

# Legal capacity and the right to decide

WHO QualityRights core training: mental health & social services



Transforming services and promoting the rights of people with psychosocial, intellectual and cognitive disabilities

Legal capacity and the right to decide. WHO QualityRights Core training: mental health and social services. Course guide

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## Foreword

Ensuring mental health and well-being has become a worldwide imperative and an important target of the Sustainable Development Goals.

But in all countries around the world, our response has been woefully insufficient, and we have made little progress to advance mental health as a fundamental human right.

One in ten people are affected by a mental health condition, up to 200 million people have an intellectual disability and an estimated 50 million people have dementia. Many persons with mental health conditions, or psychosocial, intellectual, or cognitive disabilities lack access to quality mental health services that respond to their needs and respect their rights and dignity.

Even today, people are locked up in institutions where they are isolated from society and marginalized in their communities. Many are subjected to physical, sexual, and emotional abuse and neglect in health services, prisons, and the community. They are also deprived of the right to make decisions for themselves, about their care and treatment, where they want to live, and their personal and financial affairs. They are often denied access to health care, education and employment opportunities, and are prevented from full inclusion and participation in community life. As a result, people with mental health conditions and intellectual disabilities die 10 to 20 years younger than the general population in low-, middle- and high-income countries alike.

The right to health is fundamental to the World Health Organization's (WHO's) mission and vision, and underpins our efforts to achieve universal health coverage (UHC). The foundation of UHC is strong health systems, based on primary care, that deliver evidence based, person-centred services that respect people's values and preferences.

Fourteen new WHO QualityRights training and guidance modules are now available to achieve this vision. They will enable countries to translate international human rights standards into practice by influencing policy and building the knowledge and skills to implement person-centered and recovery-based approaches. This is what is required to provide quality care and support and to promote mental health and well-being.

Our conviction is that everyone—whether a service provider or member of the community, needs to have the knowledge and skills to support someone who has a mental health condition, psychosocial, intellectual, or cognitive disability.

We hope that these QualityRights training and guidance modules will be used widely and that the approach they offer will become the norm rather than the exception in mental health and social services worldwide.



**Dr Tedros Adhanom Ghebreyesus**  
*Director-General*  
*World Health Organization*

## Supporting statements

Dévora Kestel, Director, Department of Mental Health and Substance Use , World Health Organization, Geneva

Around the world, there is increasing awareness of the importance of mental health and providing services and supports that are person-centred and promote a recovery oriented and human rights-based approach. This awareness comes alongside a recognition that mental health systems in high, middle and low-income countries are failing many individuals and communities due to limited access, poor quality services and human rights violations.

It is unacceptable that people using mental health services can be exposed to inhuman living conditions, harmful treatment practices, violence, neglect and abuse. There are many reports of services not responding to people's needs or failing to support them to live the independent lives in their community - instead their interactions with services often leaves them feeling hopeless and disempowered.

In the wider community context, people with mental health conditions, psychosocial, intellectual or cognitive disabilities are subjected to stigma, discrimination and extensive inequalities that permeate all aspects of their lives. They are denied opportunities to live where they choose, marry, have families, attend school, seek employment and enjoy leisure activities.

Adopting recovery and human rights approaches is essential if we are going to change this situation. A recovery approach ensures that services place people themselves at the centre of care. It focuses on supporting people to define what recovery looks like and means for them. This approach is about helping people to regain control of their identity and life, have hope for the future, and to live a life that has meaning for them, whether that be through work, relationships, community engagement, spirituality or some or all of these.

Recovery and human rights approaches are very much aligned. Both approaches promote key rights such as equality, non-discrimination, legal capacity, informed consent and community inclusion (all enshrined in the Convention on the Rights of Persons with Disabilities). However, the human rights approach imposes obligations on countries to promote these rights.

Through these training and guidance modules developed as part of the QualityRights initiative, the World Health Organization has taken decisive action to address these challenges and to support countries to meet their international human rights obligations. These tools enable several key actions to be realized around: promoting participation and community inclusion for people with lived experience; capacity building in order to end stigma and discrimination and promote rights and recovery; and strengthening peer support and civil society organisations to create mutually supportive relationships and empower people to advocate for a human rights and person-centred approach in mental health and social services.

I look forward to seeing these World Health Organization tools used in countries to provide a comprehensive response to the challenges faced by people with mental health conditions, psychosocial, intellectual or cognitive disabilities.

## **Dainius Puras, Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest attainable Standard of Physical and Mental Health.**

QualityRights offers a new approach to mental health care which is rights-based and recovery-oriented.

This initiative of the World Health Organization is very timely. There is increasing understanding that mental health care policies and services worldwide need to change. Too often services for people with psychosocial disabilities and other mental health conditions are reliant on coercion, overmedicalization and institutionalization. This status quo is not acceptable, as it may continue to reinforce stigma and helplessness among both users and providers of mental health services.

All stakeholders – including policy-makers, mental health professionals and people using mental health services – need to be equipped with knowledge and skills in effective ways to manage change and to develop sustainable rights-based mental health services.

The QualityRights initiative, through specific well-designed modules, provides the necessary knowledge and skills, convincingly demonstrating that change is possible and that this change will lead to a win-win situation. Firstly, persons with disabilities and other mental health conditions, who may need mental health services, will be motivated to use services that empower them and respect their views. Secondly, providers of services will be competent and confident in applying measures that prevent coercion. As a result, power asymmetries will be reduced, and mutual trust and therapeutic alliance will be strengthened.

To abandon the legacy of outdated approaches in mental health care – based on power asymmetries, coercion and discrimination – may not be an easy direction to take. But there is growing understanding that the change towards rights-based and evidence-based mental health services is needed around the globe – in high-, middle- and low-income countries. WHO's QualityRights initiative and its training and guidance materials are extremely useful tools that will support and empower all stakeholders willing to go in this direction. I strongly recommend all countries to take QualityRights on board.

## **Catalina Devandas Aguilar, Special Rapporteur on the Rights of Persons with Disabilities**

Persons with disabilities, particularly those with psychosocial and intellectual disabilities, often experience human rights violations in the context of mental health services. In most countries, mental health legislation allows involuntary hospitalization and treatment of persons with disabilities on grounds of their actual or perceived impairment, plus factors such as “medical necessity” and “dangerousness”. Seclusion and restraints are regularly used during emotional crisis and severe distress in many mental health services, but also as form of punishment. Women and girls with psychosocial and intellectual disabilities are regularly exposed to violence and harmful practices in mental health settings, including forced contraception, forced abortion and forced sterilization.

Against this background, the WHO QualityRights initiative can provide essential guidance on the implementation of mental health services and on community-based responses from a human rights perspective, offering a path towards ending institutionalization and involuntary hospitalization and treatment of persons with disabilities. This initiative calls for training health-care professionals to provide health care and psychosocial support to persons with disabilities in a way that is respectful of their rights. By promoting compliance with the CRPD and the 2030 Agenda frameworks, the WHO QualityRights modules bring us closer to realizing the rights of persons with disabilities.

### **Julian Eaton Director, Mental Health, CBM International**

The increase in interest in mental health as a development priority offers the opportunity to close the huge gap in care and support, enabling people to realize their right to good health care where this has previously been lacking. Historically, mental health services have often been of very poor quality and have ignored the priorities and perspectives of people who were using them.

The WHO QualityRights programme has been instrumental in putting in place the means for measuring mental health services according to the standards of the Convention on the Rights of Persons with Disabilities. This often marks a paradigm shift from the way that services have historically worked. The new training and guidance modules are an excellent resource, facilitating better practice in supporting people with mental conditions and psychosocial disabilities, enabling their voices to be heard, and promoting healthier environments that foster recovery. There is a long way to go, but QualityRights is a crucial resource for service providers and users, guiding practical reform for services that value dignity and respect, wherever they may be in the world.

### **Charlene Sunkel, CEO, Global Mental Health Peer Network**

The World Health Organization's QualityRights training and guidance package promotes a strong participatory approach. It recognizes and values the importance of the lived experience of people with psychosocial, intellectual or cognitive disabilities in promoting recovery, undertaking advocacy, conducting research and reducing stigma and discrimination. The QualityRights tools ensure compliance with human rights standards, implementing strategies to end coercive practices. They show how persons with lived experience can provide peer support and can also contribute to the development, design, implementation, monitoring and evaluation of mental health and social services.

Lived experience is much more than just knowledge and skills. Expertise emanates from people's in-depth understanding of the social and human rights impact of living with a psychosocial, intellectual or cognitive disability and the adversities of being shunned, segregated and discriminated against. It emanates from having to struggle to navigate a mental health system that often fails to provide services or support that would be beneficial to the person as a unique individual and that speaks to their specific recovery needs.

The mental health system is not the only societal system that presents barriers through which the person must navigate; access to other life opportunities such as education, employment, housing and overall health and well-being can be equally challenging. The unique and in-depth perspectives of people with lived experience can be the catalyst for change and transformation of all societal systems in order to protect human rights, encourage inclusion in the community, improve quality of life, and promote empowerment – all of which can contribute towards improved mental health and well-being.

### **Kate Swaffer, Chair, CEO Dementia International Alliance**

It has been an honour and pleasure for Dementia Alliance International (DAI) to work with the WHO QualityRights initiative and its collaborators on this very important project. Human rights have generally been ignored in practice for people with dementia. However, these modules introduce a new approach to mental health, and also to dementia which is a neurodegenerative condition that causes cognitive disabilities. In contrast to the current post-diagnostic pathway for dementia, which is a pathway focused only on deficits and leading only to disability and dependence, this new approach and these unique and enabling modules promote rights and encourage and support people with dementia to live more positively.

By promoting the need for clear access to rights, the modules are practical tools that can be used by everyone, regardless of who they are. The modules, which take key human rights principles and make them actionable in practice, are as applicable and effective for health professionals as they are for people with dementia and their family members. For example, highlighting the need and benefits of peer-to-peer support – which is a free service DAI has been offering people with dementia since 2013, even before it was officially launched – and focusing on the issue of legal capacity and its relevance in terms of Article 12 of the CRPD provide tangible ways to better inform professionals and families to ensure that the rights of people with dementia will no longer be denied. I personally have every confidence that these modules will support all people experiencing mental health problems and psychosocial, intellectual or cognitive disabilities to live with a better quality of life.

**Ana Lucia Arellano, Chair, International Disability Alliance**

The United Nations Convention on the Rights of Persons with Disabilities, or CRPD, is the groundbreaking human rights treaty that promotes the paradigm shift from considering persons with disabilities as objects of charity or medical treatment to fully recognizing them as subjects of rights. This paradigm shift is particularly significant for persons with intellectual, psychosocial and multiple disabilities, or for persons with more intense support needs. Article 12 of the CRPD is key in promoting this shift in that it recognizes that persons with disabilities can exercise full legal capacity. This is the core human right that establishes the foundation on which all the others can be exercised.

QualityRights is a superb tool for enabling professionals and health practitioners to better understand and embrace the CRPD. The tool creates a bridge between persons with psychosocial disabilities, users and survivors of psychiatry and mental health services and the health sector, respecting the principles and values of the CRPD. The QualityRights modules have been developed in close consultation with users and survivors of mental health services, linking their voices to messages conveyed to States Parties of the CRPD. The International Disability Alliance (IDA) and its member organizations offer congratulations for the work developed under the QualityRights initiative. We strongly encourage WHO to continue efforts to transform mental health laws, policies and systems until they are CRPD-compliant, echoing the strong voices that call out for “Nothing about us, without us!”

**Connie Laurin-Bowie, Executive Director, Inclusion International**

WHO QualityRights aims to empower individuals and Disabled Persons Organizations to know their human rights and to advocate for change to enable people to live independently in the community and receive appropriate supports. Inclusion International welcomes this initiative which seeks to promote rights that are often denied to people with intellectual disabilities – namely the right to access appropriate mental health services in the community, the right to choose, the right to have a family life, the right to live in the community, and the right to be active citizens. QualityRights is a valuable contribution to our collective efforts to shape and influence policies and practice which enable everyone to be included in their communities.

**Alan Rosen, Professor, Illawarra Institute of Mental Health, University of Wollongong, and Brain & Mind Centre, University of Sydney, Australia.**

Freedom is therapeutic. Facilitating human rights in our mental health services can bring healing. It can ensure that, whenever possible, the person who is living with a mental health condition: a) retains choice and control over the assistance and care provided and b) is offered good-quality clinical and home support, if needed, to live in the community without disruption and "on their own turf and terms".



Following a long history of human rights advocacy in psychiatry, these modules show how the right to adequate care and all human rights and fundamental freedoms can be met without contradiction. Coercion in care – such as restraints, seclusion, forced medications, locked inpatient units, being cooped up in restrictive spaces, and institutional warehousing – must be curtailed. The optimal attainment of liberty in care entails immense change. This includes the widespread systematizing of practical evidence-based alternatives to avoid coercion – i.e. open doors, open respite facilities, open and free access, open communities, open minds, open conversations between equals, supported community living, enhancement of individual and family communication, problem-solving skills and support, advance directives, training in soothing and de-escalation, supported decision-making, the recovery orientation of all services and peer workers, and the co-production of policy with all stakeholders.

The WHO QualityRights programme, based on the United Nations CRPD, has been transformed here into a highly practical set of modules. For our professions, these modules offer a trajectory and a horizon to work towards rather than a finite answer or deadline. As well as optimizing clinical and support services, our political, legal and social actions with service users and their families have to be combined with our own emancipation as professionals from institutional thinking and from being yoked to habitual practices in mental health care. Only then and together can we vastly improve the prospects for an empowered, purposeful, contributing life, with full citizenship and full rights, for persons living with severe, persistent or recurrent mental health problems.

**Victor Limaza, Activist and facilitator of Justice for People with Disabilities, Documenta AC (Mexico)**

Dignity and well-being are closely related concepts. Nowadays, those criteria by which we judge psychological suffering only in terms of neurochemical imbalances are being questioned, as is the view that certain manifestations of human diversity are pathologies that must be attacked to protect the person and society from supposed dangers, even though the interventions used may violate rights and cause irreversible damage. The interdisciplinary and holistic outlook in which subjective discomfort is addressed without undermining the dignity and ability of the person to make decisions, even in critical situations, should be the foundation on which the new mental health care models are constructed, respecting the principles of the CRPD. Understanding the experience of a person facing a critical state in their mental health is possible thanks to the bond generated through empathy, listening, open dialogue, accompaniment (especially among peers), support in decision-making, life in the community and the advance directives under strict safeguards. People with psychosocial disabilities are experts from experience and must be involved in developing the instruments that seek to lead to recovery. The QualityRights initiative of WHO is a good example of this paradigm shift providing tools and strategies for mental health care with the highest standards of respect for human rights. Undoubtedly, the full and equitable enjoyment of all human rights by every person promotes mental health.

**Peter Yaro, Executive director, Basic Needs Ghana**

The WHO package of training and guidance documents is a rich collection of material that aims to enhance work in mental health and rights-based inclusive development. The materials provide a significant step towards effective programming and mainstreaming of disabilities – especially psychosocial, intellectual and developmental disabilities – in interventions to address individuals' needs and rights as provided for in the CRPD. The QualityRights package marks a giant stride towards the longstanding recommendation that persons with lived experience be part and parcel of the conceptualization and implementation of interventions, together with the monitoring and evaluation of the project's achievements. With this guidance, the sustainability of initiatives can be assured and, for this reason, practitioners, service users, caregivers and all stakeholders are encouraged to utilize

the documents. In the approach presented here, there is no place for perpetrating violence and abuse on already vulnerable persons.

**Michael Njenga, Chairperson of the Pan African Network of Persons with Psychosocial Disability, Executive Council Member, Africa Disability Forum and C.E.O. Users and Survivors of Psychiatry, Kenya**

There is paradigm shift in the way we need to address mental health globally. The impetus for this shift has been created by the Convention on the Rights of Persons with Disabilities (CRPD) and by the adoption of the Sustainable Development Goals (SDGs) and the 2030 Agenda for Sustainable Development.

WHO's QualityRights tools and materials for training and guidance build on this key international human right as well as on international development instruments. The QualityRights initiative adopts a human rights-based approach to ensure that mental health services are provided within a human rights framework and are responsive to the needs of persons with psychosocial disabilities and mental health conditions. These materials also lay emphasis on the need to provide services as close as possible to where people live.

The QualityRights approach recognizes the importance of respecting each individual's inherent dignity and ensuring that all persons with psychosocial disabilities and mental health conditions have a voice, power and choice while accessing mental health services. This is an integral element in reforming mental health systems and services both globally and at local and national levels. It is essential, therefore, to make sure that these training tools and guidance materials are widely used so that they result in tangible outcomes at all levels for people with lived experience, their families, communities and entire societies.

## What is the WHO QualityRights initiative?



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

- 1** Build capacity to combat stigma and discrimination, and to promote human rights and recovery.
- 2** Improve the quality of care and human rights conditions in mental health and social services.
- 3** Create community-based and recovery-oriented services that respect and promote human rights.
- 4** Support the development of a civil society movement to conduct advocacy and influence policy-making.
- 5** Reform national policies and legislation in line with the Convention on the Rights of Persons with Disabilities 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 – Training and guidance tools

The following training and guidance modules and accompanying slide presentations available as part of the WHO QualityRights initiative, can be accessed at the following link: <https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools>

## Service transformation tools

- The WHO QualityRights assessment toolkit
- Transforming services and promoting human rights

## Training tools

### Core modules

- Human rights
- Mental health, disability and human rights
- Recovery and the right to health
- Legal capacity and the right to decide ←
- Freedom from coercion, violence and abuse

### Specialized modules

- Supported decision-making and advance planning
- Strategies to end seclusion and restraint
- Recovery practices for mental health and well being

## Evaluation tools

- Evaluation of the WHO QualityRights training on mental health, human rights and recovery: pre-training questionnaire
- Evaluation of the WHO QualityRights training on mental health, human rights and recovery: post-training questionnaire

## Guidance tools

- One-to-one peer support by and for people with lived experience
- Peer support groups by and for people with lived experience
- Civil society organizations to promote human rights in mental health and related areas
- Advocacy for mental health, disability and human rights

## Self-help tools

- Person-centred recovery planning for mental health and well being – self-help tool

## About this training and guidance

The QualityRights training and guidance modules have been developed to enhance knowledge, skills and understanding among key stakeholders on how to promote the rights of persons with psychosocial, intellectual or cognitive disabilities and improve the quality of services and supports being provided in mental health and related areas, in line with international human rights standards, and in particular the United Nations Convention on the Rights of Persons with Disabilities and the recovery approach.

### Who is this training 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 social services**
- **Managers of general health, mental health and social services**
- **Mental health and other practitioners** (e.g. doctors, nurses, psychiatrists, psychiatric and geriatric nurses, neurologists, geriatricians, psychologists, occupational therapists, social workers, community support workers, personal assistants, peer supporters and volunteers)
- **Other staff working in or delivering mental health and social services, including community and home-based services** (e.g. attendants, cleaning, cooking, maintenance staff, administrators)
- **Nongovernmental organizations (NGOs), associations and faith-based organizations working in the areas of mental health, human rights or other relevant areas** (e.g. organizations of persons with disabilities (DPOs); organizations of users/survivors of psychiatry, advocacy organizations)
- **Families, support persons and other care partners**
- **Relevant ministries (Health, Social Affairs, Education, etc.) and policymakers**
- **Relevant government institutions and services** (e.g. the police, the judiciary, prison staff, bodies that monitor or inspect places of detention including mental and social services, law reform commissions, disability councils and national human rights institutions)
- **Other relevant organizations and stakeholders** (e.g. advocates, lawyers and legal aid organizations, academics, university students, community or spiritual leaders, and traditional healers if appropriate)

### Who should deliver the training?

Training should be designed and delivered by a multidisciplinary team, including people with lived experience, members of disabled persons' organizations (DPOs), professionals working in mental health, disability and related fields, families and others.

If the training is about addressing the rights of people with psychosocial disabilities specifically, it is important to have representatives from that group as leaders for the training. Likewise, if the purpose is to build capacity on the rights of persons with intellectual or cognitive disabilities, the leaders of the training should also be from these groups.

In order to liven up discussions, different options can be considered. For instance, facilitators with specific knowledge of a particular part of the training can be brought in for specific aspects of the training. Another option may be to have a panel of trainers for specific parts of the training.

Ideally, facilitators should be familiar with the culture and context of the location where the training is taking place. It may be necessary to conduct train-the-trainer sessions in order to build up a pool of

people who are able to carry out the training within a particular culture or context. These train-the-trainer sessions should include persons with psychosocial, intellectual or cognitive disabilities. They should also include other relevant local stakeholders who contribute to improving the quality of mental health and social services and the human rights of people with psychosocial, intellectual or cognitive disabilities.

### How should the training be delivered?

Ideally, all the QualityRights training modules should be delivered, starting with the five core foundational modules. This can be followed by more in-depth training using the specialized modules (see above).

The whole training can be conducted through multiple workshops taking place over the course of several months. Each separate training module does not necessarily have to be completed in one day. It can be divided into topics and can be conducted over the course of several days, as required.

Since the training materials are quite comprehensive and time and resources may be limited, it may be useful to adapt the training according to the existing knowledge and background of the group, as well as the desired outcomes of the training.

Thus, the way these training materials are used and delivered can be adapted according to the context and requirements.

- For example, if participants do not yet have any expertise in the areas of mental health, human rights and recovery, it would be important to conduct a 4–5-day workshop using the five core training modules. A 5 day sample agenda available at the following link: <https://qualityrights.org/wp-content/uploads/Sample-program-QR-training.pdf>
- If participants already have a basic understanding of the human rights of people with psychosocial, intellectual and cognitive disabilities but require more advanced knowledge about how specifically to promote the right to legal capacity in practice, then a workshop could be organized to focus on the module *Legal capacity and the right to decide* on day 1 and on the specialized module on *Supported decision-making and advance planning* (or selected parts of that module) on days 2, 3 and 4.

When adapting the training materials according to specific training requirements it is also important, prior to the training, to go through all the modules to be covered in order to get rid of unnecessary repetition.

- For example, if a training is planned, covering all the core modules, then it will not be necessary to cover topic 5 (zooming in on article 12) or topic 6 (zooming in on article 16) since these issues will be covered in much greater depth in the subsequent modules (module on *Legal capacity and the right to decide* and on *Freedom from coercion, violence and abuse* respectively).
- However if an introductory training is planned based solely on module 2, then it is essential to cover topics 5 and 6 of this module, since this will be the only exposure that the participants will receive on these issues and articles.

These are examples of the different and varied ways in which the training materials can be used. Other variations and permutations are also possible on the basis of the needs and requirements of the training in a particular context.

# Guidance for facilitators

## Principles for running the training programme

### Participation and interaction

Participation and interaction are crucial to the success of the training. All participants should be viewed as individuals who can contribute valuable knowledge and insights. By providing sufficient space and time, the facilitator(s) must first and foremost make sure that people with psychosocial, intellectual or cognitive disabilities are being listened to and included. Existing power dynamics in services and the broader society may make some people reluctant to express their views. In general, however, the facilitator must emphasize the importance of listening to the views of all participants.

Some people may feel shy or uncomfortable and not express themselves – which may be a sign of lack of inclusion or a feeling of insecurity in the group. Facilitators should make every effort to encourage and engage everyone in the training. Usually, after people have expressed themselves once and feel they have been heard, they are more able and willing to speak out and engage in discussions. The training is a shared learning experience. Facilitators should take time to acknowledge and as far possible answer all questions, so that nobody feels left out.

### Cultural sensitivity

Facilitators should be mindful of participants' diversity, recognizing that multiple factors have shaped their experiences and knowledge, such as culture, gender, migrant status or sexual orientation.

Using culturally sensitive language and providing examples relevant to people living in the country or region where the training is taking place is encouraged. For example, depending on the country or the context, people may express or describe their emotions and feelings, or talk about their mental health, in different ways.

In addition, facilitators should make sure that some of the 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 during the training. Feelings of shame or taboo about the issues being discussed will need to be taken into consideration.

### Open, nonjudgemental 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 respect for the rights of people using mental health and social services and of people with psychosocial, intellectual and cognitive disabilities within the broader community. During this training, some people may express strong reactions and feelings. It is important that the facilitator provides space during the training for people to express opinions and feelings. This means allowing people time to talk about their experiences without interruption and ensuring that others listen and respond to them in a sensitive and respectful manner.

It is not necessary to agree with people in order to communicate with them effectively. When discussion arises, it may be useful to remind all participants that they all share the same goal: to achieve respect for human rights in mental health and social services and in the community, and that all voices need to be heard in order to learn together. It may be helpful to share some basic ground rules with the group (e.g. respect, confidentiality, critical reflection, non-discrimination) to refer back to when needed.

Note that some people may never before have had the opportunity to speak out freely and safely (e.g. people with lived experience, family members, and also practitioners). Therefore creating a safe space to enable all voices to be heard is essential.

### Use of language

Facilitators should be mindful of the diversity of the participants. People taking part 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. by avoiding the use of/explaining highly specialized medical, legal and technical terms, acronyms, etc.) and to ensure that all participants understand the key concepts and messages. The language and the complexity of the training should be adapted to the specific needs of the group. With this in mind, facilitators should pause, provide examples when necessary, and take time to ask and discuss questions with participants to ensure that concepts and messages are properly understood. As far as possible, facilitators should use language that allows for nonmedical and/or culturally-specific models of distress to be part of the discussion (e.g. emotional distress, unusual experiences, etc.) (1).

### Accommodations

Accommodating different means of communication – such as by using visual and audio materials, easy-to-read adaptations, signing, providing assistance with writing for some of the exercises, or enabling people to come with their personal assistant – may be necessary at times to ensure that all people are included in the training.

### Operating in the current legislative and policy context

During the training, some participants may express concerns about the legislative or policy context in their countries which may not be in line with international human rights standards, including the Convention on the Rights of Persons with Disabilities (CRPD). Similarly, some of the content of the training may contradict current national legislation or policy. For instance, laws that provide for involuntary detention and treatment contradict the overall approach of these training modules. Moreover, the topic on supported decision-making may appear to conflict with existing national guardianship laws. Another concern may be that national resources for implementing new approaches may be scarce or not available. These preoccupations can lead to questions from the participants about liability, safety, funding and about the larger political and societal context in which they live and work.

First, facilitators should reassure participants that the modules are not intended to encourage practices which conflict with the requirements of national law or policy, or which could put anyone in danger of being outside the law. In contexts where the law and policy contradict the standards of the CRPD it is important to advocate for policy change and law reform. Even though States Parties to the CRPD have an *immediate* obligation to cease violations of this Convention and other international human rights instruments, it is important to acknowledge that achieving full respect for the rights in the CRPD takes time and requires a variety of actions at all levels of society.

Consequently, 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 and to start implementing the CRPD. For example, even if guardians are officially mandated on the basis of a country's law to make decisions on behalf of other



persons, this does not prevent them from supporting those persons in reaching their own decisions and from ultimately respecting their choices.

This training provides guidance on dealing with various topics which are key to fostering the human rights-based approach in mental health and social services. Throughout the training, facilitators should encourage participants to discuss how the actions and strategies promoted in the training materials affect them and how they can be implemented within the parameters of existing policy and law frameworks. Shifts in attitudes and practices, along with effective advocacy, can lead to positive change in policy and law.

### Being positive and inspiring

Facilitators should emphasize that the training is intended to share basic knowledge and tools, and to stimulate reflection in order to find solutions that are useful in participants' own context. It is likely that some positive actions already exist and that participants themselves, or other people or services, are already carrying them out. It is possible to build on these positive examples to create unity and to demonstrate that everybody can be an actor for change.

### Group work

Throughout the exercises, the facilitator will ask participants to work in groups, which may be flexibly composed, by choice or randomly, depending on the preferences of participants. If participants do not feel comfortable in certain groups, this should be taken into account.

Exercises throughout the training are meant to foster participation and discussion. These exercises are designed to allow participants to come up with ideas and to identify solutions by themselves. The facilitators' role is to guide discussions and, when appropriate, to stimulate debate with specific ideas or challenges. If participants do not want to take part in some of the activities of the training, their wishes should be respected.

### Facilitator notes

The training modules have 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 that are intended to be read out to participants are written in **black**.

Separate course slides accompanying the training modules to deliver the content of the modules are available at the following link <https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools>

### Evaluation of the QualityRights training

The QualityRights pre/post-evaluation questionnaires that come as part of this training package have been designed to measure the impact of the training and to improve it for future training workshops.

Participants are required to complete the pre-training evaluation questionnaire before the training starts. 30 minutes should be set aside for this.

At the end of the training, participants should complete the post-training evaluation questionnaire. Again, 30 minutes should be allowed for this.

A unique ID needs to be created for each participant, whether they are completing the form by hand or online. This ID will be the same for both the pre-evaluation and the post-evaluation questionnaire. Unique IDs can be created, for example, by using the name of the country where the training is taking place followed by numbers 1 to 25 (or however many participants there are in the group). For instance, a participant could receive the unique ID of Jakarta12. It could be useful to include the pre and post questionnaires with unique IDs in the participants' folders before the training starts to ensure that the unique IDs are given to the correct participants. There is no need to track who gets which unique ID since the questionnaires are anonymous, but it is important to ensure that each person has same ID on both questionnaires.

Once the post-training evaluation questionnaire has been completed, the facilitator should open the discussion to all participants to express their views about the training, what parts they enjoyed and found useful and what parts they did not enjoy or find useful, as well as any other views they wish to share. This is also an opportunity to discuss what actions and strategies discussed during the training the participants intend to implement.

The pre and post questionnaires should be printed for each participant prior to the training. The versions for printing and distributing are available here:

- Evaluation of the WHO QualityRights training on mental health, human rights and recovery: PRE-training questionnaire: <https://qualityrights.org/wp-content/uploads/20190405.PreEvaluationQuestionnaireF2F.pdf>
- Evaluation of the WHO QualityRights training on mental health, human rights and recovery: POST-training questionnaire: <https://qualityrights.org/wp-content/uploads/20190405.PostEvaluationQuestionnaireF2F.pdf>

### Training videos

Facilitators should review all the videos available in the module and chose the most appropriate ones to show during the training. The video links may change over time. It is therefore important to check that the links work prior to the training. If a link is not working an appropriate alternative link to a comparable video should be found.

## Preliminary note on language

We acknowledge that language and terminology reflects the evolving conceptualization of disability and that different terms will be used by different people across different contexts over time. People must be able to decide on the vocabulary, idioms and descriptions of their experience, situation or distress. For example, in relation to the field of mental health, some people use terms 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 stigmatizing or use different expressions to refer to their emotions, experiences or distress. Similarly, intellectual disability is referred to using different terms in different contexts including, for example, “learning disabilities” or “disorders of intellectual development” or “learning difficulties”.

The term “psychosocial disability” has been adopted to include 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 the full and effective participation in society of people with actual or perceived impairments and the fact that they are protected under the CRPD. The use of the term “disability” in this context does not imply that people have an impairment or a disorder.

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

In addition, the use of the term “mental health and social services” in these modules refers to a wide range of services currently being provided by countries including, for example, community mental health centres, primary care clinics, outpatient services, psychiatric hospitals, psychiatric wards in general hospitals, rehabilitation centres, traditional healers, day care centres, homes for older people, and other “group” homes, as well as home-based services and services and supports offering alternatives to traditional mental health or social services, provided by a wide range of health and social care providers within public, private and nongovernmental sectors.

The terminology adopted in this document has been selected for the sake of inclusiveness. It is an individual choice to self-identify with certain expressions or concepts, but human rights still apply to everyone, everywhere. Above all, a diagnosis or disability should never define a person. We are all individuals, with a unique social context, personality, autonomy, dreams, goals and aspirations and relationships with others.

# Learning objectives, topics and resources

## Learning objectives

During this training, participants will:

- learn 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 specific 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

**Topic 1:** Understanding the right to legal capacity (2 hours 30 minutes)

**Topic 2:** Supported decision-making and advance planning (3 hours 15 minutes)

**Topic 3:** Informed consent and person-led treatment and recovery plans (45 minutes)

**Topic 4:** Avoiding involuntary detention and treatment in mental health and social services (3 hours 15 minutes)

## Resources required

- **accompanying course slides, Legal capacity and the right to decide. WHO QualityRights Core training: mental health & social services (Course Slides), are available here <https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools>**
- **room requirements: to optimize 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 environment conducive to free and open discussions;
  - seating arrangements that allow people to sit in groups (e.g. “banquet style” where several round tables are arranged around the room, allowing for several participants to sit together around each of the tables. This has the added benefit of encouraging interaction between participants and also of creating ready-made groups for group work exercises.)
- **reasonable accommodations, as required, ensuring inclusive access to the training for all persons.**
- **internet access in the room, in order to show videos**
- **loudspeakers for the video audio**
- **a projector screen and projector equipment**
- **1 or more microphones for facilitator(s) and at least 3 additional wireless microphones for participants (ideally one microphone per group table).**
- **at least 2 flipcharts or similar, plus paper and pens**

## Additional resources required for this training module include:

- **copies of *Annex 1: Scenarios* for all participants**
- **copies of *Annex 2: CRPD original with associated easy-read text* for all participants**

- copies of *Annex 3: Checklist for implementing supported decision-making* for all participants
- copies of *Annex 4: The experience of involuntary admission and treatment* for all participants

### Time

Approximately 8 hours

### Number of participants

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

**The issues covered in this module are particularly complex. To conduct this training, facilitators should 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.**

**In addition, the issues covered in this module – in particular the right to legal capacity and informed consent for admission and treatment – are challenging issues to which there may be resistance. It is therefore important to discuss these issues with the management and senior staff of any mental health or related service or organization in which this training is taking place, prior to the start of the training, to encourage a thorough understanding of these issues.**

## Introduction

This module is focused on the right to legal capacity. This right, enshrined in the Convention on the Rights of Persons with Disabilities, means that persons with disabilities have the same right as anyone else to make their own decisions. The Convention also states that States Parties should provide persons with disabilities with the support they need to exercise their right to legal capacity.

It is often supposed by many in society that persons with psychosocial, intellectual or cognitive disabilities are not able to reach their own decisions about every issue that concerns them. The Convention, as reflected in this training module, makes clear that, since all persons have equal rights, it is up to society to enable them to exercise those rights, not ignore them on the basis of outdated prejudices.

The module takes participants through the concept of legal capacity – the right to decide, to choose, to own property, to enter into agreements – and points out that the right can never be taken away. Sometimes persons with psychosocial, intellectual or cognitive disabilities may experience challenges in making decisions about the kind of medical treatment they receive, but that issue applies to most people also. In such situations, people should have access to trusted support persons of their choosing, who can assist them in understanding the options available to them, help them to weigh up the pros and cons of a particular choice or course of action, and support them to assert and communicate their will and preference.

In this module participants will learn about “supported decision-making”, “advance planning” “informed consent” and “person-led treatment” and will acquire knowledge and skills on how these concepts can be applied in practice.

The final part of the module looks at the issue, still widely prevalent in mental health and social services worldwide, of detaining people against their will and compelling them to take medication. No one, whether having a disability or not, should be compelled to undergo a treatment they do not want.

## Topic 1: Understanding the right to legal capacity

### Time for this topic

Approximately 2 hours and 30 minutes.



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

The purpose of this brief introduction is to pre-empt the issues that participants will need to grapple with in relation to promoting legal capacity even in the face of extremely challenging situations and circumstances.

In this training we will explore how to promote a person's right to legal capacity within mental health and social services. In other words, we will explore how to make sure that mental health and social services respect the right of people using those services to make choices and decisions 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 situations and circumstances. For instance, what about people who want to end their lives or people with severe dementia? What if someone is experiencing an acute crisis or extreme states or is doing things that are, or seem, dangerous? What if refusing treatment means the person might get worse? What if someone is unconscious or otherwise unable to communicate their will and preference? Is it really feasible to promote the right of people to make decisions for themselves even in these kinds of scenarios?

The answer is that, even in these challenging situations, we must always strive to find ways to ensure that people have the final say in all decisions concerning their lives.

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



### **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 professional training or from common assumptions present in society and reflected in laws, policies, 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 flipchart, write down participants' ideas.

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

- There are times when people simply cannot make decisions for themselves and others have to step in to prevent them from harming themselves or others.
- Someone who is “psychotic” cannot make decisions, cannot be reasoned with nor understood and cannot communicate their will and preferences.
- Sometimes decisions concerning mental health treatment have to be taken against a person’s will because the person does not know or understand that they need it.
- People with psychosocial, intellectual or cognitive disability cannot be trusted to make decisions in all areas of their lives.
- Doctors are in the best position to decide on medical matters and they will protect the person on the basis of what they believe to be in the person’s best interest.
- If people are resident in a care home or a mental health or other related service, it is logical that all decisions concerning their care needs should be made by mental health and other practitioners.

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 that these situations are addressed without the denial or restriction of a person’s rights. These strategies are explained in this module.



**Presentation: The right to legal capacity (2), (3) (1 hour, 30 min.)**

### **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 (Annex 2).

The provisions of article 12 have already been explained in the module *Mental health, disability and human rights*. 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 (4),(5)**

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 decisions 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 equal rights of people with disabilities:

- to have or be given property;
- to control their money;
- to borrow money; and
- 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, and
  - 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 recognized 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:

- understand information about a decision
- understand the potential consequences of the decision
- communicate the decision.

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

However, the concept of “mental capacity” and “capacity tests” is flawed because the way we make decisions cannot be measured scientifically. Sometimes we make decisions based on 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 is not capable of making the decision due to their “condition”. However, everyone sometimes makes decisions and choices in life that others do not agree with or that they consider unwise; 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 do not have. However, how well we make decisions varies at different times in our lives. For example, making decisions at certain times may be more difficult because of stress or tiredness, or because of a health condition, etc. In addition, our ability to make decisions may also improve over time as we learn new skills and have new experiences.

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 or cognitive disabilities – do not have the mental capacity to make decisions.

Both these misconceptions and the misinterpretation of the term “mental capacity” (which will be referred to as “decision-making skills” or “ability to make decisions” in the rest of 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 can never be taken away from a person. Everybody has the right to legal capacity irrespective of their decision-making skills. A psychosocial, intellectual or cognitive disability can never justify denying someone the right to legal capacity.

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

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

Article 12 clearly states that all people, including people with disabilities, must have the right to make decisions for themselves, to have those decisions respected by others, and to have the decisions recognized as valid 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 – e.g. regarding marriage, divorce, renting, buying or selling property, signing contracts, treatment choices – decisions for people with psychosocial, intellectual or cognitive disabilities are often made by court-appointed guardians, health practitioners and families. This process has different terms in different countries – such as guardianship, conservatorship, etc.

In the case of **informal** decision-making, many of the day-to-day decisions in all aspects of life are taken out of the hands of people with psychosocial, intellectual or cognitive disabilities and instead are made by others, particularly families and care partners. Examples of these decisions include how money is spent, living arrangements, personal relationships, choosing clothes to wear, choice of food and daily routines.

## **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 social 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, in the workplace, at the bank, etc.)
- at home
- in mental health and social 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 often done with good intentions and a desire to (over)protect their relatives from potential harm. Families often fear that their relative will fail, be abused, get hurt or be taken advantage of.

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

- Involuntary admission and treatment in mental health and social services denies people the right to exercise free and informed consent to health care and therefore denies them the right to legal capacity.
- In many cases, 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 the staff are in a better position to decide.
- In addition, the simple threat of involuntary admission and treatment may result in the acceptance of unwanted practices by some people.

Such practices in services may reflect common negative stereotypes and discriminatory views – for instance, that people using the service cannot make decisions for themselves or that, if they refuse treatment, it is because they do not realize that they need it (e.g. that they lack insight).

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 powers are taken away from people and there is a general failure to talk with and listen 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.).

In addition, people with psychosocial, intellectual and cognitive disabilities also face denial of their right to legal capacity on a day-to-day basis **in their own communities** (e.g. staff at the bank refusing people access to their money without a guardian/family member present; social services refusing to give people the paperwork they need to access support and instead giving it only to their guardian).

### **Gender and legal capacity (6)**

Women with disabilities may face even more denial of their right to legal capacity as a result of multiple discrimination. Their rights to maintain control over their reproductive health, including on the basis of free and informed consent, and rights to found a family, to choose where and with whom to live, to physical and mental integrity, to own and inherit property, and to control their own financial affairs – including equal access to bank loans, mortgages and other forms of financial credit – are often violated through patriarchal systems of substituted decision-making.

At this point of the presentation, show participants the following video:

Women institutionalized against their will in India. Human Rights Watch (4.15) December 2013.  
<https://youtu.be/NZBxI9pNYHw> (accessed 9 April 2019).



### **Exercise 1.2: Denial of legal capacity (20 min.)**

Ask participants to read the following scenario, available in *Annex 1: Scenarios – Soledad (7)*:

#### **Scenario - Soledad**

Soledad is a 40-year-old woman who has lived for 10 years in a social care home.

She lives in a small, clean room, that she shares with a roommate she has not chosen herself. She was brought to the social care home because of mood swings and loss of memory. She suffers from infections and describes her health as bad.

Her days are long and empty and constantly follow the same, boring routine: early rise, some cleaning, food, mandatory rest as if they are toddlers and exercise twice a week (an hour in the yard of the fenced social care home).

There is hardly an opportunity to leave the home. All residents are told that the outside world is extremely dangerous and that they are kept behind closed doors for their own security. Many of the residents have internalized this fear and therefore prefer to stay inside.

There is no possibility for Soledad to escape from the rigid life at the home; no individuality is allowed and there is no possibility to engage in her hobbies of playing the piano and singing.

She is convinced that, should she be given the opportunity, she could have a job, for instance in a sewing studio. The quality of life often lies in small things. She likes reading, but her glasses are broken. Although she often asks the staff for a replacement, so far her requests have been to no avail. The antenna from her small television set is broken but no one is able to repair it.

Soledad longs for more attention and affection from the staff. If residents don't comply with the rules and regulations they are sometimes threatened with the use of straightjackets or being tied to a bed.

Now, ask participants the following question:

In which ways are Soledad's right to legal capacity being violated?

Answers may include:

- She did not choose to stay at the social care home as she was brought there and cannot leave.
- She could not choose her roommate.
- She does not seem to be able to get adequate care for her infection and general health.
- She has no choice concerning her daily routine.
- She cannot practice her hobbies.
- She cannot find a job.
- She cannot read or watch television although she wants to.
- If she does not follow the rules, she is threatened by the staff.



**Presentation: The consequences of denying the right to legal capacity (10 min.)**

At this point ask participants the following questions:

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

Potential answers for participants may include:

- It decreases self-esteem.
- It prevents people from participating fully in society.
- It negatively impacts people's mental health.
- It furthers social exclusion and discrimination
- It prevents people from taking control and responsibility for their lives.
- It prevents people from learning from their mistakes.
- It creates a potential for violence, abuse and coercive practices (e.g. forced treatment, involuntary admission, etc.) to occur.
- It prevents people from defending themselves against acts of violence, abuse and exploitation.

After the discussion, show the following slide:

Denying people the right to make their own decisions means that they have very little (or no) control over some or all aspects of 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:

- It allows people to control their own lives.
- It allows people to be full members of their community and for others to respect them as such.
- It allows people to better defend themselves against abuses, exploitation and discrimination.
- It conveys to everyone that people with psychosocial, intellectual and cognitive disabilities must be respected and treated as equals.



**Presentation: Summary of the topic (10 min.)**

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

UN CRPD: What is Article 12 and Legal Capacity? Mental Health Europe (2:53 min.)

<https://youtu.be/8WhxKJtOXec> (accessed 9 April 2019).

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

1. **Common misconceptions and stereotypes about people’s decision-making skills must be challenged:** People with psychosocial, intellectual or cognitive disabilities can make decisions and have the right to do so.
2. **Everyone’s ability to make decisions can 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 decisions cannot be a reason to deny people the right to legal capacity.** According to article 12, all people with disabilities must be able to exercise their right to legal capacity at all times.
4. **The right to legal capacity is a critical and fundamental right:** we all need to enjoy this right to be recognized and to participate in society.

Pre-empt the following topic by explaining that:

Having the right to legal capacity at all times does not mean that people never need or want support in making decisions. The CRPD acknowledges this and states that people should have access to the support they may want and require in order to be able to exercise their right to legal capacity. This is known as “supported decision-making”.

## Topic 2: Supported decision-making and advance planning

### Time for this topic

Approximately 3 hours and 15 minutes.

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

Supported decision-making is key to respecting a person's right to legal capacity.

- A supported decision-making approach involves cooperating with the person in the process of making a decision and upholding the person's right to have a final say over that decision.
- Implementing a supported decision-making approach can improve everyday practice in mental health and social services.
- We will explore the meaning of decision-making in this part of the module.



### **Exercise 2.1: Discussion on supported decision-making (10 min.)**

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

Ask participants the following question:

In what ways do you think persons can be supported to make their own decisions in the context of a mental health or related service?

Some possible suggestions might include:

- Give people the opportunity to identify persons they trust who can support them in making decisions (e.g. trained peer workers) and allow people to come to the service with their trusted persons.
- Try to understand the type of information or support that would help the person to make decisions.
- Enable access to support which is independent from the service.
- Allow people more time to make decisions (i.e. 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 or a better location to provide information.
- Work collaboratively with people in the development of their treatment and/or recovery plans, enabling them to express their opinions and preferences.





### **Presentation: Supported decision-making (8) (50 min.)**

At times, we may all need support to make decisions in different areas of life. Also, there may be times in life when we all may find it difficult and challenging to make decisions by ourselves.

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 when making decisions and choices, especially when we need other people's perspectives and skills to supplement our own.

In acknowledgement of this, article 12 of the CRPD recognizes and promotes the concept of "supported decision-making". This 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 ombudsperson, etc.).

It 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 decisions to others.

- For instance, in the context of a mental health and related service, a peer supporter can support a person to understand and weigh up the benefits and/or negative effects of a particular course of treatment, discuss the pros and cons of the treatment, and support the person to assert and communicate choices if the person has difficulties in doing so.

It is important to note that support needs to be tailored to the individual. Decision-making skills, and hence the level of required support, can vary at different stages in a person's life. At times people may need no support at all, while at other times they need low-level support, and sometimes more intensive support.

- For instance, a person in the early stages of dementia may need minimal or no support at all, whereas in later years the same person may need more intensive support. In addition, some people may require support only for complex decisions while others may require support even for 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 accepted as having the right to make their own decisions.

Different support options – both formal and informal – may exist.

Some examples of support models are presented below. Most existing models of support are not yet fully compliant with the CRPD. Criticisms may include objections that some models are led and directed by professionals or that they still use involuntary treatment (although this may be to a lesser extent than other mental health and social services, such as with Open Dialogue). It is important to acknowledge these limitations and keep in mind that these services could be further improved to achieve full compliance with the CRPD.

- **Circle of support (Australia, 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, when needed, with support to achieve what they want in life. The person being supported is in charge of:

- deciding who to invite to be in the Circle
- deciding on the direction that the Circle's energy should be employed.

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:

**Circles of Support, Inclusion Melbourne** (6:19)  
<https://youtu.be/fhF6mv03Cx0> (accessed 9 April 2019).

- **Personal ombudsperson (Sweden) (10)**

The Personal Ombudsperson in Sweden is a model of supported decision-making being offered by several NGOs. A personal ombudsman is a skilled person who helps clients with a range of issues: family-matters, housing, access to services or employment. A personal ombudsman 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 personal ombudsman and the clients.

For more information, participants can watch Maths Jespersen speaking about Swedish psychiatric reform and the innovative policy Personal Ombudsperson System in the following video: ([13:50 min.](#))

<https://youtu.be/5aVdoaX9YXk> (accessed 9 April 2019).

- **Personal assistance (11)**

Personal assistance refers to person-directed/user-led human support delivered to a person with disability. Personal assistance is a tool for independent living. Regarding supported decision-making, personal assistants can be trusted individuals who will talk through options with the person, and support them in communicating their will and preferences to others, etc.

- **Open Dialogue: Finland** (12),(13)

Open Dialogue is a Finnish alternative to the traditional mental health system for people diagnosed with "psychoses" such as "schizophrenia". This approach is based on a supported decision-making process and 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. A shared language is created and the participants build up a new understanding between each other.

The Open Dialogue team provides immediate help within 24 hours of the first contact. The team seeks 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.

Show participants the following video:

Daniel Mackler and Jaakko Seikkula Speak on Finnish Open Dialogue, social networks, and recovery from psychosis (8:24 min.)

[https://youtu.be/b5\\_xaQBgkWA](https://youtu.be/b5_xaQBgkWA) (accessed 9 April 2019).

### **The importance of support**

Formal forms of support should not replace informal support networks (e.g. family, friends, etc.) which are essential in people's day-to-day lives. When informal networks are non-existent or weakened, it is very important to support the person to rebuild and/or consolidate the informal networks.

At the same time, it may also be necessary to advocate for more formalized forms of support networks for people who need and want them.

### **How can mental health and social services facilitate supported decision-making?**

Mental health and social services have a responsibility to facilitate supported decision-making actively 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, advocates or peer supporters who can act as a decision supporter if this is what the person wants.

Distribute to participants copies of Annex 3 (also represented below).

The following box (14) is a useful checklist tool for supporters to initiate a supported decision-making approach. However, additional steps may need to be included on a person-by-person basis.

### Supported decision-making checklist

#### Do you?

- Provide relevant information:
  - Does the person have all the relevant information he or she needs to make a particular decision?
  - Does the person have all the information they are asking for?
  - Have they been given information on all available options?
- Communicate in an appropriate way:
  - Explain or present the information in a way that is easier for the person to understand (e.g. by using simple, clear and concise language or visual aids).
  - Explore different methods of communication if required, including nonverbal communication.
  - Ascertain if anyone else can help with communication (e.g. a family member, support worker, interpreter, speech and language therapist or advocate) and that the person accepts this help
- 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 behalf of, or 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 their best interest (i.e. what others determine to be 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 by, for example:
    - referring to what is already known about the person, e.g. views on different matters, beliefs, values in life, etc. (these are often known by the person's close friends or relatives);
    - referring to advance planning documents which should contain information about the person's will and preference;
    - even when nothing is known about the person (e.g. first contact with a service) and the person does not appear to be able to communicate their wishes, service staff must do their best to try to understand the will and preferences of the person (e.g. trying different modes of communication, paying attention to the person's reactions, etc.)

- 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 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 are many things 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 – 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 and/or in the future. The harm caused to the person can take many forms including, trauma, humiliation or physical injuries.

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 and other supporters are well-intentioned but sometimes, in the context of providing supported decision-making, some people may try to take advantage, exploit or harm the person (e.g. through physical, emotional, sexual abuse, financial abuse or neglect, etc.). Safeguards are therefore necessary to make sure that exploitation does not take place or that potential situations of abuse are recognized and addressed early.

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

- people with psychosocial, intellectual or 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.

The training should address the social factors and processes that might make exploitation more likely to occur – such as power dynamics and discrimination across gender, age or disability.

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 through power imbalances 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 by promoting supported decision-making and adopting a supportive approach in their day-to-day work.
- Supporters' roles should last for the shortest time possible and should be 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 supporters from outside or inside the mental health or related service – such as informal support, advocates or peer supporters – should be made available whenever a person asks for them. They should be able to freely meet with and talk to people within services.
- When the support is formal and/or intensive, there should be safeguards to make sure that the supporters respect the will and preferences of the person or the best interpretation of the will and preferences of the person, including that the person still wants the support.
- Complaints, monitoring and legal mechanisms should be in place to hold accountable people who abuse their supportive role. Complaints mechanisms should be easily accessible to the persons receiving support.



### ***Exercise 2.2: Scenarios on supported decision-making (45 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 outlined in the module on *Supported decision-making and advance planning*.

Select one or more of the following scenarios below. Ask participants to take copies of *Annex 1 – Scenarios on supported decision-making* and read the selected scenario(s).

### Scenario – Rohini’s story

Rohini is a 27-year-old woman. Her work colleagues became concerned for her as they noticed important changes in her behaviour. The colleagues suggested that they accompany Rohini to a community-based mental health service and Rohini agreed to this.

At the community-based mental health service, Rohini is received by two mental health workers. Rohini becomes increasingly distressed, saying that they want to harm her. She starts shouting that she does not want them to give her an injection. A nurse, one of the mental health workers, reassures her that nothing bad is going to happen, and that they want to help her. She then asks Rohini if she would like to move to a quieter space so that they can talk and identify what type of support would be helpful.

The nurse asks Rohini if she would like to call someone who she trusts, who could help her. Rohini informs her that she would like to see her mother. When her mother arrives, Rohini is still very distressed, shouting that she does not want an injection. Her mother explains 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 explains that Rohini had reacted badly to this medication, experiencing painful muscle contractions and confusion as a result.

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

In addition, after consultation with people of her choice – including her mother, the doctor and nurse – Rohini develops an advance plan so that staff will know never to give her haloperidol, and also so that they will know her preferences for treatment. In the plan she nominates her mother to be contacted in case of an emergency to support her, if desired, in communicating her wishes during crisis situations. The staff ask 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 agrees. After three days she feels much better and is 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 can get emotional and practical support from other members. She has also arranged to meet with her boss and other close colleagues to discuss what has 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 the 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 haloperidol was respected, which helped to build trust with the staff.
- She felt listened to and respected. This had a positive impact on her sense of well-being.
- Staff made an effort to try and understand what was happening to Rohini before making quick judgements, 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 to understand Rohini's view of medication and to 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 of the different options and the side-effects of treatment.
- Her informed consent to treatment was sought.
- An advance plan was developed to ensure that Rohini did not receive treatment (haloperidol) which would cause 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.

Participants may ask about advance planning since it is mentioned in the scenario. Explain that advance planning is covered in detail in the following presentation.

### **Scenario - Zaitin's story**

Zaitin is unhappy with her current living arrangement with her grandmother and wishes to move. She is 33 years of age and has a boyfriend she hopes to marry in the future. Once married, she would like to move in with his family. In the past, Zaitin's grandmother has ignored her opinions and has made decisions for her. Her grandmother does not believe that people with intellectual disabilities, including Zaitin, should marry.

Zaitin feels her grandmother is overprotective. She feels conflicted because she would like to have more independence and to make her own choices about marriage, but she also wants to maintain a positive relationship with her grandmother.

She has a support worker, Rosa, whom she trusts and has chosen to seek her support in making decisions. Zaitin shares with Rosa her unhappiness concerning the disagreement she is having with her grandmother and her desire to marry.

They discuss the possibilities of moving once married. They also discuss options to improve Zaitin's relationship with her grandmother, so Zaitin feels more confident and independent. Rosa and Zaitin discuss if she would like to arrange a meeting with her grandmother to discuss her desire to be married and move. They also discuss a plan to arrange a meeting with her grandmother and her boyfriend's parents.

Zaitin was not sure how soon she would like to schedule these conversations. After the conversation, Zaitin decides to discuss this topic next week with Rosa.



Ask participants the following questions:

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

Possible responses may include:

- Rosa does not tell Zaitin what to do; instead, Rosa listens and is attentive.
- Rosa was able to discuss and offer support to Zaitin.
- Zaitin was given the opportunity to discuss the possibilities of moving.
- Zaitin has the opportunity to take the time she needs to become confident in her decision.

### Scenario - Samir's story

Samir is 68 and was diagnosed with dementia several years ago. When he first arrived at the care home, he did not feel his own choices were respected. He felt that some of the staff made him do things that he did not want to do and they also often rushed him to make quick decisions during the course of his day. After several months, Samir spoke with management to make a complaint. Since then, another member of staff, Fadi, supports Samir in his day-to-day life. When Fadi visits Samir each morning he asks him what he would like to do first to begin the day. He often does not respond immediately, so Fadi gives him time to speak. When it appears Samir is struggling for ideas of what to do, Fadi offers suggestions. Samir then has the opportunity to choose for himself what he would like to do first.

Ask participants the following questions:

- **What were the positive aspects of this case?**
- **How was Samir's right to legal capacity respected by Fadi?**

Possible answers may include:

- Samir is not told what to do each day.
- Fadi, his support worker, listens to Samir in order to get to know him and his preferences.
- Fadi does not press Samir to make decisions.
- When Samir does not make a decision straight away, Fadi allows time to pass before offering his own suggestions.
- Even in small daily decisions, Samir has the opportunity to choose how he begins his day.



### ***Presentation: Advance planning (30 min.)***

Advance planning is another useful form of support which helps to ensure that a person's preferences are considered and respected. Advance planning may be useful to everyone, especially during times when people may be having difficulties in making or communicating decisions.

Advance planning refers to the process of giving directives about future situations when persons may experience difficulties in making their will and preferences known to others, and when they would like support from or actions to be taken by others.

Advance planning can have two functions:

- If a person has difficulty in expressing his or her wishes, the people providing support and care to that person can refer to the advance plan as a communication tool and reference to find out the person's wishes and preference. Supporters can remind the person of what they discussed and what they outlined in the advance plan.
- In addition, in some countries, advance plans can also be used as a legal document in which the person authorizes – or refuses – certain actions to be undertaken in a particular situation in the future.
- At the same time, it is important to be aware that advance plans are not a static, non-changing document. People's views, will and preferences may evolve and people can and do change their minds about things. Supporters should therefore engage and consult with the person on a regular basis to determine if their will and preferences have changed and if they agree with the actions being proposed.

Advance plans are sometimes also known as living wills or advance directives.

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

- An advance plan is a written document that specifies future choices. This can include a description of desired support, designated supporters and/or advocates, recovery options, treatments and place of care or respite (including the option to receive support in one's own home), as well as directives concerning day-to-day life and obligations (children, bills, pets, etc.).
- For health-related decisions, people can generally specify if they would refuse certain support, care or treatment options. Sometimes, they can also specify what supports, treatments and care options they would be prepared to accept.
- If the advance plan is intended as a legal document, it should state in which situation it comes into effect and in which situation it ceases to have effect.

In some communities 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 be more appropriate. However, this does not prevent people from making their wishes known orally to their family, friends, care partners and other relevant people.

In addition, some people may *want* to delegate choice and control to other persons they trust at certain times. Advance planning should allow for this kind of situation, as long as it respects the will and preference of the person.

At this point of the presentation, show participants the following video on advance planning for health care:

Planning ahead – living with younger-onset dementia, Ageing, SA Health, Adelaide, Australia.  
<https://youtu.be/8sVCoxYbLIk> (5:08) (accessed 9 April 2019).  
Acknowledgement: Kate Swaffer, Co-founder, Chair & CEO of Dementia Alliance International ([www.infodai.org](http://www.infodai.org)).

## Advance planning and the law

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

To date, binding advance planning documents in countries have not been fully compliant with the CRPD:

- In some countries advance planning documents can be overridden when a person is involuntarily admitted to a mental health or related service. Therefore, persons who are detained involuntarily can also be given treatment against their will despite the existence of an advance directive to the contrary.
- In addition, the advance plan will often come into effect only after an assessment of the person's mental capacity and subsequent deprivation of the right to legal capacity. In this situation, although the content of the advance plan must be followed, the person is no longer allowed to make their own decisions directly or to change their mind.

Although these types of advance documents can allow people to assert a degree of control regarding proposed support, care or treatment options, they are nevertheless not fully compliant with the CRPD.

### Example: German law (15)

Germany has a law that makes advance directives binding, including in the context of mental health care. In their advance directives, people may nominate a supporter whose role is to assert the person's will to the practitioner. The law also specifies that, if the person does not have an advance directive, their presumed will and preference concerning treatment must be determined on the basis of specific evidence such as previous oral statements.

Following the entry into force of the law, people using mental health services have developed a model of advance directive against any form of coercion in psychiatry, which is called *PatVerfü*.

Even when countries do not have laws or legal provisions relating to advance plans/directives, this does not prevent mental health or social services from implementing such plans. Services can allow and encourage people to make advance plans and, when the situation requires their use, respect the directives stated in a person's plan.

In addition, advance directives do not replace the need and duty to respect a person's autonomy and right to legal capacity at all times. This means respecting people's support, care and treatment choices, including in crisis situations.

Again, these issues are explored in more detail in the training module on *Supported decision-making and advance planning*.



### **Exercise 2.3: Discussion on advance planning (25 min.)**

Ask participants to read one or more of the following scenarios, available in *Annex 1 Discussion on advance planning – scenarios*:

#### **Scenario - Jasmine's story**

Before her discharge from hospital, Jasmine 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 it makes her very anxious. She also specifies in the plan that she finds one-to-one counselling useful when she is depressed.

Two years later Jasmine presents herself to the psychiatric unit of a hospital where she is admitted 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.

While trying to facilitate communication with her, staff members 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 Jasmine to undertake counselling sessions with the service psychologist. To make sure that they respect Jasmine's dignity and legal capacity they regularly ask her how she feels about these actions being put in place.

After reading the scenario above, ask participants the following question:

What do you think the impacts of Jasmine's advance planning might be?

Possible answers may include:

- She is not forced to take a treatment that 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.

#### **Scenario - Hiroto's story**

Hiroto is 52 years of age and has intellectual disabilities. He lives with his mother and father, of his own choice. As Hiroto's main supports, his parents wanted to ensure that his personal wishes continue to be honoured when they die. To prepare for this time, Hiroto's parents support him to write an advance directive. The aim of the directive is to set out his wishes with his physician and social services.

He decides he would like to remain at home living independently for as long as he is comfortable, but he would like the option to live with his brother if he needs to. Hiroto trusts his brother and has a close relationship with him. Hiroto gives permission for his brother to speak to staff in the event he is finding it difficult to communicate. If he is having difficulty communicating, he has requested his brother use a method they have used at home which allows Hiroto to point to images to indicate his choices and preferences in response to a question.

After reading the scenario above, ask participants the following question:

What do you think the impacts of Hiroto's advance planning might be?

Possible answers may include:

- His personal wishes will be respected.
- He will be able to live where he is most comfortable and at a place of his choice.
- In the event that he is not able to communicate with medical staff, he has already determined he would like his brother to communicate his wishes.
- Others will be aware of the communication methods he prefers.

### **Scenario - Bintou's story**

Bintou is a 31-year-old woman who lives in a small village with her older sister who provides her with ongoing support. Bintou received a diagnosis of autism at the age of 10. Two months ago, Bintou fell and broke her ankle. Her sister looked for Bintou when returning home from the market. She was informed by a neighbour that several hours ago Bintou had been taken to the hospital to be treated.

Bintou finds it difficult to communicate verbally. The hospital staff did not know Bintou or how to best communicate with her. When Bintou became distressed and confused, the staff isolated her and tied her to a bed and gave her sedatives to calm her down. She was alone and did not have her sister to help with communication. This was a very stressful and frightening experience for Bintou.

Bintou and her sister have talked about planning ahead if a similar situation should arise one day in the future. Both Bintou and her sister want to make sure that what happened two months ago does not happen again. Together they recorded Bintou's preferences and wishes should she need support to make decisions for herself or during a time when her sister is unavailable. Bintou specifically states she does not want to be tied to a bed again or to be given sedatives. She requests that her sister be her main contact in case of emergencies.

Ask participants the following question:

What do you think the impacts of Bintou's advance planning might be?

Possible answer may include:

- She will not be restrained or given medications she does not want.
- She will be able to communicate her wishes either directly or through her sister.
- Bintou has identified her sister as the person to be contacted in the event of an emergency to help ensure that her will and preferences are respected.

## Topic 3: Informed consent and person-led treatment and recovery plans

### Time for this topic

Approximately 45 minutes.

Explain to participants that this topic focuses specifically on the context of mental health and social services. Explain how informed consent and person-led treatment and recovery plans are essential for respecting people's right to legal capacity.



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

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

Informed consent means that (16):

- 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 alternatives.
  
- The information is given in a way that the person can understand and is adapted to their needs (e.g. the person giving the information avoids using highly technical terms that the person receiving the information may not understand, and adds or incorporates visual aids to written information or uses sign language if the person receiving the information is deaf or hard of hearing). The information must also be given in a way which is culturally and otherwise acceptable to the person.
  
- The consent to treatment is given voluntarily.
  - It is given without threat or coercion (e.g. mental health and other practitioners should not tell the person that they will be involuntarily admitted to a service if they refuse the treatment proposed).
  - Consent is given without undue influence (e.g. practitioners should not make the person concerned think that there may be unpleasant consequences, such as withdrawal of privileges, if they refuse the treatment proposed).
  - Consent is given without deception, fraud, manipulation or false reassurance (e.g. practitioners should not tell anyone that they will be given a sleep therapy when it is planned to give them electro-convulsive therapy).

It is important to be aware of the risk of undue influence due to the power imbalance in relationships that exists within mental health and social services. There is sometimes a fine line between supporting people in making their decision and unduly influencing them.

To minimize the risk of undue influence and to be more independent, the support should ideally come from outside the service ([for more information on power dynamics, see the module on \*Transforming services and promoting human rights\*](#)).

Another critical point is that the right to informed consent also includes the right to refuse treatment. This means that if a person, after being offered information about treatment options, decides they do not want any kind of treatment, this is their right and 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, among 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 to 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.

Blank and completed templates of a recovery plan can be found in the module *Recovery practices for mental health and well being*

When people make decisions about their treatment and support, they are likely to choose options that meet their needs and to which they are prepared to try and see if they can help. Consequently, it is more likely that the support or treatment they have chosen will be more effective than a treatment or support which has been imposed on them (17). This can also avoid traumatization or re-traumatization resulting from coercion.

Initially, the person should be offered as much information as is available about different options and the opportunities to try different options. As the support and/or treatment process evolves, the person will gain more and more knowledge about what works for them and will be able to make even more well-informed choices. They may continue to seek and investigate new options or may find one or more that work well and stick to those. Again, everyone’s recovery journey is unique.

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 a person’s recovery journey.

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

**Peer advocacy in action. iNAPS, 2012 (13:00)**

<https://youtu.be/zDkfPVG-xA4> (accessed 9 April 2019).

This is an 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 4: Avoiding involuntary detention and treatment in mental health and social services

### Time for this topic

Approximately 3 hours and 15 minutes.

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

In many countries, laws and policies authorize people to be involuntarily admitted and treated in mental health and social services. While this is contrary to the CRPD, legislative, administrative and other measures to end these discriminatory laws and policies may take time.

While pursuing full compliance with human rights instruments, there is a lot that can be done to end involuntary detention and treatment and to 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 4 - The experience of involuntary admission and treatment* (18).

#### **The words of a survivor of the mental health system, Australia**

“Nothing could prepare me for the experience of being taken against my will – not by the police or even an ambulance, but by an older sister who felt she knew best. What followed was the most violent of admissions. Totally traumatized 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 hospitalization brings, patients who are said to be capable of harm are 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 hospitalization but also when community orders dictate what medications must be taken after patients are no longer hospitalized. Since failing to comply with such orders leads to further incarcerations, this is nothing more than a form of control. Most patients 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 United Nations Convention”.



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

- **How do you feel about this testimony?**

Some people with lived experience may be in favour of involuntary admission and treatment as they feel that has been beneficial for them personally. While these views should be respected, it is important to be aware that, had there been a choice of noncoercive alternatives within services, involuntary admission or treatment may not have been their preference.

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 social 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 family members. It is therefore important to discuss and encourage a thorough understanding of these issues.

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

Sometimes, people may voluntarily enter mental health and social services because no alternatives are available. They may then be denied the right to leave and thus end up being detained in the service against their will.

In addition, homeless people may be sent to services and institutions against their wishes because it is believed they are better off within a service or because they are seen as a nuisance on the streets.

People detained against their wishes are very often given forced treatment. In addition, people can be required to undergo forced treatment in the community through community treatment orders, court orders or other means.

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

Some laws allow people to be detained and treated on the basis that they are diagnosed – or perceived – as having a particular condition or disability. The law may require other criteria (e.g. that the person is believed to be in need of care and treatment, or that their health may deteriorate if they do not receive treatment, that the person is considered dangerous to themselves or to others).

These laws discriminate against people with psychosocial, intellectual and cognitive disabilities in that they allow for these persons' detention in situations where other persons would not be involuntarily detained. Even other groups at higher risk of violence (e.g. gang members, persons drinking alcohol with a history of domestic violence) cannot be detained on the basis of increased violence risk.

At this point in the presentation, encourage participants to express their views and feelings about involuntary detention and treatment. It is important that people who have not experienced involuntary detention and/or treatment themselves should 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 you were detained and treated against your will?**
- **How did you feel when you were detained and treated against your will?**

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 *Mental health, disability and human rights*, 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.

### **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 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 on all aspects of their lives, including 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 service. Mental health and other practitioners should, above all, engage directly with the person and not only with the person's family or supporters. Practitioners should also try to ensure that the person is not unduly influenced by family, care partners or other supporters when making a decision on care or treatment. Practitioners must also make sure that people receive accommodation for their disability and any independent support that they need in order to make or communicate their decisions on care and treatment.

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

Article 14 guarantees the right to liberty and security. It makes 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. following a criminal sentence).

Therefore people with psychosocial, intellectual or cognitive disabilities should never be detained in mental health and social 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.) (19).

**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 social services often causes people severe pain and suffering and can have extremely negative consequences for their health and well-being. Involuntary admission and treatment are experienced, and considered as, violent and abusive acts which can amount to torture and ill-treatment in violation of articles 15 and 16 of the CRPD (20), (21).

**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 contrary to 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 social services is a direct violation of article 19.

**Article 22: Respect for privacy**

Detention in mental health and social services can violate people's right to privacy.

For example, when people are detained and treated against their will, often mental health and other practitioners are allowed to access personal information without the person's consent.

People may share personal information with their mental health professional and then discover the information has been given to many other people – such as the person's general practitioner, social worker, police, immigration authorities or even family members.

In addition, people often lack privacy because practitioners and others can access their room without their consent, because 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 treatment can be given to people only if they *explicitly* give their informed consent.

**In summary:**

These are some of the key CRPD articles which are violated when involuntary admission and treatment take place. However, other articles are frequently violated as well (e.g. article 6 – women with disabilities are at risk of unfair treatment; article 27 – work and employment opportunities are interrupted; article 29 – participation in political and public life is denied; article 30 – participation in cultural life, recreation, leisure and sport is often limited).

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 or cognitive disabilities continue to be subject to these practices in mental health and social services.

Monitoring and review mechanisms need to be in place to ensure that people are not being detained or treated involuntarily and, if people are found to be under forced detention and treatment, they should be released immediately. The need for independent monitoring in facilities and services for people with disabilities is in fact an explicitly expressed in article 16 of the CRPD.

At the end of the presentation, encourage participants to ask for any clarification they may need.



#### **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 issues with mobility, you can ask the participants to raise their hands if they agree or disagree with the following statement.

***People with psychosocial, intellectual or cognitive disabilities need, in some cases, 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 on the flipchart and, where possible, the participants 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 treat a person involuntarily if the belief is that 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.
- They may not be in a state of mind to know what is best for them and their future.

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

- The right to informed consent to treatment is so fundamental that it should not be taken away from anyone.

- People with psychosocial, cognitive or intellectual disabilities should have the same rights as everyone else.
- People are free to take the same risks and make the same mistakes as everyone else.
- Having a psychosocial, intellectual or cognitive disability does not mean you are automatically a risk to others and therefore need treatment. For example, society often equates people with psychosocial disabilities with dangerousness, violence and crime. In fact, people with psychosocial disabilities, along with people who have intellectual or cognitive disabilities are far more likely to experience violence, abuse and crime than the rest of the population.
- “Dangerousness”, which is often invoked to justify involuntary treatment when the person poses a risk to themselves or others, is very hard to predict and is a very subjective term. Other people are not treated against their will even when their lives are at risk. We should treat people with disabilities in the same way as everyone else.
- Having separate health-care procedures and treatment for people with psychosocial, intellectual or cognitive 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 or in providing high-quality care.
- Other people whose lives depend on treatment (e.g. people with cancer, HIV, Jehovah’s Witnesses requiring blood transfusions to live) are not forced to receive treatment. In a fair society, we must retain the right to make decisions for ourselves and to say “no”.

Now ask participants:

- **After this discussion, has anyone changed their mind?**

This is an opportunity for participants to discuss why they may have changed their mind (or not). Many participants may still have strong feelings one way or the other. The task of the 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, legislative framework) 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. In this case, 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 opinions and responses regarding involuntary treatment.



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

Ask participants to consider the following scenario, available in Annex 1: Scenario on avoiding coercive measures:

## Scenario - George

One night, George was brought to the emergency department of the hospital by the police. George was distressed, agitated and anxious, shouting and making wild gestures. Without a full assessment and without contacting George's supporters in order to try to better understand what may be happening with George, doctors decided that George was unsafe to be in the community and required treatment. George makes it very clear that he did not want to be treated.

The doctor in charge decided that the quickest way to deal with this situation was to get four staff persons to restrain George, tie his arms and legs to a bed in an isolation room, and to give him an injection of an antipsychotic 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 ongoing basis by staff hiding 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:

- No-one took the time to listen to George in order to better understand his distress. Quick assumptions were made as to his state of mind and needs.
- Medication was given to George despite the fact that he stated clearly that he did not want it.
- Medication is given without his knowledge. This means that he is not given appropriate information and that his consent to treatment is not sought. This is likely to have a long-term impact on George's future well-being as well as damage his trust in staff and treatment.
- The way George was treated was damaging to his mental health and well-being. No-one listened to his concerns and they were assumed to be part of a mental health condition.
- George's supporters were not called to try and find a way to understand 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).
- George was put in restraints and secluded in an isolation room to receive forced medication.
- **Which of the CRPD rights were violated in George's scenario?**

These actions by staff violate George's right to:

- legal capacity (CRPD article 12)
- liberty and security of person (CRPD article 14)
- freedom from torture and cruel, inhuman or degrading treatment or punishment (CRPD article 15).
- freedom from exploitation, violence and abuse (CRPD article 16)

- respect for the integrity of the person (article 17)
- health (CRPD, article 25).

Now ask participants:

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

Some potential responses might include:

- People could have taken the time to listen and talk to George, to find out and understand why George did not want to receive treatment, instead of resorting to forced/covert treatment, restraint and isolation.
- Staff could have reassured George that they would respect his will and preferences and not do anything against his will.
- Someone could have called supporters nominated by George, other friends or family members that George agrees to, in order to try and find a way of understanding George's background and perspective and to help him protect his rights.
- Someone could have discussed with George the pros and cons of receiving (or not receiving) treatment.
- Before the situation escalated, George could have been supported to develop an advance directive/plan when he was feeling well. This would have provided a clear statement of 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 a future crisis and that he would not be forcibly treated.
- Before the situation escalated, George could have been encouraged to nominate a trusted person in his advance plan/directive to communicate his wishes in a crisis. This could have also included a person for emergency contacts.
- People could have facilitated George's contact with an advocacy group, such as a peer-run nongovernmental organization that provides legal assistance.
- De-escalation techniques or other alternative responses could have been used (this topic is developed in the module on *Strategies to end seclusion and restraint*).

Follow this discussion by asking:

- **What do you think the outcome would have been if things had been done in a way that respected George's will and preferences?**

Some potential responses might include:

- George's human rights would have been respected.
- 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 started to build a 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 crisis in future.
- George may have felt less isolated and depressed as people would have taken the initiative to ensure he felt more connected and open to working with others to overcome this difficult situation.
- The service would not have resorted to coercive practices against George and would have provided better quality care and support.
- It would have supported George's recovery journey.



#### **Exercise 4.4: A challenging situation (30 min.)**

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

Read with participants the following scenario:

##### **Scenario - Soren**

One morning, a young woman named Soren 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. Soren tells the mental health worker 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. Soren 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 support Soren and avoid the use of involuntary detention and/or treatment?**

Some possible answers from the group may include:

- Someone could ask Soren what she thinks would help her to feel better and if there is a safe place where she would like to be supported.
- Staff should try to understand why she wants to kill herself.
- She should be helped to identify people she trusts and who would be able to stay with her.
- She could be given the opportunity to talk to a trained peer worker if no one she trusts can be identified.
- Someone could try to understand why she does not want treatment, and whether she does not want 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 – e.g. at the home of a trusted relative).
- People could ask Soren if she wants to receive home support or access support services in her community during the day, or if she wishes to 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, Soren 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 Soren's story:



### Scenario - Soren's story – a positive outcome

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

Soren 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 Soren is willing, she will work with her over the next weeks to find a solution to this problem and explore different options and resources for financial assistance and for finding another job. Soren's sister says that she can come and live with her until she feels better.

The nurse also proposes to Soren 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, Soren 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 other services and supports which are available to her in the community.

Following this case study, ask participants:

- **What are your thoughts about the support Soren received in this case?**

It is important to enable participants to share their opinions and potential concerns openly 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 sent home by themselves without any offer of support. People should be provided with options for support which respect their rights, including their right to legal capacity and to liberty and security of person. This may include, for instance, the support of someone they trust who can stay with them or check on them regularly. It may mean 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.

It is also important to note that advance directives may provide a useful framework for ensuring people's choices, will and preferences in situations of high emotional distress. If someone's preference is to be admitted and treated at a certain point in the future and under certain circumstances (including against their wishes) at that specific time, he or she should be able to state so in the form of an advance directive, and this directive should be respected. These types of provisions in advance directives are called "Ulysses clauses" in some jurisdictions. However, this should not detract from ensuring that all efforts are made to offer people noncoercive options.

After this exercise, show participants the following video:

Neil Laybourn and Jonny Benjamin discuss mental health (2:43 min.), <https://youtu.be/GTURfplghls> (accessed 9 April 2019).

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 training (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 today's session.

- Everyone 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 or cognitive disabilities must be recognized, 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, respect for informed consent, 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 social 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.

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# Annexes

## Annex 1: Scenarios

### Topic 1: *Exercise 1.2 – Denial of legal capacity, Soledad*<sup>1</sup>

Soledad is a 40-year-old woman who has lived for 10 years in a social care home.

She lives in a small, clean room, that she shares with a roommate she has not chosen herself. She was brought to the social care home because of mood swings and loss of memory. She suffers from infections and describes her health as bad.

Her days are long and empty and constantly follow the same, boring routine: early rise, some cleaning, food, mandatory rest as if they are toddlers and exercise twice a week (an hour in the yard of the fenced social care home).

There is hardly an opportunity to leave the home. All residents are told that the outside world is extremely dangerous and that they are kept behind closed doors for their own security. Many of the residents have internalized this fear and therefore prefer to stay inside.

There is no possibility for Soledad to escape from the rigid life at the home; no individuality is allowed and there is no possibility to engage in her hobbies of playing the piano and singing.

She is convinced that, should she be given the opportunity, she could have a job, for instance in a sewing studio. The quality of life often lies in small things. She likes reading, but her glasses are broken. Although she often asks the staff for a replacement, so far her requests have been to no avail. The antenna from her small television set is broken but no one is able to repair it.

Soledad longs for more attention and affection from the staff. If residents don't comply with the rules and regulations they are sometimes threatened with the use of straightjackets or being tied to a bed.

### Topic 2: *Exercise 2.2 – Scenarios on Supported Decision-Making, Rohini*

Rohini is a 27-year-old woman. Her work colleagues became concerned for her as they noticed important changes in her behaviour. The colleagues suggested that they accompany Rohini to a community-based mental health service and Rohini agreed to this.

At the community-based mental health service, Rohini is received by two mental health workers. Rohini becomes increasingly distressed, saying that they want to harm her. She starts shouting that she does not want them to give her an injection. A nurse, one of the mental health workers, reassures her that nothing bad is going to happen, and that they want to help her. She then asks Rohini if she would like to move to a quieter space so that they can talk and identify what type of support would be helpful.

The nurse asks Rohini if she would like to call someone who she trusts, who could help her. Rohini informs her that she would like to see her mother. When her mother arrives, Rohini is still very distressed, shouting that she does not want an injection. Her mother explains 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

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<sup>1</sup> Transforming social care homes in Ukraine. Proposals regarding the Slavyansk and Svyatoshinsky social care homes. Hilversum: Human Rights in Mental Health - FGIP; 2018. (<https://www.gip-global.org/files/ss-fin-eng.pdf>, accessed 18 November 2018).

haloperidol (an anti-psychotic medication). Her mother further explains that Rohini had reacted badly to this medication, experiencing painful muscle contractions and confusion as a result.

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

In addition, after consultation with people of her choice – including her mother, the doctor and nurse – Rohini develops an advance plan so that staff will know never to give her haloperidol, and also so that they will know her preferences for treatment. In the plan she nominates her mother to be contacted in case of an emergency to support her, if desired, in communicating her wishes during crisis situations. The staff ask 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 agrees. After three days she feels much better and is 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 can get emotional and practical support from other members. She has also arranged to meet with her boss and other close colleagues to discuss what has happened and what actions can be taken by them to support her in the future, should another crisis arise.

## **Topic 2: Exercise 2.2 – Scenarios on Supported Decision-Making, Zaitin**

Zaitin is unhappy with her current living arrangement with her grandmother and wishes to move. She is 33 years of age and has a boyfriend she hopes to marry in the future. Once married, she would like to move in with his family. In the past, Zaitin's grandmother has ignored her opinions and has made decisions for her. Her grandmother does not believe that people with intellectual disabilities, including Zaitin, should marry.

Zaitin feels her grandmother is overprotective. She feels conflicted because she would like to have more independence and to make her own choices about marriage, but she also wants to maintain a positive relationship with her grandmother.

She has a support worker, Rosa, whom she trusts and has chosen to seek her support in making decisions. Zaitin shares with Rosa her unhappiness concerning the disagreement she is having with her grandmother and her desire to marry.

They discuss the possibilities of moving once married. They also discuss options to improve Zaitin's relationship with her grandmother, so Zaitin feels more confident and independent. Rosa and Zaitin discuss if she would like to arrange a meeting with her grandmother to discuss her desire to be married and move. They also discuss a plan to arrange a meeting with her grandmother and her boyfriend's parents.

Zaitin was not sure how soon she would like to schedule these conversations. After the conversation, Zaitin decides to discuss this topic next week with Rosa.

## **Topic 2: Exercise 2.2 – Scenarios on Supported Decision-Making, Samir**

Samir is 68 and was diagnosed with dementia several years ago. When he first arrived at the care home, he did not feel his own choices were respected. He felt that some of the staff made him do

things that he did not want to do and they also often rushed him to make quick decisions during the course of his day. After several months, Samir spoke with management to make a complaint. Since then, another member of staff, Fadi, supports Samir in his day-to-day life. When Fadi visits Samir each morning he asks him what he would like to do first to begin the day. He often does not respond immediately, so Fadi gives him time to speak. When it appears Samir is struggling for ideas of what to do, Fadi offers suggestions. Samir then has the opportunity to choose for himself what he would like to do first.

### **Topic 2: Exercise 2.3 - Discussion on advance planning, Jasmine**

Before her discharge from hospital, Jasmine 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 it makes her very anxious. She also specifies in the plan that she finds one-to-one counselling useful when she is depressed.

Two years later Jasmine presents herself to the psychiatric unit of a hospital where she is admitted 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.

While trying to facilitate communication with her, staff members 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 Jasmine to undertake counselling sessions with the service psychologist. To make sure that they respect Jasmine's dignity and legal capacity they regularly ask her how she feels about these actions being put in place.

### **Topic 2: Exercise 2.3 - Discussion on advance planning, Hiroto**

Hiroto is 52 years of age and has intellectual disabilities. He lives with his mother and father, of his own choice. As Hiroto's main supports, his parents wanted to ensure that his personal wishes continue to be honoured when they die. To prepare for this time, Hiroto's parents support him to write an advance directive. The aim of the directive is to set out his wishes with his physician and social services.

He decides he would like to remain at home living independently for as long as he is comfortable, but he would like the option to live with his brother if he needs to. Hiroto trusts his brother and has a close relationship with him. Hiroto gives permission for his brother to speak to staff in the event he is finding it difficult to communicate. If he is having difficulty communicating, he has requested his brother use a method they have used at home which allows Hiroto to point to images to indicate his choices and preferences in response to a question.

### **Topic 2: Exercise 2.3 - Discussion on advance planning, Bintou**

Bintou is a 31-year-old woman who lives in a small village with her older sister who provides her with ongoing support. Bintou received a diagnosis of autism at the age of 10. Two months ago, Bintou fell and broke her ankle. Her sister looked for Bintou when returning home from the market. She was informed by a neighbour that several hours ago Bintou had been taken to the hospital to be treated.

Bintou finds it difficult to communicate verbally. The hospital staff did not know Bintou or how to best communicate with her. When Bintou became distressed and confused, the staff isolated her and tied her to a bed and gave her sedatives to calm her down. She was alone and did not have her sister to help with communication. This was a very stressful and frightening experience for Bintou.

Bintou and her sister have talked about planning ahead if a similar situation should arise one day in the future. Both Bintou and her sister want to make sure that what happened two months ago does not happen again. Together they recorded Bintou's preferences and wishes should she need support to make decisions for herself or during a time when her sister is unavailable. Bintou specifically states she does not want to be tied to a bed again or to be given sedatives. She requests that her sister be her main contact in case of emergencies.

#### **Topic 4: Exercise 4.3 – Scenario on avoiding coercive measures - George**

One night, George was brought to the emergency department of the hospital by the police. George was distressed, agitated and anxious, shouting and making wild gestures. Without a full assessment and without contacting George's supporters in order to try to better understand what may be happening with George, doctors decided that George was unsafe to be in the community and required treatment. George makes it very clear that he did not want to be treated.

The doctor in charge decided that the quickest way to deal with this situation was to get four staff persons to restrain George, tie his arms and legs to a bed in an isolation room, and to give him an injection of an antipsychotic 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 ongoing basis by staff hiding medication in his food. He is becoming increasingly depressed and isolated, refuses to talk to anybody and shows no sign of improvement.

#### **Topic 4: Exercise 4.4 – A challenging situation, Soren (1)**

One morning, a young woman named Soren 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. Soren tells the mental health worker 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. Soren does not have an advance plan or directive.

#### **Topic 4: Exercise 4.4 – A challenging situation, Soren (2)**

##### **A positive outcome**

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

Soren 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 Soren is willing, she will work with her over the next weeks to find a solution to this problem and explore different options and resources for financial assistance and for finding another job. Soren's sister says that she can come and live with her until she feels better.

The nurse also proposes to Soren 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, Soren 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 other services and supports which are available to her in the community.



## Annex 2: The Convention on the Rights of Persons with Disabilities

(Original version [with associated simplified version](#)) <sup>2,3</sup>

**Different language versions (including sign language) are accessible at the following link:**

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> (accessed 5 March 2018).

### 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;

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<sup>2</sup> Convention on the Rights of Persons with Disabilities (CRPD). United Nations (UN) General Assembly Resolution A/RES/61/106, 24 January 2007. New York (NY): United Nations; 2007. (<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>, accessed 20 November 2018).

<sup>3</sup> United Nations (UN) Enable. International agreement on the rights of disabled people (easy-read version) [online publication]. New York (NY): United Nations; 2012. (<https://resourcecentre.savethechildren.net/sites/default/files/documents/6761.pdf>, accessed 2 February 2017).

**"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, organizations 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 realize 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 adults 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 organizations) 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 buildings, 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 equal 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. They should make sure that support for preventing abuse takes into account women, older persons, children and persons with different kinds of disabilities.
  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 keep 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. Encouraging 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.
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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 others 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 is 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 a 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:

1. 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:
  - a. Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;

- b. 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;
  - c. 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;
2. 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:
- a. 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;
  - b. 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:

1. 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:

- a. Making sure voting is easy and understandable to people with disabilities.
  - b. Making sure voting is secret and free. They must also make sure that people with disabilities can stand for election and become public officials.
  - c. Allowing people with disabilities to choose someone to help them with voting if they want to.
2. Encourage the participation of people with disabilities in public affairs. This means that:
- a. People with disabilities have the right to join nongovernmental organizations and associations.
  - b. 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 3: Checklist for implementing supported decision-making<sup>4</sup>

### Supported decision-making checklist

#### Do you?

- Provide relevant information:
  - Does the person have all the relevant information he or she needs to make a particular decision?
  - Does the person have all the information they are asking for?
  - Have they been given information on all available options?
- Communicate in an appropriate way:
  - Explain or present the information in a way that is easier for the person to understand (e.g. by using simple, clear and concise language or visual aids).
  - Explore different methods of communication if required, including nonverbal communication.
  - Ascertain if anyone else can help with communication (e.g. a family member, support worker, interpreter, speech and language therapist or advocate) and that the person accepts this help
- 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.

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<sup>4</sup> Department of Constitutional Affairs. Mental Capacity Act, 2005, Code of Practice. London: The Stationery Office on behalf of the Department for Constitutional Affairs; 2005. ([https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/497253/Mental-capacity-act-code-of-practice.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf), accessed 9 February 2017).

## Annex 4: The experience of involuntary admission and treatment<sup>5</sup>

### The words of a survivor of the mental health system, Australia

“Nothing could prepare me for the experience of being taken against my will – not by the police or even an ambulance, but by an older sister who felt she knew best. What followed was the most violent of admissions. Totally traumatized 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 hospitalization brings, patients who are said to be capable of harm are 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 hospitalization but also when community orders dictate what medications must be taken after patients are no longer hospitalized. Since failing to comply with such orders leads to further incarcerations, this is nothing more than a form of control. Most patients 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 United Nations Convention”.

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<sup>5</sup> Mental health: a closed door policy. Isle of Capri (QLD): Independent Australia; 3 December 2015. (<https://independentaustralia.net/life/life-display/mental-health-a-closed-door-policy,8443>, accessed 9 February 2017).



The World Health Organization's QualityRights training and guidance modules focus on the knowledge and skills required to provide good quality mental health and social services and supports and to promote the rights of people with psychosocial, intellectual or cognitive disabilities.

Through exercises, presentations, case scenarios, extensive discussions and debates, the **QualityRights training modules** unpack some critical challenges that stakeholders are facing in countries everywhere. For instance:

- How do we respect people's will and preference, even in challenging situations?
- How do we ensure people's safety and at the same time respect each person's right to decide about their treatment, their life and their destiny?
- How do we end seclusion and restraint?
- How does a supported decision-making approach work if someone is unable to communicate their wishes?

The **QualityRights guidance modules** complement the training materials. The guidance modules on *Civil Society Organizations* and on *Advocacy* provide step-by-step guidance on how civil society movements in countries can take action to advocate for human rights-based approaches in the mental health and social sectors in order to achieve impactful and durable change. The guidance modules on *One-to-one peer support* and on *Peer support groups* provide concrete guidance on how to effectively set up and run these critical but often overlooked services.

The ultimate goal of the WHO QualityRights modules is to change mindsets and practices in a sustainable way and empower all stakeholders to promote rights and recovery in order to improve the lives of people with psychosocial, intellectual or cognitive disabilities everywhere.