



**QualityRights**

# Protecting the right to legal capacity in mental health and related services

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*WHO QualityRights training to act, unite and empower for mental health*  
**(PILOT VERSION)**

**Contact Information:**

**Michelle Funk, Coordinator**

[funkm@who.int](mailto:funkm@who.int)

**Nathalie Drew, Technical Officer**

[drewn@who.int](mailto:drewn@who.int)

**Prepared by**

*Mental Health Policy and Service Development  
Department of Mental Health and Substance Abuse  
World Health Organization, Geneva*



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# Acknowledgments

## Coordination, conceptualisation and writing:

Michelle Funk (WHO, Geneva)

Natalie Drew Bold (WHO, Geneva)

## Advisors and contributing writers

WHO would like to thank the following individuals in their advisory role and for writing contributions:

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## **WHO Interns**

Gunnhild Kjaer (Denmark), Jade Presnell (USA), Kaitlyn Lyle (USA), Yuri Lee (Republic of Korea), Stephanie Fletcher (Australia), Paul Christensen (USA), Jane Henty (Australia), Zoe Mulliez (France), Mona Alqazzaz (Egypt), Peter Varnum (USA).

## **WHO Staff**

Global coordination of the QualityRights initiative is overseen by Michelle Funk and Natalie Drew (WHO Geneva).

QualityRights implementation is being supported across the world by Nazneen Anwar (WHO/SEARO), Darryl Barrett (WHO/WPRO), Daniel Chisholm (WHO/EURO), Sebastiana Da Gama Nkomo (WHO/AFRO), Dévora Kestel (WHO/AMRO), Dr Maristela Monterio (WHO/AMRO), Khalid Saeed (WHO/EMRO) and Shekhar Saxena (WHO, Geneva).

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# What is the WHO QualityRights initiative?



WHO QualityRights is an initiative which aims to improve the quality of care in mental health and related services and to promote the human rights of people with psychosocial, intellectual and cognitive disabilities, throughout the world. QualityRights uses a participatory approach to achieve the following objectives:

- 1** Build capacity to understand and promote human rights, recovery and independent living in the community.
- 2** Create community based and recovery oriented services that respect and promote human rights.
- 3** Improve the quality of care and human rights conditions in inpatient, outpatient and community based mental health and related services.
- 4** Develop a civil society movement to conduct advocacy and influence policy-making to promote human rights.
- 5** Reform national policies and legislation in line with best practice, the CRPD and other international human rights standards.

For more information: [http://www.who.int/mental\\_health/policy/quality\\_rights/en/](http://www.who.int/mental_health/policy/quality_rights/en/)

# WHO QualityRights - Guidance and training tools

The following guidance and training tools are available as part of the WHO QualityRights initiative:

## Service assessment and improvement tools

- The WHO QualityRights Assessment Tool Kit
- Implementing improvement plans for service change

## Training tools

### Core modules

- Understanding human rights
- Promoting human rights in mental health
- Improving mental health and related service environments and promoting community inclusion
- Realising recovery and the right to health in mental health and related services
- Protecting the right to legal capacity in mental health and related services ←
- Creating mental health and related services free from coercion, violence and abuse

### Advanced modules

- Realising supported decision making and advance planning
- Strategies to end the use of seclusion, restraint and other coercive practices
- Promoting recovery in mental health and related services
- Promoting recovery in mental health and related services: handbook for personal use and teaching

## Guidance tools

- Providing individualized peer support in mental health and related areas
- Creating peer support groups in mental health and related areas
- Setting up and operating a civil society organization in mental health and related areas
- Advocacy actions to promote human rights in mental health and related areas
- Putting in place policy and procedures for mental health and related services (in preparation)
- Developing national and state-level policy and legislation in mental health and related areas (in preparation)
- Guidance on CRPD compliant community-based services and supports in mental health and related areas (in preparation)

## About this training and guidance

This document provides training and guidance on legal capacity and how supported decision making, recovery plans and advance plans help to avoid involuntary detention and treatment and ensure people are able to exercise their right to legal capacity.

### Who is this training workshop and guidance for?

- **People with psychosocial disabilities**
- **People with intellectual disabilities**
- **People with cognitive disabilities, including dementia**
- **People who are using or who have previously used mental health and related services**
- **Managers of general health, mental health and related services**
- **Mental health and other practitioners** (e.g. doctors, nurses, psychiatrists, psychiatric nurses, neurologists, geriatricians, psychologists, occupational therapists, social workers, peers supporters and volunteers)
- **Other staff working in or delivering mental health and related services** (e.g. attendants, cleaning, cooking, maintenance staff)
- **Non-Governmental Organizations (NGOs), associations and faith-based organizations working in the area of mental health, human rights or other relevant areas** (e.g. Organizations of Persons with Disabilities (DPOs); Organization of users/survivors of psychiatry, Advocacy Organizations)
- **Families, care partners and others support people**
- **Ministry of Health policymakers**
- **Other government institutions and services** (e.g. the police, the judiciary, prison staff, law reform commissions, disability councils and national human rights institutions)
- **Other relevant organizations and stakeholders** (e.g. advocates, lawyers and legal aid organizations)

### Who should deliver the training?

Training should be delivered by a multi-disciplinary team including people with psychosocial, intellectual and cognitive disabilities, DPOs, professionals working in the area of mental health and related services, families and others with lived and/or professional experience in the area of mental health

The team conducting the training may differ depending on focus. For example, if the training is about addressing the rights of people with a psychosocial disability, it would be more important to have representatives from that group as leads to delivering the training rather than people with dementia, intellectual disabilities, autism or others and vice versa. However, nothing precludes the possibility of having multiple groups leading the training.



# Guidance for facilitators

## Principles for running the training programme

### *Participation and interaction*

Participation and interaction are crucial to the success of the training. By providing sufficient space and time, the facilitator must first and foremost make sure that the people who are using mental health and related services are being listened to and included. Certain power dynamics within services might make some people reluctant to express their views. In general, the facilitator must emphasize the importance of including the views of all participants.

Some people may feel quite shy and not express themselves. Facilitators should make sure to encourage and engage everyone. Usually, after people have expressed themselves once, they are more able and willing to speak and engage in ongoing discussions. The training is a shared learning experience.

Facilitators are expected to engage participants in a way that draws on the experience and knowledge already existing within the group participating in the training. They will need to supervise and monitor the dynamics and discussions among participants.

### *Cultural sensitivity*

Facilitators should be mindful of using culturally sensitive language and providing examples relevant to people living in the country or region where the training is taking place. In addition, facilitators should make sure that the specific issues faced by particular groups in the country or region (e.g. indigenous people and other ethnic minorities, religious minorities, women, etc.) are not overlooked when carrying out the training.

### *Open, non-judgmental environment*

Open discussions are essential and everyone's views deserve to be listened to. The purpose of the training is to work together to find ways to improve the situation within the service, organisation or association, not to name and blame individuals for their particular conduct in the past. Facilitators should ensure that during the training, no-one is targeted in a way that makes them feel uncomfortable (e.g. attributing the blame to staff or families, etc.). Facilitators should avoid interrupting participants. It is not necessary to agree with people to effectively communicate with them. It may be necessary to withhold criticisms in order to fully understand a person's perspective.

### *Use of language*

In addition, facilitators should be mindful of the diversity of the audience. People participating in the training will have different backgrounds and levels of education. It is important to use language that all participants are able to understand (e.g. avoiding the use of highly specialised medical, legalistic and technical terms, acronyms, etc.) and to ensure that all participants understand the key concepts and messages. With this in mind, facilitators should pause, take the time to ask and discuss questions with participants to ensure that concepts and messages are properly understood.

### *Operating in the current legislature and policy context*

During the training, some participants may express concerns about the legislative or policy context in their countries. Indeed, some of the content may contradict national legislation or policy. For example, the topic on supported decision making may appear to conflict with existing national guardianship laws. Similarly, laws that provide for involuntary detention and treatment contradict

the overall approach of these modules. This can raise issues and concerns, particularly around professional liability.

First, facilitators should reassure participants that the modules are not intended to encourage practices which conflict with the requirements of the law. When the law and policy contradict the standards of the CRPD it is important to advocate for policy change and law reform. In this context it is also necessary to acknowledge that it will not happen immediately. However, an outdated legal and policy framework should not prevent individuals from taking action. A lot can be done at the individual level, on a day to day basis to change the attitudes and practices within the boundaries of the law. For example, even if guardians are officially mandated to make decisions on people's behalf based on a country's law, this does not prevent them from supporting people in reaching their own decisions and from ultimately respecting their choices. In this way, they will be making important strides towards implementing a supported decision making approach.

Throughout the training, facilitators should encourage participants to discuss how the new paradigms, actions and strategies promoted in the training materials can be implemented within the parameters of existing policy and law frameworks. Hopefully, the shift in attitudes and practices, along with effective advocacy, will lead to change in policy and law reform.

#### *Being positive and inspiring*

Facilitators should emphasise that the training is not about lecturing people or telling people what to do but to give them the basic knowledge and tools to find solutions for themselves. Most likely many participants already carry out many positive actions. It is possible to build on these to demonstrate that everybody can be an actor for change.

#### *Group work*

Throughout the exercises of the training, the facilitator needs to assess carefully whether participants will benefit from being placed in separate groups or in mixed groups that include both people who are using the service, staff, and family and care partners. As noted earlier, feelings of disempowerment, hesitation and fear, which can arise in mixed groups if participants do not feel comfortable in that setting, should be taken into account. Exercises are based on participation and discussion and should allow participants to reach solutions by themselves. The facilitators' role is to guide plenary discussions and when appropriate, prompt with specific ideas or challenges to facilitate the discussion.

#### *Facilitator notes*

The training modules incorporate facilitator notes which are in **blue**. The facilitator notes include examples of answers or other instructions for facilitators, which are not intended to be read out to participants. The content of the presentation, questions and statements intended to be read out to participants are written in **black**.

**The issues covered in this topic are particularly complex. Facilitators need to have an in-depth knowledge and understanding of the Convention on the Rights of Persons with Disabilities (CRPD) and of the topics covered in this module to conduct this training.**

## Preliminary note on language

We acknowledge that language and terminology reflects the evolving conceptualisation of disability and that different terms will be used by different people across contexts over time. People must be able to decide on the words that others use to describe them. It is an individual choice to self-identify or not, but human rights still apply to everyone, everywhere.

Above all, a diagnosis or disability should never define a person because we are all individuals, with a unique personality, autonomy, dreams, goals and aspirations and relationships to others.

The choice of terminology adopted in this document has been selected for the sake of inclusiveness.

The term psychosocial disability includes people who have received a mental health related diagnosis or who self-identify with this term. The terms cognitive disability and intellectual disability are designed to cover people who have received a diagnosis specifically related to their cognitive or intellectual function including but not limited to dementia and autism.

The use of the term disability is important in this context because it highlights the significant barriers that hinder people's full and effective participation in society.

We use the terms "people who are using" or "who have previously used" mental health and related services to also cover people who do not necessarily identify as having a disability but who have a variety of experiences applicable to this training.

In relation to mental health, some people prefer using expressions such as "people with a psychiatric diagnosis", "people with mental disorders" or "mental illnesses", "people with mental health conditions", "consumers", "service users" or "psychiatric survivors". Others find some or all these terms stigmatising.

In addition, the use of the term "mental health and related services" in these modules refers to a wide range of services including for example, community mental health centres, primary care clinics, outpatient care provided by general hospitals, psychiatric hospitals, psychiatric wards in general hospitals, rehabilitation centres, day care centres, orphanages, homes for older people, memory clinics, homes for children and other 'group' homes, as well as home-based services and supports provided by a wide range of health and social care providers within public, private and non-governmental sectors.

# Learning objectives, topics and resources

## Learning objectives

Participants will:

- Be able to challenge the misconceptions around the decision making skills of people with psychosocial, intellectual and cognitive disabilities.
- Understand article 12 of the CRPD and the right to legal capacity.
- Learn how to respect the right to legal capacity in concrete scenarios.
- Gain applied knowledge of supported decision making and advance planning.
- Explore how to ensure that people are not detained and/or treated against their wishes.

## Topics covered

**Topic 1:** Understanding the right to legal capacity

**Topic 2:** Informed consent and person led treatment and recovery plans

**Topic 3:** Supported decision making and advance planning

**Topic 4:** Avoiding involuntary detention and treatment in mental health and related services

## Resources required

To optimise the learning experience for participants, the room in which the training takes place should be:

- Large enough to accommodate everyone, but also small enough to create an intimate environment conducive to free and open discussions
- Flexible, in terms of enabling the change of seating arrangements (for example movable seats so that people can get into groups for group discussions)

## Additional resources needed include:

- Internet access in the room, in order to show videos
- Loud speakers for the video audio
- Projector screen and projector equipment
- 1 or more microphones for facilitator(s) and at least 3 additional wireless microphones for participants
- At least 2 flip charts or similar and paper and pens
- Copies of *Appendix 1: CRPD original with associated easy read text* for all participants
- Copies of *Appendix 2: The experience of involuntary admission and treatment* for all participants
- Copies of *Appendix 3: Checklist for implementing supported decision making* for all participants
- Copies of *Appendix 4: Concrete scenario on supported decision* for all participants

## Time

Approximately 7 hours and 40 minutes

## Number of participants

Based on experience to date, the workshop works best with about 25 people. This allows sufficient opportunities for everyone to interact and express their ideas.

## Welcome and Introduction

Give participants an opportunity to explain their own background and their expectations for the day (if relevant). **(10 min)**



**Trigger warning:** It is important to highlight at the start of the training that this module may provoke difficult emotions for people who may have been through traumatic experiences of non-recovery approaches. Moreover, mental health and other practitioners may feel that they have been responsible for preventing recovery despite good intentions.

Facilitators should be mindful of this and let participants know that they should feel free to step out of the training session if they need to until they feel able to participate again (please refer to *Guidance for facilitators* for more information).

## Topic 1: Understanding the right to legal capacity



### **Presentation: Brief introduction to the module (5 min.)**

The purpose of this brief introduction is to pre-empt the challenges that participants will need to grapple with in promoting legal capacity in challenging scenarios.

In this training we will be exploring how to promote the right to legal capacity within mental health and related services. In other words, the right of people using services to make decisions and choices for themselves at all times.

It is important to acknowledge that upholding people's right to make their own choices and decisions can seem challenging in certain scenarios. For example, what about people who want to commit suicide or people with severe dementia? What if someone is experiencing an acute crisis and is doing things that are or seem dangerous? What if refusing treatment means the person is going to get worse? What if someone is unconscious? Is it really feasible to promote the right of people to make decisions for themselves even in these types of scenarios?

The answer is that even in these challenging scenarios we must always strive to find ways to ensure that people remain at the centre of all decisions concerning their lives.

There are always ways to promote people's right to exercise their legal capacity. This training module will explore these.



### **Exercise 1.1: It's my decision (10 min.)**

This exercise is designed to explore common misconceptions around decision making. Some of the participants are likely to have preconceived ideas about decision making that they hold from their training or from common assumptions present in society and reflected in the law and policy, in the media and in professional practice.

Ask participants the following question:

Do all people have the ability to make their own decisions at all times?

Allow the group to share their own thoughts. On the flip chart, write down participants' ideas.

Common [stereotypes and misconceptions](#) on people's decision making skills that may arise during the discussion include:

- Having a psychosocial, intellectual or cognitive disability means that you cannot make decisions and decisions in all areas of your life should be made for you.
- Only doctors are in the best position to decide on medical matters and they will protect you in what they believe to be your "best interest".
- People with psychosocial, intellectual and cognitive disabilities cannot make decisions by themselves and the best place for them is in a mental health institution or social care home where others can 'take charge' of them.
- Once your ability to make decisions has been impaired, you should no longer be able to make decisions for yourself, now or in the long term, as you no longer know what is best for you.
- If someone is a resident in a care home or a mental health or other related service, then all decisions concerning their care needs to be made by mental health and other practitioners as they are the experts in the area of treatment and care.
- If someone has nominated a support person (e.g. power of attorney), then practitioners should only liaise with the nominated person, rather than the person concerned.
- A friend, relative, or mental health and other practitioners can prepare an advance directive on behalf of a person.

At the end of this exercise explain to participants that:

It is important to acknowledge that there may be situations or times when making decisions is more difficult. However, this should not be a reason for depriving people of their rights. There are many strategies that can be used to ensure these situations are addressed without the denial or restriction of an individual's rights. These strategies will be elaborated in this module.



**Presentation: *The right to legal capacity (1),(2)*(1 hour, 20 min.)**

The issue of the right to legal capacity and its implications on the requirement of informed consent for admission and treatment are sensitive issues which may engender strong resistance. It is therefore important to discuss and encourage a thorough understanding of these issues with the staff of the service and the management of the mental health and related service prior to the start of the training (For more information, see *Guidance for Organisers and facilitators*).

## **1. The right to legal capacity**

The right to legal capacity is guaranteed by article 12 of the CRPD.

Ask participants to take their copies of the CRPD (Appendix 1).

The provisions of article 12 have already been explained in the module *Understanding human rights in mental health*. If a recap is necessary, go through each paragraph of the article with participants. Remind them that they can use the easy read version of the article to better understand the content of the CRPD.

### **Article 12: Equal recognition before the law (3),(4)**

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

The law must recognize that people with disabilities are human beings with rights and responsibilities like anyone else.

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

People with disabilities have the same rights as everybody else and must be able use them. People with disabilities must be able to act under the law which means they can engage in transactions and create, modify or end legal relationships. They can make their own decisions and others must respect their decisions.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

When it is hard for people with disabilities to make decisions on their own, they have the right to receive support to help them make decisions.

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

When people receive support to make decisions, they must be protected against possible abuse. Also:

- the support that the person receives should respect the rights of the person and what the person wants;
- It should not be in the interest of or benefit others;
- The persons providing support should not try to influence the person to make decision they do not want to make;



- There should be the right amount of support for what the person needs;
- The support should be for as short a time as possible;
- It should be checked regularly by an authority which can be trusted.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Countries must protect the rights of people with disabilities:

- To have or be given property;
- To control their money;
- To borrow money; and
- Not to have their homes or money taken away from them.
- 

### **Understanding the distinction between legal capacity and mental capacity**

Legal capacity and mental capacity are two separate concepts but are often mistakenly seen as one. The CRPD has clarified and elaborated the differences:

- **Legal capacity** is an **inherent and inalienable right**. It includes two dimensions:
  - The right to hold rights
  - The right to exercise these rights

The right to legal capacity is necessary for the enjoyment of all other rights. It allows people to participate in society and to be recognised as full citizens.

- **Mental capacity** is a term used to refer to the decision-making skills (or decision making abilities) of a person.

In the mental health field, capacity tests are often used in an attempt to determine whether a person can:

- 1) Understand information about a decision
- 2) Understand the potential consequences of the decision
- 3) Communicate the decision

Capacity tests are generally carried out by health practitioners or capacity assessors.

However, the concept of 'mental capacity' and 'capacity tests' are flawed because the way we make decisions cannot be measured scientifically. Sometimes we make decisions based on very rational reasons and sometimes they are based on our emotions and feelings. There is no universal process of decision making or right or wrong way to make decisions.

Nevertheless, when a person with a psychosocial, intellectual or cognitive disability makes a decision that others do not agree with, it is often assumed that the person was not capable of making the decision to begin with. However, everyone sometimes makes decisions and choices in life that others do not agree with and this should not be a reason for denying people the right to make decisions.

In addition, having 'mental capacity' is often incorrectly considered to be a stable and permanent status that people either have or don't have. However, how well we make decisions varies during different times of our lives. For example, making decisions may be more difficult because of stress, tiredness, because of a health condition, etc. When we learn new skills and have new experiences, our ability to make decisions also improves.

One of the most important challenges is to change the negative stereotypes and misconceptions where assumptions are made that people with disabilities and in particular, people with psychosocial, intellectual and cognitive disabilities do not have the mental capacity to make decisions.

Both these misconceptions and the misinterpretation of the term 'mental capacity' (which will now be referred to as 'decision making skills' or 'ability to make decisions' in this module) have led to the denial of the right to legal capacity.

- According to article 12 of the CRPD, the right to legal capacity cannot ever be taken away from people. Everybody has the right to legal capacity irrespective of their decision making skills. A psychosocial, intellectual or cognitive disability can never justify denying people the right to legal capacity.

### **Formal and informal decision making**

The right to legal capacity concerns **all areas of life**. When someone is denied the right to make decisions, they are in fact deprived of a critical and fundamental right to live their life as they wish, which includes the right to make mistakes and celebrate success like everyone else.

Article 12 clearly states that all people, including people with disabilities, must have the right to make decisions for themselves and to have those decisions respected by others, and recognized as valid decision under the law. Article 12 provides protection for both formal decision making and informal day-to-day decision making.

In the case of **formal** decisions, for example, around marriage, divorce, buying or selling property and signing contracts, decisions for people with psychosocial, intellectual and cognitive disabilities are often made by court appointed guardians, health practitioners and families. This process is called differently in different countries, for example, guardianship, conservatorship, etc.

In the case of **informal** decision making, many of the day-to-day decisions that people with psychosocial, intellectual and cognitive disabilities make in all aspects of their lives are also typically made by others, in particular families and care partners. Examples of these decisions include how money is spent, living arrangements, personal relationships, choosing clothes to wear, choice of food, daily routines and treatment choices.

## **Settings where the right to legal capacity is denied**

Ask participants the following question:

Where does the denial of the right to legal capacity occur?

Some possible answers may include:

- At home
- In mental health and related services
- Everywhere!

Once participants have had the opportunity to provide answers show the following:

The denial of the right to legal capacity happens:

- In communities (e.g. in school, workplace, at the bank, etc.)
- At home
- In mental health and related services (both inpatient and outpatient)
- In places where people are detained (e.g. mental health facilities/ institutions, forensic services, police or prison cells)

**At home**, people are in some cases denied the right to make decisions about their own lives and daily activities. Family members may make all these decisions for them; this is sometimes as a consequence of good intentions and their desire to (over)protect their relatives from potential harm. Often, families fear that their relative will fail, be abused, get hurt or be taken advantage of.

This denial of legal capacity also very often occurs **in mental health and related services**. In some services, the right to legal capacity appears to be systematically violated.

- This is particularly true for people who are involuntary detained and treated because staff members have (legal) authority to make decisions for them.
- But legal capacity is also denied to people who are not involuntarily admitted and treated because even in these cases, staff members assume that a person cannot make decisions, and that they themselves are in a better position to decide.
- In addition, the simple threat of involuntary admission and treatment may result in the acceptance of unwanted treatment by some.

Such practices in services may reflect common negative stereotypes, for example, that people using the service cannot make decisions for themselves.

In addition, assumptions about people's decision making abilities are often made quickly because staff members find it easier and less time consuming to make these decisions themselves.

The result is that decision making power is taken away from people without talking with or listening to them (e.g. about their treatment, about what medicines they wish to take, about how long they need to stay in the service etc.).

## **The consequences of denying the right to legal capacity:**

At this point ask participants the following questions:

- What are the harmful consequences of the deprivation of the right to legal capacity on people's lives?
- How would you feel if you were deprived of your right to legal capacity?

Potential answers for participants may include:

- It prevents people from participating fully in society.
- It prevents people from taking control and responsibility for their lives.
- It prevents people from learning from their mistakes.
- 

After the discussion, show the following:

Denying people the right to make their own decisions means that they have very little (if any) control over their lives. The right to legal capacity is fundamental to human personhood and freedom. It protects the dignity of the person as well as their autonomy (i.e. their ability to take charge of their own lives and make their own decisions).

Making one's own decisions is very important because (1):

- It allows us to develop a sense of control over our lives.
- It teaches us responsibility.
- It makes us less vulnerable to exploitation.
- It helps us develop positive relationships with others.



**Presentation: Summary of the topic (15 min.)**

To sum-up this topic, show participants the following video:

**Mental Health Europe, UNCRPD: What is Article 12 and Legal Capacity? (5) (2:53 min.)**

<https://www.youtube.com/watch?v=J3PVqTYI05s> Date accessed 04/07/2016

Ask participants to briefly recap what they have learned in this topic. Once they have had the opportunity to provide answers, show the following:

1. **Common misconception and stereotypes about people's decision making skills must be challenged:** People with psychosocial, intellectual and cognitive disabilities can and have the right to make decisions.
2. **Everyone's ability to make decision vary for many different reasons.** There may be times when people find it easier to make decisions, and other times when they find it challenging. This is true for all people.
3. **Varying abilities to make decision cannot be a reason to deny some people the right to legal capacity:** According to article 12, all people with disabilities must be able to exercise their legal capacity.
4. **The right to legal capacity is a critical and fundamental right:** we all need to enjoy this right to be recognised and participate in society.

At the end of the presentation, ask participants:

Can you think about different ways or tools to make sure that people's right to legal capacity is respected?

Give participants the opportunity to provide answers. They should not worry if they find it difficult to answer this question at this point. The following parts of the module will provide them with information and knowledge to answer this question.

Pre-empt the following topics by showing the following:

### **How can the right to legal capacity be respected?**

There are several key ways to ensure that people retain the right to legal capacity. These include:

- Informed consent
- Person-led treatment and recovery plans
- Supported decision making
- Advance planning for times of crisis

## Topic 2: Informed consent and person-led treatment and recovery plans



### **Presentation: Informed consent (10 min.)**

Obtaining **informed consent** to treatment is essential to respect the right to legal capacity.

Informed consent means (6):

- The person is given enough information about the proposed treatment to make an informed decision, including:
  - the possible benefits and negative effects/risks of the proposed treatment;
  - possible alternatives to the proposed treatment;
  - the possible benefits and risks of not accepting the proposed treatment and/or of choosing one of the alternative.
  
- The information is given in a way that the person can understand and adapted to their needs (for example, by avoiding the use of highly technical terms that the person cannot understand or by using sign language or written information if the person has a hearing impairment). The information must also be given in a way which is culturally and otherwise acceptable to the person.
  
- The consent to the treatment is voluntary:
  - It is given without threat or coercion (for example, mental health and other practitioners should not tell the person that they will be involuntarily admitted if they refuse the treatment proposed).
  - It is given without undue influence (for example, practitioners should not make the person concerned think that there may be unpleasant consequences, like withdrawal of privileges, if they refuse the treatment proposed).
  - It is given without manipulation: (for example, practitioners should not tell the person that they will be given a sleep therapy while they are in fact given Electro-Convulsive Therapy)

To give informed consent to treatment, people may need support from others to make or to communicate their decisions. This issue is developed in the next topic on supported decision making and advance planning.

It is important to be aware of the risk of undue influence due to the power imbalance in relationships that exist within mental health and related services. There is sometimes a fine line between supporting people in making their decision and unduly influencing them ([for more information on power dynamics see the Module on Implementing Improvement Plans for Service Change](#)).

The decision about the treatment must be fully respected by mental health and other practitioners. Another critical point is that the right to informed consent also includes the right to refuse treatment. This means if a person, after being offered information about treatment options, decides they don't want any kind of treatment, that is their right and it must be respected.



**Presentation: Person-led treatment and recovery plans (20 min.)**

An increasing number of services in countries around the world are adopting what is known as the recovery approach to mental health. A Recovery approach promotes the principles of legal capacity and informed consent amongst others, in line with the Convention on the Rights of Persons with Disabilities (CRPD).

- “Recovery” is different for each person. Recovery is about being able to live a life which is meaningful for the person, in the presence or absence of symptoms. With a recovery approach to mental health care, each person is empowered to lead their journey to recovery and set their own goals in life.
- Treatment and recovery plans outline which treatments or support (e.g. psychosocial interventions, counselling, medication etc.) people want to receive and which they do not want, as well as which mental health and other practitioners or supporters they want to involve in their care and recovery, if any.
- Treatment and recovery plans respect the right to legal capacity by ensuring that people make all decisions concerning their own care.

When people are allowed to make decisions about their treatment and support, they are likely to choose options that meets their needs and to which they are prepared to adhere to. Therefore, it is more likely that the treatment they have chosen will be more effective than if a treatment which has been imposed on them.

Initially, the person may need more information about different options and even opportunities to try different options. As the treatment evolves, the person will gain more and more knowledge about what treatment works for them and will be able to make even more informed choices.

Promoting the right to make decisions concerning treatment and recovery is an essential part of promoting autonomy and self-determination and respecting the right to legal capacity. It also has a positive impact on the person’s recovery journey.

At this point of the presentation you can show the following video to participants:

**iNAPS (2012). Peer Advocacy in Action (7) (13:00 min.)**

<https://vimeo.com/92155934> Date accessed 07/06/2016.

This is an excellent example of a situation where a person is able to decide about where she wants to live in the community after the closure of the state mental health hospital where she resides.

### Topic 3: Supported decision making and advanced planning

As an introduction to this topic, explain to participants that:

Supported decision making is a key way to respect a person's right to legal capacity.

Implementing a supported decision making approach can improve everyday practice in mental health and related services.



#### **Exercise 3.1: Discussion on supported decision making (10 min.)**

Before exploring in detail what is supported decision making, this exercise is designed to get participants to think about what support can be useful in helping people to make decisions.

Ask to participants the following question:

In what ways do you think a person can be supported to make their own decisions?

Some possible suggestions might include:

- Seek informed consent to treatment;
- Provide information in a way the person understands;
- Allow people more time to make decisions, give people time to think;
- Don't pressure people for a decision
- Consider whether the person can make the decision at a later time when circumstances are right for them;
- Consider if there might be a better time of day to provide information or a better location;
- Work collaboratively with people in the development of their treatment and/or recovery plans, enabling them to express their opinions and preferences;
- Respect people's decisions;
- Give opportunities to people to identify persons they trust who can support them in making decisions (e.g. trained peer workers).



#### **Presentation: Supported decision making (8) (20 min.)**

At times, all people may need support to make decisions in different areas of life. In other words, there may be times in life when a person, including a person with a psychosocial, intellectual or cognitive disability, may find it more difficult and challenging to make decisions on their own. At times like these it can be useful to turn to people we trust who can support us in the process of making our decision. In fact, we all use support at times to enable us to make decisions and choices.

In acknowledgement of this fact, article 12 of the CRPD introduces the concept of supported decision making. The article states that people must have access to a variety of support options including the support of people they trust (e.g. family, friends, peers, advocates, lawyers, personal ombudsmen, etc.). Article 12 recognizes that building on people's unique abilities and providing them with the support they require allows them to make their own decisions.



A person may need support to understand the information, weigh up different options, understand the possible consequences of different options and communicate their decision to others.

- For example, in the context of a mental health and related service, a trained advocate can support a person to understand the benefits and/or negative effects of a particular course of treatment, discuss the pros and cons of the treatment, and communicate the preferences of the person concerned, if the person is unable to do so (more concrete examples are provided in the module on *Realising supported decision making and advance planning*).

It is important to note that support needs to be tailored to the individual. Moreover, the ability to make decisions, and hence the level of required support, can vary at different stages in their life. At times people may need no support at all, at other times low-level support is required, and at yet others, more intensive support may be required. For example, a person at early stages of dementia may need minimal or no support at all, whereas in later years they may need more intensive support. In addition, some people may only require support for complex decisions while others may require support for even simple, daily decisions.

It is important to remember that, unlike the need for support, the right to exercise legal capacity never fluctuates or varies. People must always be able to make their own decisions (with or without support) irrespective of their ability to make decisions at a particular point.

Supported decision making is a way to ensure people's right to legal capacity is respected.

Different support options may exist, both formal and informal.

Some examples of support models:

- **Circle of support (United Kingdom) (9)**

A Circle of support (sometimes called a Circle of Friends), is a group of people who meet together on a regular basis to help a person (the focus person) accomplish their personal goals in life. The Circle acts as a community around the person concerned, providing them with support to achieve what they want in life, when needed. The focus person is in charge, both in deciding who to invite to be in the Circle, and also in the direction that the Circle's energy is employed, although a facilitator is normally chosen from within the Circle to take care of the work required to keep it running.

For more information, show participants the following video:

**Circle networks, Circle of Support (10) (4:58 min., starting at 0:54)**

[https://youtu.be/w6RX\\_WQmSf4?t=54](https://youtu.be/w6RX_WQmSf4?t=54) Date accessed 04/07/2016

- **Personal Ombudsman (Sweden) (11)**

The Personal Ombudsman (PO) in Sweden is a model of supported decision making being offered by several NGOs. A PO is a skilled person who helps clients with a range of issues: family-matters, housing, accessing services or employment. A PO only does what their clients want them to do.

The model is based on a long-time relationship of trust. It is a long-time engagement for both the PO and the clients.

For more information, participants can watch Maths Jespersen speaking about the Swedish psychiatric reform and present the Innovative Policy “Personal Ombudsmen System” in the following video (12): [\(13:50 min.\)](#)

<https://www.youtube.com/watch?v=xqma4wk8sC0&feature=youtu.be>

Date accessed 13/06/2016

- **Open Dialogue (Finland) (13),(14)**

Open Dialogue is a Finnish alternative to the traditional mental health system for people diagnosed with "psychoses" such as "schizophrenia". This approach aims to support the individual's network of family and friends, as well as respect the decision-making of the individual

In Open dialogue, the person seeking support, family and care partners are all invited to participate alongside the open dialogue team member in daily meetings that are open, non-secretive and non-hierarchical. Everyone openly voices and reflects on their thoughts and feelings, and everyone's voice is heard, particularly the voice of the person seeking support. By speaking openly and at the same level at all times, everyone understands what is going on and what is being talked about. Then, a shared language is created and the participants build up a new understanding between them.

The Open Dialogue team provides immediate help within 24 hours of the first contact. They seek to engage social networks, rebuild relationships and, avoid medication and the alienating experience of hospitalization by bringing together the social network of the person seeking support. No exact treatment plan is prepared. The approach is flexible and adapts to the changing needs of each person.

**Daniel Mackler, Jaakko Seikkula Speaks on Finnish Open Dialogue, Social Networks, and Recovery from Psychosis (15) (8:24 min.)**

<https://www.youtube.com/watch?v=ywtPedxhC3U&feature=related&app=desktop> Date accessed 22/07/2016

Mental health and related services have a responsibility to actively facilitate supported decision making by ensuring that people are able to invite trusted persons from the community to come to the service to support them. They can also facilitate contacts between the person and supported decision making NGOs or peer supporters who can act as a decision supporter if this is what the person wants.

The service needs to make itself open enough in order to ensure that people have access to any natural form of support (for example, support from family members or friends) or formal support services that exist in the community.

[Distribute to participants copies of Appendix 3 \(also represented below\).](#)

The following box (16) is a useful checklist tool to initiate a supported decision making approach. However, additional steps will need to be included on a person-by-person basis.

### Do you?

- Provide relevant information
  - Does the person have all the relevant information they need to make a particular decision?
  - If they have a choice, have they been given information on all the alternatives?
- Communicate in an appropriate way:
  - Explain or present the information in a way that is easier for the person to understand (for example, by using simple language or visual aids)?
  - Explore different methods of communication if required, including non-verbal communication?
  - Ascertain if anyone else can help with communication (for example, a family member, support worker, interpreter, speech and language therapist or advocate)?
- Make the person feel at ease:
  - Identify if there are particular times of day when the person's understanding is better?
  - Identify if there are particular locations where the person may feel more at ease?
  - Ascertain whether the decision could be put off to see whether the person can make the decision at a later time when circumstances are right for them?
- Support the person:
  - Ascertain if anyone else can help or support the person to make choices or express a view

### Supported decision making is not the same as substitute decision making:

- In supported decision making a support person never makes decisions for/on the behalf of/instead of the person with a psychosocial, intellectual or cognitive disability.
- All forms of support, including the most intensive, must be based on the **will and preferences** of the person concerned.
- The will and preferences of the person are different from what is perceived by others as being in their "best interest".
  - In many countries, the standard for making a decision for a person is generally "best interest" (i.e. when others determine what is the best decision or course of action for a person). This needs to change. Even in extreme circumstances, when the person is unable to communicate their wishes and preferences directly, decisions must be made based on the **best interpretation of the will and preferences of the person**. These can be determined, for example, by:
    - referring to what is already known about the person - their views on different matters, beliefs, values in life, etc. (if these are not known by supporters they can ask the person's close friends or relatives)
    - referring to advance planning documents which should contain information about the person's will and preference
- Supported decision making is therefore different from existing systems such as guardianship, wardship and other substitute decision making regimes. Supported decision making is not just a new term or word for describing these pre-existing models. It is about implementing a completely different approach of decision making in which the person always remains at the centre of the decision.

At this point in the presentation participants may express the concern that their country's legal framework requires a substitute decision-making approach (e.g. through existing national guardianship, conservatorship laws) and that therefore there is little they can do to implement supported decision making in this context.

It is important to acknowledge that:

In many countries, existing law and policy frameworks still provide for substitute decision making models. Lobbying and advocacy are key to changing existing laws, policies and practices which are not in line with the CRPD.

This kind of reform may take time, but in the meantime, there is a lot that individuals can do to support people to make their own decisions, even within existing legal or policy frameworks. In addition, it is also possible to support people to terminate their substitute decision making regimes.

**Supported decision making is voluntary:**

- It should not be imposed on people.
- If a person chooses not to have support, then their wishes should be respected.

Many people, in particular family members, mental health and other practitioners, have expressed the concern that in some situations, if the person refuses support, they may put themselves or others in danger.

However it is important to note that imposing or forcing treatment itself can cause harm either immediately or further down the track. The harm caused to the person can take many forms including, trauma, humiliation, physical injuries, negative effects of medication, etc. In addition there are tools, such as advance planning, that are available to ensure that a person's care and treatment decisions are really those that they would have wanted in this situation (i.e. that they respect their wishes and preferences).

It is important to give participants an opportunity to raise and discuss their concerns openly.

How can we avoid exploitation from supporters?

Mostly, family, friends other supporters are well-intentioned but sometimes, in the context of providing supported decision making, some people may try to take advantage of or exploit the situation. Safeguards are therefore necessary to make sure that exploitation does not take place.

It is important to train the following people on strategies to prevent and deal with potential exploitation from supporters:

- People with psychosocial, intellectual, and cognitive disabilities
- Families, care partners and other supporters
- Mental health and other practitioners
- Peer workers and advocates
- Legal professionals
- Other relevant people from the community

Key issues to consider:

- Practitioners should not take on the role of formal supporters because of the huge conflict of interest and risk of undue influence due to power imbalance in relationships within mental health or related service settings. Although they should not be nominated as supporters, they still have an important role to play in promoting supported decision making in their day-to-day work.
- Supporters' role should be for the shortest time possible and tailored to the person's circumstances.
- Supporters must not profit from the funds of the people they are working for, caring for or otherwise supporting.
- Independent support from outside the mental health or related service should be offered and made available whenever a person asks for it.
- **Independent** groups working outside or inside the service, such as advocacy and peer supporters, should be able to freely access and talk to people within the service.

**Safeguards, such as monitors, should exist to ensure that no exploitation occurs (17).**

- A monitor is a person whose role would be to protect the decision-making rights, will and preferences of the person concerned, including the right to take risks and make mistakes.
- More specifically, the monitor would need to ensure that supporters comply with all the duties expected of them. They must be able to challenge the actions of supporters if they are not acting in accordance with the will and preferences of the person.
- Monitors should not be service staff. They should be fully independent.
- In addition, there should be mechanisms (such as complaint and monitoring mechanisms) to hold people who abuse their supportive role accountable.

The topic of supported decision making (including different models of support) is explored in greater detail in the training module on *Realising supported decision making and advance planning*.



**Presentation: Advance planning (45 min.)**

In addition to supported decision making, another means of ensuring that a person's preferences are considered and respected is through advance planning. Advance planning applies especially during times when people may be having difficulties in making or communicating decisions.

Advance planning refers to the process of making choices about one's own future care or treatment and support and ensuring that other people are aware of these choices.

If the person concerned becomes unable to express their wishes, the people providing support and care to the individual can refer to that person's advance plan to make sure they follow the

treatment and care options the person wants or doesn't want. Advance plans are sometimes called living wills or advance directives.

Studies have shown that advance plans or directives give people more control over their treatment and reduce the use of coercive intervention (18). In particular, a recent comprehensive review and meta-analysis has found that advance statements reduce by 23% the use of compulsory admissions. In comparison, Community Treatments Orders or other coercive community measures were not successful in reducing rates of involuntary admissions (19).

#### **Content of advance plans:**

- An advance plan is a written document that specifies future choices about healthcare. This can include treatments and place of care.
- It can also include treatment, supports, and recovery options that a person does not want to have, and as such can help to ensure that the person concerned does not receive any intervention against their wishes.
- It can be used if a person becomes unable to communicate their choices.
- People may also want to specify their wishes about other aspect of their lives in the plan (e.g. taking care of the children, home, bills, taxes, pets, etc. when the person is unable to). This is discussed further in the module on *Promoting recovery in mental health and related services*.

In some countries and cultures, people may not have a tradition of writing documents (such as wills, contracts, etc.) and other forms of support, such as support networks, may seem more appropriate. However, it does not prevent people from orally making their wishes known to their family, friends, care partners and other relevant people.

Some countries have developed legislation to make certain advance planning documents are binding. This means that mental health and other practitioners, and anyone else involved in the person's care are legally required to follow the directives stated in the documents.

For example, the UK has provisions for advance decisions, which allow people to refuse specific types of treatment in advance.

British Columbia, Canada, also has binding advance directives in which people can specify the treatment they refuse to receive, and the health care professional is legally bound to respect this. In the British Columbia model however, people may also specify which treatments they would be prepared to accept.

It's important to note that advance refusal of treatment is different from advance consent to treatment.

- Advance refusal guarantees that a person will not be given that specific form of treatment.
- However, advance consent to treatment or support does not guarantee that you will be given that form of treatment (for example if the service does not offer this treatment or if resources in the service do not allow for this treatment).

To date, binding documents have been limited in scope. The law in both these countries envisages situations when binding advance directives can be overridden (e.g. lifesaving emergencies, incompatibility with the known wishes and preference of the person, etc.).

Sometimes many good things that some countries have put in place are undone by the fact that advance plans can be overridden when a person is, for example, involuntarily admitted (this is the

case, for example, under the Mental Health Act in UK). Therefore, a person who is detained involuntarily can also be given treatment against their will despite the existence of an advance directive. This is a situation that is not in line with the CRPD.

Even when countries do not legally recognise advance plan/directives; this does not prevent mental health or related services from implementing them. They can allow and encourage people to make advance plans and when the situation requires their use, respect the directives stated in the person's plan.

It is important to make sure that advance plans are regularly updated so they reflect the current wishes and preference of the person.

Again, these issues are explored in more detail in the training module on *Realising supported decision making an advance planning*.

Example of advance planning:

Ask participants to read the following scenario:

#### **Sue's story**

Before her discharge from hospital, Sue decides to make an advance plan. She specifies in her plan that she absolutely does not want to be given a specific type of antidepressant as they make her very anxious. She also specifies in the plan that she finds one-to-one counseling useful when she is depressed.

Two years later Sue admits herself into the psychiatric ward of a hospital as she is feeling very depressed. Because of her state of mind, she is finding it very hard to communicate with staff at the hospital.

They therefore refer to her advance plan, and are able to see that she must not be given the specific antidepressants she does not like. They also organize for Sue to undertake counseling sessions with the ward psychologist.

After reading the scenario above ask participants the following question:

What do you think the impacts of Sue's advanced planning might be?

Possible answer may include:

- She is not forced to take a treatment she does not want.
- The staff know how to support her effectively.
- She is likely to recover more quickly.
- She feels that her wishes are respected.



### **Exercise 3.2: Concrete scenario on supported decision making (15 min.)**

The purpose of this exercise is to understand the concept of supported decision making and how it can be implemented. Therefore the scenario described below is relatively basic. More complex and challenging scenarios are offered in the module on *Realising Supported Decision Making and Advance Planning*.

Ask participants to consider this scenario (Annex 4):

#### **Rohini's story**

Rohini is a 27 year old woman. She has been accompanied into the mental health service of a general hospital because her work colleague is concerned for her, as Rohini started to get very distressed, saying that her colleagues wanted to harm her.

On arrival at the facility Rohini started to get increasingly agitated, shouting that she did not want an injection. A nurse reassured her that nothing bad was going to happen, and that they wanted to help her. She took Rohini by the hand and guided her to a quiet room away from the noise and bustle of the reception area of the service.

The nurse asked Rohini if she could call anyone whom Rohini trusts, who could help her. Rohini informed her that she would like to see her mother. When her mother arrived, Rohini was still very distressed, shouting that she did not want an injection. Her mother explained to the nurse that the last time she went to a hospital, in the capital city of the country, she was given an injection of haloperidol (an anti-psychotic medication). Her mother further explained that Rohini had reacted badly to this medication, experiencing painful muscle contractions and confusion as a result.

The nurse told Rohini that she would not be given haloperidol, and Rohini started to calm down. Over the course of the week, Rohini worked with her mother, the nurse and a doctor to develop a treatment and recovery plan. She was informed of different options for treatment including benefits and negative effects, and asked for her consent to treatment.

In addition, Rohini, after consultation with people of her choice including her mother, the doctor and nurse, developed an advance plan so that staff would know never to give her haloperidol, and also so that they would know her preferences for treatment. In the plan she nominated her mother to be contacted in case of an emergency to support her in communicating her wishes during crisis situation. Staff asked Rohini if it would be helpful for her to stay at the service for a few days to start her off on her treatment, to which she agreed. After three days she felt much better and was subsequently discharged.

Rohini has since joined a peer support group which meets once every two weeks in her neighbourhood. At these meetings she is able to share her knowledge and experiences with others in the group, and also get emotional and practical support from other members. She also set up a meeting with her boss and other close colleagues to discuss what had happened and what actions can be taken by them to support her in the future, should another crisis arise.



Ask participants the following questions:

- **What were positive aspects of this case?**
- **How was Rohini's right to legal capacity respected?**

Many actions were taken in this case to promote Rohini's right to legal capacity, which resulted in benefits for everyone involved:

- Rohini was guided to a quiet room to calm her down and was not restrained.
- Her wish not to be given an injection was respected, which helped to build trust with the staff.
- She felt listened to and respected. It had a positive impact on her sense of well-being.
- Staff made an effort to try and understand what was happening to Rohini, which meant they were able to understand that the fear of being given a particular medication was contributing significantly to her agitation.
- With Rohini's agreement, staff contacted her mother, who was able to help others understand Rohini's perspective about medication and support Rohini in making decisions about her treatment.
- Rohini was given the opportunity to develop her own treatment and recovery plan, with people of her choice
- Rohini was informed about the different options and side effects of treatment.
- Her informed consent to treatment was sought.
- An advance plan was developed, to ensure that Rohini did not get treatment (haloperidol) which caused her harm, and so that staff would know her preferences for treatment in the future.
- She was not forced to stay at the service against her wishes, but rather was asked whether this would be helpful.

#### Topic 4: Avoiding involuntary detention and treatment in mental health and related services

At the beginning of this topic, explain to participants that:

In many countries, laws and policies authorise people to be involuntarily admitted and treated in mental health and related services; reforming these laws and policies in line with the CRPD may take time.

Nevertheless, in the meantime, there is a lot that can be done to avoid involuntary detention and treatment and respect people's right to legal capacity in these matters, even within existing legal or policy frameworks.



#### **Exercise 4.1: The experience of involuntary admission and treatment (25 min.)**

As an introduction to this topic, distribute to participants copies of Annex 2 (The Experience of Involuntary Admission and Treatment) (20).

“Nothing could prepare me for the experience of being taken against my will — not by the police, or even an ambulance but an older sister who felt she knew best. What followed was the most violent of admissions. Totally traumatised and in shock, the sheer panic of dealing with my new reality never went away. I was manhandled, forcibly injected and held against my will for more than a month [...].

Along with the feeling of disempowerment and humiliation that involuntary hospitalisation brings, a patient said to be capable of harm is more often violated and harmed themselves. It is made all the worse since most are never believed — instead they are accused of being delusional and ungrateful. This, in itself, is a barrier to true healing since inhumane treatment leaves one feeling less than human. While some may see the psychiatric ward as a place of safety, for most it is nothing more than a prison [...].

There remains a huge power imbalance, not only during hospitalisation but also when community orders dictate what medications must be taken after patients are no longer hospitalised. With failing to comply with such orders leading to further incarcerations, this is nothing more than a form of control. Most leave this system with lost dreams and lives forever watched over by the system they can never escape. This is a violation of our human rights as outlined in the UN Convention”.

Give participants 5 min to read the extracts of the testimony. Once they have read the document, ask the group:

- **How do you feel about the testimony you have read?**

After the discussion, show the following presentation.



**Presentation: What does the CRPD say about involuntary detention and treatment? (40 min.)**

At this point the focus of the module will shift to the issue of involuntary detention and treatment in mental health and related services. It will clarify the link between the right to legal capacity (article 12 of the CRPD), other articles of the Convention and the issue of involuntary detention and treatment. This issue may be sensitive and may engender strong resistance from mental health and other practitioners, as well as for family members. It is therefore important to discuss and encourage a thorough understanding of these issues with the staff and management of the service prior to the start of the training. (See the *Guidance for Facilitators and Organisers* for more information).

People with psychosocial, intellectual and cognitive disabilities are very often detained in mental health and related services against their wishes. This is known as involuntary, forced, coerced admission, or admission without informed consent.

People detained against their wishes are also very often given forced treatment. This generally happens in mental health or related services but in some countries, people can be required to undergo forced treatment in the community for example via Community Treatment Orders, court orders or other means.

Sometimes people are detained and treated, simply on the basis that they are diagnosed or perceived to have a condition or disability. At other times it is justified on the basis that the person is considered dangerous to themselves or to others. This is despite the fact that other groups at higher risk of violence (e.g. gang members, persons drinking alcohol with history of domestic violence) cannot be detained on the basis of increased violence risk.

People can be detained because no community based mental health or related services exist, and closed and isolated institutions or hospitals are the only services available. Sometimes also homeless people are sent to institutions against their wishes because they are seen as a nuisance on the streets.

Involuntary detention and treatment can last for days, weeks, months and even years.

At this point of the presentation, encourage participants to express their opinions and feelings about involuntary detention and treatment. It is important that people who have not experienced involuntary detention and/or treatment themselves try to imagine how they would feel in this situation. To prompt the discussion, it is possible to ask the following questions:

- **How would you feel if your liberty and choices were taken away? / How did you feel when your liberty and choices were taken way?**

After the discussion, ask participants to take their copies of the CRPD and continue the presentation with the following:

**The CRPD aims to address this situation by offering clear guidance on changing practices and laws.**

As explained in the module on *Promoting Human Rights in Mental Health*, the rights protected by the CRPD are all interrelated. Many of these rights reinforce the fact that people must not be detained or treated against their wishes or on the basis of having a disability. In particular:

#### **Article 12: Equal recognition before the law**

Article 12 underlies, and is indispensable to all the other articles of the CRPD. By protecting the right to legal capacity, the CRPD ensures that people have the right to make decisions about their care and treatment. This means that their informed consent must always be sought before admission or treatment in a mental health or related services. Mental health and other practitioners should engage directly with the person and not only with the person's family or supporters. To the best of their ability they should also make sure that the person is not unduly influenced by family, care partners or other supporters when making a care or treatment decision.

Practitioners must also make sure that people can access the support they need, to make or communicate their care and treatment decisions.

#### **Article 14: Liberty and security of person**

Article 14 guarantees the right to liberty and security. It makes it clear that "disability shall in no case justify a deprivation of liberty".

This means that disability can never be a basis for depriving someone of their liberty. People with disabilities can only be detained on the same basis (or for the same reasons) as all other citizens (e.g. criminal sentence).

Therefore people with psychosocial, intellectual, and cognitive disabilities should never be detained in mental health and related services or institutions because they have a disability (whether diagnosed or perceived), ***even when*** other additional criteria are involved (e.g. danger to self or others, need for medical treatment, etc.) (21).

#### **Article 5: Equality and non-discrimination**

According to article 5, people with disabilities should enjoy their rights on an equal basis with others. People being treated for physical health conditions cannot generally be detained in health services and treated without their informed consent. The fact that people with psychosocial, intellectual and cognitive disabilities *can* be detained and treated against their wishes constitutes discrimination on the basis of a disability, hence this violates article 5.

#### **Article 15: Freedom from torture or cruel, inhuman or degrading treatment or punishment and Article 16: Freedom from exploitation, violence and abuse**

Involuntary admission and treatment in mental health and related services often causes people severe pain and suffering and can have extremely negative consequences for their health and well-being. They are experienced and considered by many people as violent and abusive acts which can amount to torture and ill treatment in violation of articles 15 and 16 of the CRPD (22).

### **Article 17: Protecting the integrity of the person**

Article 17 recognizes that people with disabilities have a right to respect for their physical and mental integrity on an equal basis with others. Forced detention and treatment violates people's physical and mental integrity and are therefore, not in line with article 17.

### **Article 19: Living independently and being included in the community**

Article 19 states that people with disabilities have the right to live independently and to be included in the community. They must be able to 'choose their place of residence and where and with whom they live on an equal basis with others' and must not be 'obliged to live in a particular living arrangement'. Thus, the involuntary detention of people with psychosocial, intellectual and cognitive disabilities in mental health or related services is a direct violation of article 19.

### **Article 22: Respect for privacy**

Detention in mental health and related services violates people's right to privacy in many different ways.

For example, when people are detained and treated against their will, mental health and other practitioners may access very personal information without the person's consent. People may share very personal information with their mental health professional and then discover the information has been given to many other people such as, for example, the person's GP, social worker or even family member. In addition, people detained in mental health and related services often lack privacy because: they have to share a room/bathroom with other people; practitioners can access their room without their consent; they have no space to store their personal belongings, etc.

### **Article 25: Health**

Article 25 explicitly requires that health professionals provide care on the basis of free and informed consent. This means that people must explicitly give their informed consent before receiving any treatment.

These are some of the key CRPD articles which are violated when involuntary admission and treatment are used. However, other articles are violated as well (e.g. article 6 – women with disabilities, article 27 – work and employment; article 29 – Participation in political and public life; article 30 – Participation in cultural life, recreation, leisure and sport).

### **In sum:**

Despite the fact that involuntary detention and treatment violate the rights guaranteed by the CRPD, in countries all over the world people with psychosocial, intellectual and cognitive disabilities continue to be subject to these practices in mental health and related services.

Monitoring and review mechanisms need to be in place to ensure that people are not being involuntarily detained or treated and that, if people are detained and/or treated against their will, they are immediately released and that involuntary measures are ended. The need for independent monitoring in facilities and services for people with disabilities is in fact an explicitly expressed in Art 16 of the CRPD.

[At the end of the presentation, encourage participants to ask for any necessary clarification.](#)



### **Exercise 4.2: What about in my country? (1 hour)**

For this exercise, ask the participants to gather in the centre of the room. Explain that you will read out a statement and ask people to move to the (right) of the room if they agree with the statement or to the (left) if they disagree.

If participants have mobility issues, you can simply ask the whole group to raise their hands if they agree or disagree with the following statement.

### ***People with psychosocial disabilities in some cases need to be given treatment against their wishes.***

Ask participants for their opinions on why they have chosen to agree or disagree with the above statement. Ideas can be written down on the flip chart and where possible the group should discuss their ideas directly with each other.

If all participants agree or disagree with the above statement then randomly divide participants into two groups and ask one group to think of reasons in favour of the statement and the other group to think of reasons against the statement.

#### **Possible opinions that might be expressed in favour of this statement:**

- For their own safety people may on occasions (e.g. emergency situations) need to be forcibly treated.
- If someone is a danger to themselves or others, it may be necessary to treat them against their wishes, in order to keep everybody safe.
- It may be necessary to involuntarily treat a person if failing to do so will bring about a worsening of their condition.
- Involuntary treatment is sometimes necessary to enable people to recover their ability or capacity to make future treatment decisions
- When treatment is given by force, it is more effective and the person gets better more quickly.

#### **Possible opinions that might be expressed against this statement:**

- The rights give informed consent to treatment are so fundamental that they should not be taken away from people.
- People with psychosocial disabilities should have the same rights as everyone else.
- People are free to take the same risks and make mistakes as everyone else.
- Having a psychosocial disability does not mean you are automatically a risk to others and need to be treated. It is necessary to stop equating people with psychosocial disabilities with dangerousness, violence and crime. In fact people are far more likely to experience violence, abuse and crime than the rest of the population.
- 'Dangerousness', which is often invoked for involuntary treatment, is very hard to predict and are very subjective. In the criminal justice system, we do not detain or treat people because they 'may be dangerous' some time now or in the future. Why should we treat people with

psychosocial disabilities any differently while other groups at higher risk of violence (e.g. gang members, persons drinking alcohol with history of domestic violence) cannot be detained or treated on the basis of increased violence risk?

- Having separate procedures of health care and treatment for people with psychosocial disabilities is discriminatory.
- Involuntary treatment is often the easy option and people are deprived of their rights because we do not want to invest in better alternatives, better quality care etc.
- Other people (e.g. people with cancer, HIV, Jehovah's witnesses requiring blood transfusion to live) are not forced to receive treatment. In a just society, we must retain the right to make decisions for ourselves and to say 'no'.
- The focus of the law should be the protection of human rights, not a so-called need to 'protect society'.

Now ask participants:

- **After the discussion has anyone changed their mind?**

Anyone who changes position can be asked to discuss why they changed their mind. This is an opportunity to reflect on why they have changed their views, and ask them to discuss with other participants whose views have not shifted.

Many participants may still have strong feelings one way or another. Your task as facilitator is to help participants move forward towards a new understanding that there are many things that can be done to avoid involuntary treatment and that the situation on the ground (lack of resources) or beliefs that coercion is sometimes required in extreme situations, should not stop people continually striving to find non coercive solutions and practices

If necessary and if time permits, this exercise can be repeated with the focus on involuntary detention. E.g. Participants could debate the following statement:

*"People with psychosocial disabilities in some cases need to be involuntarily admitted to mental health facilities."*

Many of the possible opinions and responses to this question are likely to be similar to the responses/opinions related to involuntary treatment.



### **Exercise 4.3: Scenario on avoiding coercive measures (40 min.)**

Ask participants to consider the following scenario:

#### **Scenario 1:**

I was working in the emergency department of the hospital one night when a man, George, was brought in. George was distressed, agitated and anxious, shouting and making wild gestures. Without a full assessment doctors made a decision that George was psychotic and required treatment. George stated categorically that he did not want to be treated.

The doctor in charge decided that the quickest and only way to deal with this situation was to get four nurses to restrain George, tie his arms and legs to a bed in an isolation room, and to give him an injection of an anti-anxiety medication.

George still remains in the hospital one week later. He is extremely distrustful of the staff and continues to resist treatment. George is therefore being covertly medicated on an on-going basis (the staff hide medication in his food). He is becoming increasingly depressed and isolated, refuses to talk to anybody and shows no sign of improvement.

Ask participants the following questions:

- **What went wrong in this situation?**

Allow participants to come up with their own list of answers.

Some potential responses may include:

- Nobody took the time to listen to George despite the fact that he stated clearly that he did not want to be treated.
- Treatment is covertly given to him: this means that he is not given appropriate information and that his consent to treatment was not sought. This is likely to have a long term impact on George's future well-being as well as damage his trust towards staff and treatment.
- The way George was treated was very damaging to his mental health and well-being. No-one listened to his concerns and they were assumed to be part of his mental health condition.
- His supporters were not called to try and find a way of understanding George's perspective despite the fact that they could have provided valuable insight into the situation and provided George with emotional and practical support (e.g. in supporting him to make decisions about his situation and treatment and helping him to communicate more forcefully his right to refuse treatment).
- Forced and forceful treatment: he was put in restraints and secluded in an isolation room to receive forced treatment.

- **What CRPD rights of George's were violated?**

These actions by staff violate George's right to:

- Legal capacity (CRPD article 12)
- Freedom from exploitation, violence and abuse (CRPD article 16)
- Freedom from torture and cruel, inhuman or degrading treatment or punishment (CRPD article 15).



- Liberty and security of person (CRPD article 14)
- Right to health (CRPD, article 25)
- Right to respect for the integrity of the person (article 17)

Now ask participants:

- **What could have been done differently?**

Some potential responses might include:

- A more private room could have been found, away from potentially distressing stimuli, where efforts could have been made to reassure George and help him calm down.
- De-escalation techniques or other alternative response could have been used (this topic is developed in the module on *Strategies to end the use of seclusion, restraint and other coercive practices*).
- Others could have taken the time to listen and talk to George, instead of resorting to forced/covert treatment, restraint and isolation.
- Staff in the service could have tried to understand and find out why George did not want to receive treatment.
- Someone could have discussed with George the pros and cons of receiving (or not receiving) treatment.
- Someone could have called supporters nominated by George or other friends, family members that George agrees to, in order to try and find a way of understanding George's perspective and help him protect his rights.
- George could have been supported to develop an advance directive/plan when he was feeling well which would have provided a clear statement as to his wishes and response to the crisis. A legally binding advance directive would have given George the assurance that his wishes would be respected in future crisis and that he won't be forcibly treated.
- George could have nominated a trusted person in his advance plan/directive to communicate his wishes in a crisis. He could have also included an emergency contact person.
- George could have been encouraged to contact an advocacy group, such as peer-run non-governmental organisation that provide legal assistance.

Follow this discussion by asking:

- **What do you think the outcome would have been if things had been done differently?**

Some potential responses might include:

- It would have avoided the use of forced treatment and of seclusion and restraint.
- It would have avoided George's detention in the hospital.
- Staff could have retained relationship based on trust with George.
- George would have felt that he had been respected and would have been more likely to seek help if he experienced a future crisis.
- George may have felt less isolated and depressed as people would have taken the initiative to ensure he felt more connected and open to work with others to overcome this difficult situation.
- It would have supported George's recovery journey.



#### **Exercise 4.4: A challenging situation (40 min.)**

This exercise should allow participants to start to consider different options they could use to avoid involuntary detention and treatment and enable people to enjoy their rights including their right to legal capacity, even in the most challenging situations.

##### **Kaja's story**

One morning, a young woman named Kaja is brought to the local mental health service. She has tried to kill herself by jumping off a bridge, but police officers were present at the scene and they prevented her from killing herself. Kaja tells nurses that she still wants to end her life. She does not want any treatment and asks to be allowed to go back home, where she lives alone. Kaja does not have an advance plan or directive.

Ask participants the following question:

- **Could you suggest positive actions that could be taken in the above situation to avoid Kaja's involuntary detention and/or treatment?**

Some possible answers from the group may include:

- Someone could ask Kaja what she thinks would help her to feel better and if there is a safe place where she would like to be supported.
- She could be asked if there is a person she trusts who can help in this situation.
- She could be given the opportunity to talk to a trained peer worker if no one she trusts can be identified.
- People could try to understand why she wants to kill herself.
- Someone could try to understand why she does not want treatment, and if it is one particular type of treatment or all treatments.
- People could suggest to her that it is better not to stay alone for the moment (which might mean staying in a place other than home that is safe and where she would not be alone – for example the home of a trusted relative).
- People could ask Kaja if she wants to receive home support or access support services in her community during the day, or stay for a couple days in the service itself where people can provide her with care and support.
- In order to avoid this situation again, Kaja could be encouraged, at an appropriate moment after the crisis, to prepare an advance plan/directive to help and guide others to support her if a similar situation happens in the future.

Follow up this discussion by sharing with participants the following outcome of Kaja's story:

##### **Kaja's story – a positive outcome**

On arrival at the service, the nurse in charge asks Kaja what would help her at the moment. Kaja says that having her sister to talk to about her distress would make her feel safer.

Kaja also explains that she has just lost her job and feels hopeless about how she can support herself in the future. The nurse says that if Kaja is willing, she will work with Kaja over the next weeks to find a solution to this problem and explore different options for financial assistance and for finding another job. Kaja's sister says that she can come and live with her until she is back on her feet again.

The nurse also proposes to Kaja that she can visit the mental health service two or more times a week to receive counselling and discuss other care and support options.

The following week, Kaja reports that she feels listened to, safe and supported now and is reassured that she is receiving the support she needs and wants from her sister and staff at the service. She is also continuing to explore different support methods which are available to her in her community.

Following this case study, ask participants:

- **How do you feel about the support Kaja received in this case?**

It is important to enable participants to openly share their opinions and potential concerns about this scenario. Family members, mental health and other practitioners may be concerned for the safety of the person. Practitioners may also raise concerns in terms of liability if they do not resort to coercive measures such as involuntary admission and treatment.

Emphasize to participants that:

In a situation like this people should not be left alone, without any form of support. It is important to find forms of support that are acceptable to the person. This means listening to the person and sometimes thinking creatively and “outside the box”. This is extremely important because coercion is counterproductive and damaging for the person.

After this exercise you can show participants the following video:

**Neil Laybourn and Jonny Benjamin discuss mental health (2:43 min.),**  
<http://www.tubechop.com/watch/8198127> Date accessed 07/06/2016

The video explains how Neil Laybourn, a passer-by, prevented Jonny Benjamin from jumping from a bridge by simply talking and listening to him.



### **Concluding the session (5 min.)**

To conclude this session, ask participants:

What are the key points that you have learned from this session?

Follow the discussion with these take home messages from the today's session.

- Everybody has a right to legal capacity, and to make decisions concerning all aspects of life.
- Negative assumptions, stigma and stereotypes about people with psychosocial, intellectual and cognitive disabilities must be challenged and changed. People CAN make decisions on all aspects of their lives (including about their treatment, where to live, and their financial and personal affairs).
- Treatment and recovery plans and respect for informed consent as well as supported decision making and advance planning are all important measures to ensure that people are able to exercise their right to legal capacity on an equal basis with others.
- People with psychosocial, intellectual and cognitive disabilities have the right not to be detained in mental health and related services.
- They have the right not to be treated without their consent.
- Coercion is damaging to people's well-being and alternatives should always be sought. Outcomes of non-coercive measures are more beneficial for everyone: the person, their family, other supporters, and mental health and other practitioners.



### **Reflective exercise (5 min.)**

Ask participants the following:

Now that we have explored the key concepts around the right to legal capacity, prior to the next session try to think about:

- How does supporting the rights of persons with psychosocial, intellectual and cognitive disabilities to make their own decisions help them to live independently and be included in their community?

# Annexes

## Annex 1: The Convention on the Rights of Persons with Disabilities

(Original version **with associated simplified version**) (3),(4)

### Article 1 - Purpose of the Convention

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

The goal of this Convention is to make sure that people with disabilities have the same rights as everybody else and that they are respected by others.

### Article 2 – Definitions

For the purposes of the present Convention:

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

**"Language"** includes spoken and signed languages and other forms of non spoken languages;

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

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

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

**"Communication"** means all the ways used by people with disabilities to talk and understand information, for example computers, easy read or Braille.

“**Discrimination**” means being treated unfairly because you have a disability. It includes not getting reasonable accommodation.

“**Language**” means any way people talk to each other including sign language.

“**Reasonable accommodation**” means modifications of the environment which allow people with disabilities to enjoy their rights (for example this includes making adjustments and accommodations in educational, employment, and other contexts to make sure that people with disabilities have the same opportunities as others).

“**Universal design**” means products and items made for and usable by everybody, including people with disabilities.

### **Article 3 - General Principles**

The principles of the present Convention shall be:

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

The basic ideas of the convention are:

- a. People must be respected for who they are and are free to make their own choices;
- b. No one should be discriminated against (i.e. treated unfairly);
- c. People with disabilities have the right to be part of, and participate in, the life of the community and society;
- d. Everybody, including people with disabilities, is different and this is a good thing. People with disabilities must be respected and accepted like everybody else;
- e. Everyone should have the same chances in life;
- f. People with disabilities should have access to all the services and activities that others enjoy;
- g. Men and women are equal;
- h. The capacities of children with disabilities to make decisions and to do things for themselves will develop as they grow up and this needs to be respected.

## Article 4 - General Obligations

1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

- a. To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;
- b. To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
- c. To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;
- d. To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;
- e. To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;
- f. To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;
- g. To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;
- h. To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;
- i. To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.

2. With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.

3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

4. Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of persons with disabilities and which may be contained in the law of a State

Party or international law in force for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent.

5. The provisions of the present Convention shall extend to all parts of federal states without any limitations or exceptions.

### What do countries need to do?

1. All countries should make sure the rights of people with disabilities are respected and that they are treated equally. They do this by:
  - a. Making or changing laws and rules;
  - b. Changing law, rules or behaviours that cause people with disabilities to be treated unfairly;
  - c. Taking into account the human rights of people with disabilities anytime they put in place a policy or programme;
  - d. Not doing things that are against the Convention and making sure that the government and authorities respect this Convention;
  - e. Taking steps to make sure that people, organisations or companies treat people with disabilities equally and fairly.
  - f. Developing items and services that everybody can use;
  - g. Developing and using technology to help people with disabilities and making sure that they can access this technology without spending a lot of money;
  - h. Giving accessible information to people about things or services that can be useful and helpful;
  - i. Training people so they can respect the rights protected by this Convention.
2. All countries should do as much as they can afford to make sure people with disabilities are not discriminated against.
3. All countries should involve people with disabilities in making new laws and policies.
4. When countries have rules or laws which are even better than the Convention, they should not change them.
5. The Convention applies everywhere in countries.



### **Article 5 - Equality and non-discrimination**

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.
2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.
4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

1. Countries agree that everyone is equal.
2. Discrimination against people with disabilities is not allowed and the law protects people against discrimination.
3. Countries should make sure that people get the reasonable accommodation they need (i.e. that modifications and adjustments are made within society so that people can access information, services, activities and opportunities like everybody else).
4. When countries make specific laws or rules to make sure that people with disabilities are equal in practice, this is not discrimination.

### **Article 6 - Women with disabilities**

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

1. Women and girls with disabilities are often treated even more unfairly. They should also enjoy all their human rights.
2. Countries should make sure that women and girls have enough chances in life and power and control over their lives to enjoy all the rights of the Convention.

### **Article 7 - Children with disabilities**

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

1. Children with disabilities should enjoy their human rights, like other children.
2. When things are done for children, what is best for them is the most important thing to think about.
3. Countries should make sure that children with disabilities have the right to give their opinion. Their point of view should be respected more and more as they grow up and mature. When necessary, help needs to be given to children to express their opinion.

#### **Article 8 - Awareness raising**

1. States Parties undertake to adopt immediate, effective and appropriate measures:

- a. To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
- b. To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
- c. To promote awareness of the capabilities and contributions of persons with disabilities.

2. Measures to this end include:

- a. Initiating and maintaining effective public awareness campaigns designed:
  - i. To nurture receptiveness to the rights of persons with disabilities;
  - ii. To promote positive perceptions and greater social awareness towards persons with disabilities;
  - iii. To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;
- b. Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;
- c. Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;
- d. Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.

1. Countries should immediately:
  - a. Help everybody realise that people with disabilities have equal rights;
  - b. Combat false ideas about people with disabilities and practices which hurt them;
  - c. Show that persons with disabilities can and do contribute to society.
2. They should do this by:
  - a. Campaigning to make people think positively about disability.
  - b. Teaching children and adult the importance of respecting the rights of people with disabilities.
  - c. Encouraging the media to talk positively and in a respectful way about people with disabilities.
  - d. Supporting other awareness-raising programmes.

#### **Article 9 - Accessibility**

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

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

2. States Parties shall also take appropriate measures to:

- a. Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
- b. Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
- c. Provide training for stakeholders on accessibility issues facing persons with disabilities;
- d. Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;
- e. Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
- f. Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;

- g. Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
  - h. Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.
1. To make it possible for people with disabilities to be with others in society and to do the same activities as others, countries should give them access to transport, information, buildings, services and any other service or item to allow this. Countries should also remove all the obstacles that make it difficult for people to be with others in society.
  2. They should do this by:
    - a. Making rules to make public buildings and services accessible to people with disabilities;
    - b. Making sure that building and services offered by private companies (or other private organisations) are accessible to people with disabilities;
    - c. Training people on accessibility;
    - d. Writing signs in public buildings in Braille and in simple language or form so that everybody can understand;
    - e. Making persons available to guide people with disabilities in public building, for example guides, readers and people who can translate sign language;
    - f. Promoting other forms of assistance;
    - g. Making sure that people with disabilities have access to new technology like internet;
    - h. Supporting the creation of technology and tools which are already accessible to everybody so that people can buy them at a low price.

#### **Article 10 - Right to life**

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

Everybody has the right to life. Countries must make sure that people with disabilities enjoy this right like everybody else.

## Article 11 – Situations of risk and humanitarian emergencies

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

Countries must make sure that people with disabilities are properly protected during dangerous situations like wars and natural disasters (for example, hurricanes, earthquakes, floods, etc.).

## Article 12 - Equal recognition before the law

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

1. The law must recognize that people with disabilities are human beings with rights and responsibilities like anyone else.
2. People with disabilities have the same rights as everybody else and must be able use them. People with disabilities must be able to act under the law which means they can engage in transactions and create, modify or end legal relationships. They can make their own decisions and others must respect their decisions.
3. When it is hard for people with disabilities to make decisions on their own, they have the right to receive support to help them make decisions.

4. When people receive support to make decisions, they must be protected possible against abuse. Also:
  - the support that the person receives should respect the rights of the person and what the person wants;
  - It should not be in the interests of or benefit others;
  - The persons providing support should not try to influence the person to make decisions they do not want to make.
  - There should be enough support for what the person needs;
  - The support should be as short as possible;
  - It should be checked regularly by an authority which can be trusted.
5. Countries must protect the rights of people with disabilities:
  - To have or be given property;
  - To control their money;
  - To borrow money; and
  - Not to have their homes or money taken away from them.

#### **Article 13 - Access to Justice**

1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

1. People with disabilities have the same rights to go to court, take other people to court or take part in what happens in courts as anyone else. People with disabilities should have support to make sure they can access justice.
2. Countries should train people working in courts and tribunals and also police and prison staff so they can help people with disabilities to access justice.

## **Article 14 - Liberty and security of person**

1. States Parties shall ensure that persons with disabilities, on an equal basis with others:
  - a. Enjoy the right to liberty and security of person;
  - b. Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.
2. States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation.

1. People with disabilities have the right:
  - a. To be free like other people. The law must protect their freedom.
  - b. Not to be detained or imprisoned because they have a disability.
2. If people with disabilities are imprisoned, they must be protected by international human rights law and treated in a way that respects the objectives and principles of this Convention.

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

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

1. People with disabilities must not be tortured or treated cruelly. They cannot be experimented on by doctors or scientists unless they freely agree.
2. Countries should do everything possible to make sure that people with disabilities are not tortured or treated cruelly.

## Article 16 - Freedom from exploitation, violence and abuse

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.
2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and care partners, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.
3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.
4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.
5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

1. Countries must make laws and rules to make sure that people with disabilities are protected within and outside their home from violence, and from being exploited or abused.
2. Countries must prevent abuse by giving support, information and training to persons with disabilities, their families and care partners. Everybody should learn how to avoid, recognize and report violence and abuse. There should be extra support for women and children.
3. Countries must make sure that services that support people with disabilities are properly checked by an independent body.
4. Countries must make sure that people with disabilities who have been abused get the help and support they need to keep them safe and help them recover from the abuse.
5. Countries must make sure they create laws and policies (including ones that focus on women and children) to effectively find out if abuses are occurring, to investigate these and take abusers to court.



## **Article 17 - Protecting the integrity of the person**

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

People with disability should have their body and mind respected. Nobody should hurt their body and mind.

## **Article 18 - Liberty of movement and nationality**

1. States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including by ensuring that persons with disabilities:

- a. Have the right to acquire and change a nationality and are not deprived of their nationality arbitrarily or on the basis of disability;
- b. Are not deprived, on the basis of disability, of their ability to obtain, possess and utilize documentation of their nationality or other documentation of identification, or to utilize relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement;
- c. Are free to leave any country, including their own;
- d. Are not deprived, arbitrarily or on the basis of disability, of the right to enter their own country.

2. Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.

1. People with disabilities have the right to move around, to choose where to live and to have a country. Countries should make sure that:
  - a. People with disabilities have a right to a nationality and they can decide to change their nationality if they want. They must not be refused to have a nationality for unjust reasons or because they have a disability;
  - b. People with disabilities have the right to have identity papers, like passports, and to use them. They must have access to procedures for immigration;
  - c. They must be able to leave any country including their own;
  - d. They must not be unjustly stopped from coming back to their own country.
2. Children with disabilities have the right to be registered at birth and to have a name, to have a nationality, and if possible, to know their parents and be cared for by them.

## **Article 19 - Living independently and being included in the community**

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

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

People with disabilities have the right to live like other people and to have the same choices in life. Countries should make sure that people with disabilities:

- a. Can choose where to live and with who. They should not be forced to live somewhere if they do not want to;
- b. Have access to a lot of different community services so they can live with others in the community. They should not live in places that isolate them or keeps them away from their community;
- c. Have access to the same community services as all other people.

## **Article 20 - Personal mobility**

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

- a. Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
- b. Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
- c. Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;
- d. Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.

Countries should make sure that people with disabilities can get about as much as possible. They do this by:

- a. Helping people to get about when and how they want and for a low price;
- b. Helping people get good and cheap aids, tools and support for their mobility;
- c. Training people on mobility skills (e.g. how to get from place to place with ease, speed, safely and efficiently);
- d. Encourage companies which make mobility aids to think about all different needs of people with disabilities.

#### **Article 21 - Freedom of expression and opinion, and access to information**

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

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

People with disabilities have the right to say and think what they want. They also have the right to receive and give information. To do this they can use different forms of communication. Countries must respect this right by:

- a. Making sure that information is given in a way that people with disabilities can understand;
- b. Making sure that people can communicate with officials for example, in sign languages, Braille and other ways;
- c. Telling people working in the private sector to make their information accessible to people with disabilities;

- d. Encouraging the media, including the Internet, to make their service accessible to persons with disabilities;
- e. Recognizing and encouraging the use of sign languages.

#### **Article 22 - Respect for privacy**

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

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

1. People with disabilities have the right to have a private life, a family and a home. They also have the right to private correspondence like phone calls, letter or email. Nobody should attack their honour and reputation. This should be respected no matter where they live. The law should protect this right.
2. Countries should make sure that personal information about people with disabilities is kept confidential as is done for other people.

#### **Article 23 - Respect for home and the family**

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

- a. The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
- b. The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;
- c. Persons with disabilities, including children, retain their fertility on an equal basis with others.

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

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

comprehensive information, services and support to children with disabilities and their families.

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

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

1. People with disabilities have the right to marry, have a family, be parents and have relationships on an equal basis with others.
  - a. People with disabilities have equal rights to get married and start a family as long as both members of the couple want to.
  - b. People with disabilities have a right to decide how many and when to have children. They should receive information about having children.
  - c. People with disabilities should not be prevented from having children, for example by sterilization.
2. People with disabilities have the same rights and responsibilities as other concerning adoption. Countries must support people with disabilities to bring up their children if they need support.
3. Countries should protect children with disabilities from being concealed, abandoned, neglected or kept apart from society, by giving support and information to their families.
4. Countries should make sure children are not taken away from their parents because they have, or their parents have a disability. When a child is taken away from its parents, the law must make sure this fair and for the good of the child.
5. When parents cannot take care of a child with a disability, the child should stay with other family members. When this is not possible, the child should live within the community in a family setting.

#### **Article 24 – Education**

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning directed to:

- a. The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
- b. The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
- c. Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:

- a. Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
- b. Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
- c. Reasonable accommodation of the individual's requirements is provided;
- d. Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
- e. Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:

- a. Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
- b. Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;
- c. Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

1. People with disabilities have the right to education like others. Countries should make sure the education system accept them and that they can learn all their lives so that:

- a. They can develop their skills and abilities and be accepted and valued in the world;
  - b. They can develop their personality, creativity, talent and other abilities;
  - c. They can do activities with and for others.
2. Countries should make sure that:
    - a. They are not excluded from (kept out of) mainstream education. Children with disabilities must be allowed to go to mainstream primary and secondary schools;
    - b. They must be able to go to inclusive, good and free schools close to home, like other people;
    - c. Schools and universities must make changes to their environment so that children and adults with disabilities can access them;
    - d. People with disabilities must get the support they need to learn;
    - e. The support must be adapted to each person.
  3. Countries need to make sure that people with disabilities are able to learn life and social development skills to make sure they can live and participate in society and the life of their community on the same basis as all other people. In order to achieve this, countries must encourage people to learn all the different ways that people with disabilities can use to communicate.
  4. Countries must employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille. They must also train people who work in the area of education to learn skills and techniques which will help them to support people with disabilities in getting their education.
  5. Countries must make sure that people with disabilities can have access to educational opportunities after they have completed primary and secondary school, including training that is needed in order to get jobs, to help them to improve their lives and to strengthen their knowledge and skills.

#### **Article 25 - Health**

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

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

People with disabilities should have the same chance as others to be in good health. Countries should make sure that people with disabilities access health services. In particular, they must:

- a. Give people with disabilities access, on an equal basis with everybody else, to all types of health services which are of good quality and not expensive;
- b. Make sure people with disabilities get the types of health services they need because of their disability;
- c. Make sure services are close to people's homes even if they live in the countryside;
- d. Make sure health professionals give the same quality of service to people with disabilities as to others. Health professionals must give enough information to people and must get the consent of people with disabilities before they treat. Countries should train doctors, nurses and others to make sure that they treat people with disability with respect;
- e. Make sure people with disabilities are not discriminated against in health and life insurance and that they have access to these insurances on an equal basis with other people;
- f. Make sure people are not refused care, treatment or food and fluids.



## Article 26 - Habilitation and rehabilitation

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

- a. Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
- b. Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.

3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

1. Countries should make sure people with disabilities can lead an independent and good life. They must provide them with habilitation and rehabilitation in the areas of health, work, education and social services in order to make this happen.
  - a. Countries must make sure that they look at people with disabilities' needs and strengths at an early stage so that people with disabilities can get the supports and services they need.
  - b. These services must help people with disabilities to be included in society, to live with others and do the same activities as others. These services must be voluntary, and must be close to where people live even if they live in the countryside.
2. Countries need to train habilitation and rehabilitation professionals to provide these services for people with disabilities.
3. Countries need to make sure people with disabilities get different aids and equipment to live in the community.

## Article 27 - work and employment

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including

for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

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

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

1. People with disabilities have a right to work, like other people. They have the right to earn money and choose their job. Countries must make sure that the right to work of people with disabilities is respected. This includes:
  - a. Not allowing discrimination (i.e. making sure people with disabilities have equal job rights, rules, pay and opportunities);
  - b. Making sure people with disabilities have good and safe working conditions, that they have equal chances at getting jobs and equal pay and that they are not abused at work;

- c. Making sure people with disabilities have a right to join a trade union like others;
  - d. Making sure people with disabilities can go on work programmes and work training;
  - e. Helping people with disabilities to find and keep jobs as well as get better jobs;
  - f. Helping people with disabilities set up their own businesses;
  - g. Giving people with disabilities jobs in the public sector (public sector jobs for example, include government jobs in public schools and universities, in the police force, in public health services etc.);
  - h. Helping companies to give jobs to people with disabilities;
  - i. Making sure people with disabilities get reasonable accommodation in the workplace;
  - j. Helping people with disabilities to get work experience by spending a short period in a workplace to learn what it is like to do that kind of work;
  - k. Helping people with disabilities get a job, get back to work and retain their work through different programmes, supports and services.
2. Countries must make sure that people with disabilities are not forced to do unpaid work.

#### **Article 28 - adequate standard of living and social protection**

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

- d. To ensure access by persons with disabilities to public housing programmes;
  - e. To ensure equal access by persons with disabilities to retirement benefits and programmes.
1. People with disabilities have an equal right to satisfactory and acceptable standard of living/living conditions for them and their families. This includes food, clothing, housing and clean water.
  2. People with disabilities have the right to be protected by the state from poverty and bad living conditions. Countries should:
    - a. Give people with disabilities access to clean water and services and aids for their disability, at a price they can afford.
    - b. Make sure people with disabilities especially girls and women and older people, get help to have better living conditions.
    - c. Make sure people with disabilities who are poor get help from the state to buy the things they need because of their disability.
    - d. Make sure people with disabilities have access to public housing programmes.
    - e. Make sure people with disabilities get retirement pensions as other people.

#### **Article 29 - participation in political and public life**

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

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

- i. Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;
- ii. Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

Countries must make sure that people with disabilities are able to take part in politics on the same basis as everybody else. In order to ensure this, countries must:

- a. Take action to make sure that people with disabilities are able to participate in political life, including to vote and to be elected.

This includes:

- i. Making sure voting is easy and understandable to people with disabilities.
  - ii. Making sure voting is secret and free. They must also make sure that people with disabilities can stand for election and become public officials.
  - iii. Allowing people with disabilities to choose someone to help them with voting if they want to.
- b. Encourage the participation of people with disabilities in public affairs. This means that:
    - i. People with disabilities have the right to join Non-governmental organizations and associations.
    - ii. They have the right to create and join organizations of persons with disabilities.

### **Article 30 - participation in cultural life, recreation, leisure and sports**

1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:

- a. Enjoy access to cultural materials in accessible formats;
- b. Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;
- c. Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.

2. States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.

3. States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials.

4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

5. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures:

- a. To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;
- b. To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;
- c. To ensure that persons with disabilities have access to sporting, recreational and tourism venues;
- d. To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;
- e. To ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.

1. People with disabilities have the right to take part in cultural life like other people. This means that:

- a. Cultural materials, like books, are accessible.
- b. Television, films and theatres and other activities are made available in formats that are accessible to people with disabilities.
- c. People with disabilities can access places like theaters, museums, cinemas, libraries and touristic sites.

2. People with disabilities should be supported to express their creative, artistic and intellectual skills.

3. Countries should make sure that the rights of authors on their work do not prevent people with disabilities to access material.

4. The language and culture of people with disabilities should be respected; this includes sign language and deaf cultures.

5. People with disabilities have the right to have fun and take part in sports and leisure activities. Countries must:

- a. Encourage people with disabilities to access mainstream sporting activities;
- b. Make sure people with disabilities can create and participate in sporting and recreational activities specific to their disabilities;

- c. Make sure that persons with disabilities have access to sporting, recreational and tourist places and events;
- d. Make sure children with disabilities have equal access to all these activities including at school;
- e. Make sure that people working in the areas of recreation, tourism, leisure and sport can help people with disabilities.

## Annex 2: The experience of involuntary admission and treatment <sup>(20)</sup>

“Nothing could prepare me for the experience of being taken against my will — not by the police, or even an ambulance but an older sister who felt she knew best. What followed was the most violent of admissions. Totally traumatised and in shock, the sheer panic of dealing with my new reality never went away. I was manhandled, forcibly injected and held against my will for more than a month [...].

Along with the feeling of disempowerment and humiliation that involuntary hospitalisation brings, a patient said to be capable of harm is more often violated and harmed themselves. It is made all the worse since most are never believed — instead they are accused of being delusional and ungrateful. This, in itself, is a barrier to true healing since inhumane treatment leaves one feeling less than human. While some may see the psychiatric ward as a place of safety, for most it is nothing more than a prison [...].

There remains a huge power imbalance, not only during hospitalisation but also when community orders dictate what medications must be taken after patients are no longer hospitalised. With failing to comply with such orders leading to further incarcerations, this is nothing more than a form of control. Most leave this system with lost dreams and lives forever watched over by the system they can never escape. This is a violation of our human rights as outlined in the UN Convention”.



## Annex 3: Checklist for implementing supported decision making <sup>(16)</sup>

### Do you?

- Provide relevant information
  - Does the person have all the relevant information they need to make a particular decision?
  - If they have a choice, have they been given information on all the alternatives?
- Communicate in an appropriate way:
  - Explain or present the information in a way that is easier for the person to understand (for example, by using simple language or visual aids)?
  - Explore different methods of communication if required, including non-verbal communication?
  - Ascertain if anyone else can help with communication (for example, a family member, support worker, interpreter, speech and language therapist or advocate)?
- Make the person feel at ease:
  - Identify if there are particular times of day when the person's understanding is better?
  - Identify if there are particular locations where the person may feel more at ease?
  - Ascertain whether the decision could be put off to see whether the person can make the decision at a later time when circumstances are right for them?
- Support the person:
  - Ascertain if anyone else can help or support the person to make choices or express a view

## Annex 4: Concrete scenario on supported decision-making

Rohini is a 27 year old woman. She has been accompanied into the mental health service of a general hospital because her work colleague is concerned for her, as Rohini started to get very distressed, saying that her colleagues wanted to harm her.

On arrival at the facility Rohini started to get increasingly agitated, shouting that she did not want an injection. A nurse reassured her that nothing bad was going to happen, and that they wanted to help her. She took Rohini by the hand and guided her to a quiet room away from the noise and bustle of the reception area of the service.

The nurse asked Rohini if she could call anyone whom Rohini trusts, who could help her. Rohini informed her that she would like to see her mother. When her mother arrived, Rohini was still very distressed, shouting that she did not want an injection. Her mother explained to the nurse that the last time she went to a hospital, in the capital city of the country, she was given an injection of haloperidol (an anti-psychotic medication). Her mother further explained that Rohini had reacted badly to this medication, experiencing painful muscle contractions and confusion as a result.

The nurse told Rohini that she would not be given haloperidol, and Rohini started to calm down. Over the course of the week, Rohini worked with her mother, the nurse and a doctor to develop a treatment and recovery plan. She was informed of different options for treatment including benefits and negative effects, and asked for her consent to treatment.

In addition, Rohini, after consultation with people of her choice including her mother, the doctor and nurse, developed an advance plan so that staff would know never to give her haloperidol, and also so that they would know her preferences for treatment. In the plan she nominated her mother to be contacted in case of an emergency to support her in communicating her wishes during crisis situation. Staff asked Rohini if it would be helpful for her to stay at the service for a few days to start her off on her treatment, to which she agreed. After three days she felt much better and was subsequently discharged.

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