
- **Provide details about the location of the interview (e.g. held indoors/outdoors, type of building, type of room, who else was around, etc.).**
- **Provide information about who was present at the interview (number of monitors, interpreters …)**
- **Provide details about any challenges faced or interruptions that occurred during the interview (e.g. airplane flew overhead making it difficult to hear, lost electrical power so could not see, etc.), at what stage in the interview they occurred and what steps were taken to address them.**
- **If you have any concerns about the truthfulness and/or accuracy of statements by the interviewee, identify the statements and explain why you feel this way (e.g. answers were very inconsistent, answers seemed rehearsed, etc.)**

☐ **Be certain that one of the monitors has signed and dated the *Free and Informed Consent Form*.**

☐ **Provide the Project Coordinator or Site Coordinator with the following documents:**

  ○ **audio recording of interview - labeled with the correct Interview Code**
  ○ **completed *Interview Notes***
  ○ **completed *Identification Sheet***
  ○ **signed *Free and Informed Consent Form***

[END]

Appendix B

Possible Adaptations to the Interview Guide

The following parts of the Interview Guide in Appendix A can be adapted to meet cultural, social and economic differences in your country:

A. Options of Persons or Organizations that the Interviewee might have Reported to (Questions 1.16, 2.16 and 3.16):

Different countries will have different types of people and organizations that receive complaints from people who have had their rights abused. The options set out in Questions 1.16, 2.16 and 3.16 of the Interview Guide and highlighted below, should be adapted to identify the five or six types of persons or organizations in your country that might are most likely to receive complaints about human rights abuses.

Note that there will always be a final “other” option that will used if an interviewee says that he or she reported to a person or organization that is not on the list of the top five or six.

Here is question 1.16 of the Interview Guide, highlighting the options that can be changed:

1.16 Did you report the experience to anyone?

☐ yes ☐ no

- ***If you REPORTED the experience, what kind of person / organization did you report it to?***
  ☐ government official / social worker
  ☐ police officer
  ☐ religious leader
  ☐ human rights commission
  ☐ disability organization (DPO)
  ☐ other: ___________________________
  (explain)

- ***How did that person react?***

- ***What action was taken?***

- ***If you did NOT REPORT the experience to anyone:***
  - WHY did you not report it?

Note that the sub-questions in Question 1.16 that are not highlighted, do not have to be adapted.

Note that the same changes that are made to Question 1.16 should also be made to Questions 2.16 and 3.16.

B. Types of Schools (Question 4.5):

Different countries will have different names for the schools that people can attend. The options in Question 4.5 and highlighted in yellow below, should be adapted to fit your country:

4.5 Did you go to school?
☐ yes ☐ no

- If YES, what kind of school?
[MONITOR: interviewee should identify as many as apply]
☐ nursery school
☐ primary school
☐ secondary school
☐ vocational school
☐ short course diploma
☐ college
☐ university

C. Types of Places to Live (Question 4.6):

Different countries can have different ways that people can hold and use property, including the places where they live. Also, homes can be made out of different types of materials. The options in Question 4.6 and highlighted below should be adapted to fit your country:

4.6 Is there a specific place where you live?
☐ yes ☐ no

If YES, do you
☐ own that place?
☐ lease that place?
☐ rent that place?
☐ live with someone who owns, leases or rents the place?

Is the place in a permanent building?
☐ yes ☐ no ___________________
(explain)

If YES, what is the building made of?
☐ concrete
☐ wood
☐ other: ____________________ (explain)

D. Other Indications of Standard of Living (Questions 4.10, 4.11, 4.12 & 4.13):

In some countries, how people cook their food (Question 4.10), how they get water (Question 4.11), whether they have indoor or outdoor toilets (Question 4.12) and what type of sewage system they have (Question 4.13), are good indicators of someone's standard of living. If these are not good indicators in your country, they can be left out of the Interview Guide and replaced with one to four questions that are more appropriate.

E. Types of Health Care (Question 4.15):

Different types of health care and medicine are used in different places in the world. The options in Question 4.15 highlighted below should be adapted to fit your country:

4.10 What type of care is offered by the health centre?
☐ ***primary care***
☐ ***western medicine***
☐ ***herbal medicine***
☐ ***other*** ____________________________________
(ask interviewee to describe)

F. Other Background Information about Interviewees?:

There may be other types of background information that is important to collect in your country about persons with disabilities and the conditions and situations in which they live that is not covered by the questions in Background Information section of the *Interview Guide*.

For example, in some countries, it might be important to know whether an impairment was caused by a landmine or another weapon used in armed conflict. In that case, a question could be added to this section of the Interview Guide asking:

> ***Was your impairment caused by a landmine or another weapon used in armed conflict? Yes or No***

G. Changes to the Words and Expressions Used:

In some countries, it may be necessary to change the wording or expressions used in questions in the Interview Guide to make them easy to understand. It may be that a certain term or phrase is not used in your country and should be replaced with another term.

For example, Questions 1.15, 2.15 and 3.15 talk about being “labeled” as follows:

> ***1.15 Do you feel that people label you and then treat you differently because of the label?***
>
> ***If YES, what label do they use?***
>
> ***HOW does this label affect you?***

When someone is “labeled”, it means that they are put into a classification or category and often treated differently because of that classification or category. But, if the term ‘labeling’ is not used in your country, this question will not make sense to the interviewees and the wording should be changed.

It is important to review *all* of the questions in the Interview Guide to see whether there are any words or expressions that should be reworded so that the questions will be clearly understood.

Appendix C

[**NOTE:** This version of the Information Sheet will be adapted for the particular country where monitoring takes place.]

INFORMATION SHEET (Interviews)

for the study called

Monitoring the Individual Human Rights Experiences of People with Disabilities

This information is provided so that you can make a decision about whether or not you want to participate in this study. We are giving you a lot of information because we want you to be able to make the decision that is best for you.

Sponsors:
The study is being sponsored by:

- [List names of all partner organizations – using a separate bullet point for each partner]
- Disability Rights Promotion International (DRPI) which is a research project based at York University in Toronto, Canada (website: www.yorku.ca/drpi)

Why are we doing this study?
We are collecting information about the lives and experiences of people with disabilities by talking directly to people with disabilities. We want to see if their human rights are being respected. The information we collect will be studied and reports will be written. The names of participants will not be mentioned in the reports unless they have given us clear permission to do so. The reports will be available to organizations of people with disabilities, other groups working to improve the lives of people with disabilities, the media and governments.

The reports made will be used to:

- let people know about violations of the rights of people with disabilities
- help stop human rights violations
- provide facts to back up arguments for changes in laws, policies, and programs to
  improve the lives of people with disabilities
- keep track of the steps that the government has taken or has failed to take in order to fulfill the promises it has made to people with disabilities when it signed agreements at the United Nations saying that it would protect, promote and fulfill the rights of people with disabilities

What will happen in this study and what will you be asked to do?
Our project is going to various countries around the world to talk to people with disabilities about their lives and their experiences.

If you agree to participate, you will be asked a series of questions about your life and your experiences. We will particularly want to know if your human rights have been violated and how they have been violated. In other words, we will want to know if there are unfair things that have happened to you which have stopped you from participating in society in the way that people without disabilities participate in society.

If you agree to participate, you will be interviewed by one or more people with disabilities who are members of a local organization run by people with disabilities. We call these people the ”monitors”. We know that, in the past, people with disabilities have often been left out of research about people with disabilities. We think that it is only fair that people with disabilities play an active role in any research about them.

During the interview, the monitors will take notes. They will also audio record the interview so that we can be sure to get all of the information you provide accurately.

Depending on the methods of communication that are used, the complete interview should take approximately 2 to 3 hours to complete.

After the interview, the monitors will give all of their written and audio recordings to the person in charge of the project who we call the Project Coordinator. The monitors will not keep any copies and will not talk to anyone except for the Project Coordinator about what you said. The interview will be confidential.

The Project Coordinator will pass the written and audio recordings of your interview to the researchers who will study them. Your name will not be on any of the information given to the researchers, they will not know whose information they are studying.

After looking at your information and the information from interviews with at least 50 other people with disabilities in your country, the researchers will write reports that will be given to organizations of people with disabilities, other groups working to improve the lives of people with disabilities, the media and governments. Your name will not be mentioned in the reports without your clear permission.

Are there possible negative things that might happen if you participate in the study?
There are no negative things that will happen to you by participating in this study. However, you may feel uncomfortable when you start thinking about some of the questions that you are asked. For example, you may remember some things that

have happened to you that are not pleasant to think about. If that happens, you can take a break from the interview or, if you want, you can stop the interview completely.

If you want to continue to talk about these things, that's fine, too. If you feel upset about these things, you can ask the monitors for the name of someone you can talk to about your feelings after the interview is over.

Are there good things that might happen if you participate in this study?
You may or may not receive any direct benefit from participation. You might find that it makes you feel better to talk about some of your experiences. Also, we hope that organizations of people with disabilities, the media and governments learn from the studies and reports that are made and take steps to improve the lives of people with disabilities in your country.

Can you decide if you want to participate in the study?
You are free to choose to participate or not to participate in the study and you may choose to stop participating at any time. Your participation is completely voluntary. Your decision not to participate in the study will not influence your ongoing relationship with any of the study sponsors, monitors or any other person or group associated with the project.

Can you stop participating if you don't want to continue participating?
If, at any time during the study, you want to stop participating, for any reason, just let the monitors know and they will stop asking you questions. If you want to answer some questions, but not others, you can do that, too. It is entirely your decision.

If you decide not to participate in the study, or if you decide to stop participating in the study, we will not use your information for our research. Any written or audio recordings made up to the point you decided to stop will be destroyed. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with any of the study sponsors, monitors or any other person or group associated with the project. No one will treat you any differently if you decide that you do not want to participate in the study.

Will your information be kept confidential?
The information you provide will be kept confidential within the limits of the law. Unless you specifically provide your consent, your name will not appear in any report or publication of the research. The written and audio recordings of your interview will be safely stored in a place that is locked and will be destroyed at the end of the project.

Costs and Compensation
You will be reimbursed for the cost of your transportation to the interview location and the cost of any disability-related supports or assistance that you will need in

order to participate in the interview. You will receive these things even if you decide to stop participating in the project at some point during the interview and/or decide not to answer certain questions.

If you have questions about the study

If you have questions about the research in general or about your own role in the study, please feel free to contact:

Project Coordinator:
[insert contact information]

OR

Dr. Marcia Rioux
Principal Investigator for Project
Co-Director, Disability Rights Promotion International
Professor, School of Health Policy and Management, York University
Regular mail: York University, 4700 Keele Street, 441 HNES Building, Toronto, ON, M3J 1P3, Canada
Telephone: +1-416-736-2100 extension 22112
Email: mrioux@yorku.ca

Appendix D

[**NOTE:** This version of the Free and Informed Consent Form will be adapted for the particular country where monitoring takes place.]

FREE and INFORMED CONSENT FORM (Interviews)

I have read and understood the *Information Sheet*. The research procedures have been explained to me and all of my questions have been answered to my satisfaction. I have been informed that I can withdraw from the study at any time without penalty and that, if I choose to do so, any data collected as a result of my participation will be destroyed. The potential discomforts that I might experience because I have participated in the study have been explained to me. I also understand the potential benefits of being a part of this study.

I know that I may ask now, or at any time in the future, any questions I have about the study. I have been assured that the audio and written records related to this study will be kept confidential to the limits of the law. I have also been assured that no information will be released or printed or made public that would disclose my personal identity unless I give permission for that to happen.

I hereby consent to participate

Printed Name of Participant:..

Date: ……………………………………….

Signature of Participant: ………………………………………

I hereby consent to having my interview audio recorded

Signature of Participant: ………………………………………..…
Date: ……………………………….…………………….

Printed Name of Monitor: ………………………………………..…
Date: ………………………………………..

Signature of Monitor: ……………………………………….....

PLEASE NOTE:

This research has been reviewed by the Human Participants in Research Committee, York University's Ethics Review Board, and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines and the York Senate Policy on research ethics. If you have any questions about this process, or about your rights as a participant in the study, please contact: **Senior Manager & Policy Advisor for the Office of Research Ethics** 4700 Keele Street, 5th Floor, York Research Tower, York University, Toronto, ON, Canada M3J 1P3; telephone: +1 416-736-5914; e-mail: ore@yorku.ca

Appendix E

IDENTIFICATION SHEET

[KEEP SEPARATE FROM ALL OTHER RECORDS OF THE INTERVIEW]

Monitoring Site: ________________________

Interview Code[1]: ____________
(Remember to also state Interview Code at beginning and end of audio recording)

Name of Interviewee: _________________________

Interviewee Phone Number: ____________________________

Interviewee Address: ____

SITUATION #1 - FOLLOW-UP CONTACT INFORMATION

Name: _____________________________

Contact Details (Phone, Email or Address): _______________________________

SITUATION #2 - FOLLOW-UP CONTACT INFORMATION

Name: _____________________________

Contact Details (Phone, Email or Address): _______________________________

SITUATION #3 - FOLLOW-UP CONTACT INFORMATION

Name: _____________________________

Contact Details (Phone, Email or Address): _______________________________

ANOTHER PERSON TO INTERVIEW:

Name: _____________________________ Sex: Male or Female (circle one)

Type of Disability: _____________________________

Contact Details (Phone, Email or Address): _______________________________

---

[1] A possible Interview Code would be AF-RW-ER-A-04. This code would be put together as follows: AF= first 2 characters for all interviews in the Africa Region; RW= country where the interview takes place (e.g. Rwanda); ER= first two letters of the monitoring site where the interview takes place (e.g. East Region); A = letter designating the pair of monitors who conducted this interview (e.g. John and Mary); 04 = means that it was the fourth interview conducted by monitoring Pair A.

Appendix F

INTERVIEW NOTES

Interview Code: _______________ Page ____ of ____
(Remember to also state Interview Code at beginning and end of audio recording)

Notes Written by: _______________ Date:_____________________

NOTE: Please use as many sheets of paper as necessary to write your responses.

(a) Provide your overall impression of the interview (e.g. interviewee seemed nervous or anxious over certain questions, the atmosphere was comfortable, etc.).

(b) If any part of the audio recording of the interview is not clear, explain what is missing (if you remember).

(c) Provide details about the location of the interview (e.g. held indoors/outdoors, type of building, type of room, who else was around, etc.).

(d) Provide information about who was present at the interview (number of monitors, interpreters …)

(e) Provide details about any challenges faced or interruptions that occurred during the interview (e.g. airplane flew overhead making it difficult to hear, lost electrical power so could not see, etc.), at what stage in the interview they occurred and what steps were taken to address them.

(f) If you have any concerns about the truthfulness and/or accuracy of statements by the interviewee, explain why you feel this way (e.g. answers were very inconsistent, answers seemed rehearsed, etc.)

Signatures:

_________________________________ _________________________________
MONITOR **MONITOR**

Appendix G

Checklist of Equipment & Forms Needed for Interviews

☐ portable audio recorder (either tape or digital)

☐ cassette tapes (if using tape recorder, be sure tapes have enough minutes for each interview)

☐ batteries for audio recorder (enough for interview + extras)

☐ *Interview Guide*s (one for each Monitor)(in format accessible to Monitor)

☐ *Information Sheet*s (one copy for each Monitor + one copy to leave with each Interviewee in format accessible to Interviewee)

☐ *Consent Forms* (two for each interview)(in format accessible to Interviewee)

☐ *Interview Notes* Sheets (one for each interview)

☐ *Identification Sheet*s (one sheet for each interview)

☐ list of referrals for available counseling services (Monitors should carry a number of copies, in alternate formats)

☐ pens (one for each Monitor)

☐ pads of paper (one for each Monitor)

☐ way to communicate with Site Coordinator – this will depend on the resources available and specifics of the area where monitoring is taking place – for example, mobile phone card, long distance phone card; access to email, etc.

OPTIONAL:

☐ money for Interviewee's transportation (if necessary)

☐ identification card or letter (optional – in some places it has been found helpful for Monitors to carry some form of identification, for example, to provide if questioned by Interviewees, local authorities, etc.

☐ water for Monitors and Interviewee

☐ carry bag for Monitors to carry their equipment and forms

Appendix H

Tips on Probing for More Information

Probing involves asking follow-up questions when:

- a response is not fully understood,
- answers are vague, ambiguous, confusing or unclear
- more specific or in-depth information is needed.

When using monitoring tools like the *Interview Guide*, probes or ways of digging for more information cannot be planned in advance. It is not possible to know what issues the Interviewee might raise and how Monitors might need to probe or question further to learn more. But, it is helpful to be aware of the possible need to probe and some general ways to do so.

Here are some examples of probing questions:

- Could you please tell me more about…?
- I just want to make sure I really understood you. What was it exactly that …?
- I'm not certain what you mean by… Could you give me some examples?
- You mentioned… What stands out in your mind about that?
- This is what I thought I heard…Did I understand you correctly?
- How does it make you feel? What makes you feel that way?
- You just told me about… I'd also like to know about…
- Can I take you back to something you said earlier?..
- When you said…, what gave you that impression?
- What makes you say that?

Questions beginning with "what" or "how" are good probing questions because they ask for more detail.

IMPORTANT TIP: Avoid questions that begin with "why". They may make the Interviewee feel defensive. Instead of "why", start the question with "what" .

The questions in the *Interview Guide* have been designed to avoid "yes" and "no" responses, but it will also be important to probe for depth and ask more questions to get more details. Probing is especially important at the beginning of the interview since this lets the Interviewee know that you want to know the whole story and not just a summary. It sets the tone. If an Interviewee realizes that every brief response to an open-ended question is going to be followed by a set of extra direct questions, he or she may begin to give more details without the Monitors having to prompt.

IMPORTANT TIP: The quality of the final monitoring report depends to a great extent on the quality and richness of the data collected through personal interviews. Probing to get more complete answers to the questions or clarify the meaning of a particular statement is a very important technique for Monitors to develop.

Appendix I

Matrix Tables

(for balancing the sample in each monitoring site)

Country: ____________________

Monitoring Site: _____________________

I. Type of Disability and Gender

	Mobility	Target	Blind/ Low vision	Target	Deaf/ Hard of Hearing	Target	Intellectual	Target	Psycho-social	Target	Others	Target
Female												
Male												

II. Type of Disability and Age Group

	Mobility	Target	Blind/ Low vision	Target	Deaf/ Hard of Hearing	Target	Intellectual	Target	Psycho-social	Target	Others	Target
18-25												
26-40												
41-55												
56-70												
70+												

III. Type of Disability and Socio-Economic Status

	Mobility	Target	Blind/ Low vision	Target	Deaf/ Hard of Hearing	Target	Intellectual	Target	Psycho-social	Target	Others	Target
Insert locally appropriate indicators												

Appendix J

Checklist for Setting up Interviews

Discussion with Potential Interviewee:

☐ explain the purpose of the interview (using the *Information Sheet* as a guide)

☐ explain the time commitment needed for an interview

☐ ask if they have any questions – and answer them

☐ ask if they are interested in participating as an Interviewee:

If they answer "no": thank them for their time and end your discussion.

If they answer "yes":

☐ find a date and time for the interview

☐ agree on a location for the interview

☐ discuss how the Interviewee's travel costs will be covered

☐ ask whether they need any disability-related adaptations to participate fully

☐ tell them the names of the Monitors conducting the interview

☐ ask if they have any final questions – and answer them

☐ give them your contact information in case they need to contact you about the interview

Discussion with Monitors:

☐ give them the name and contact details for the potential Interviewee

☐ tell them the date, time and location of the interview

☐ explain the arrangement that has been made with the potential Interviewee about transportation costs

☐ explain about any disability-related adaptations required by the potential Interviewee and discuss how these will be met

☐ review the Interview Code & letter assigned to the monitoring pair for the interview.

☐ make sure they have all the equipment and forms needed for the interview.