



Supported decision-making and advance planning

WHO QualityRights specialized training

QualityRights   World Health Organization

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

Supported decision-making and advance planning. WHO QualityRights Specialized training. Course guide

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The accompanying course slides are available here: <https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools>

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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/

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

As a result of the training, participants will:

- be able to appreciate how negative assumptions about people with psychosocial, intellectual or cognitive disabilities impact on their right to make decisions;
- understand the importance of supporting people in exercising their fundamental human rights to make their own choices and have control over their lives;
- understand the difference between substitute decision-making and supported decision-making;
- gain an understanding of the human rights principles underlying the concept of supported decision-making;
- be able to take personal actions to adopt a supported decision-making approach;
- be able to use advance planning as a tool to ensure that people's will and preferences are respected.

Topics

Topic 1: Challenging denial of legal capacity in mental health (4 hours and 50 minutes)

Topic 2: Substitute versus supported decision-making (4 hours and 45 minutes if the short option was chosen, 5 hours and 50 minutes if the long option was chosen)

Topic 3: Supported decision-making in practice (1 hour and 10 minutes)

Topic 4: Nominating a person to communicate best interpretation of will and preferences (20 minutes)

Topic 5: Positive steps to adopt a supported decision-making approach (45 minutes)

Topic 6: What is advance planning? (1 hour and 20 minutes)

Topic 7: Making advance planning documents (2 hours and 10 minutes)

Resources required

- **Accompanying course slides, Supported decision-making and advance planning. WHO QualityRights Specialized training (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 to print for this training module include:

- **copies of Annex 1 – Scenarios**
- **copies of Annex 2 - Confession of a non-compliant patient for all participants**
- **copies of Annex 3 – Article 12 of CRPD with associated simplified version for all participants**
- **copies of Annex 4– General comment No 1 (2014) for all participants**
- **copies of Annex 5 – How are decisions made? for all participants**
- **copies of Annex 6 – Decision-making as means for empowerment for all participants**
- **copies of Annex 7– Supported decision-making checklist for all participants**
- **copies of Annex 8 – Extract of a recovery plan template for all participants**
- **copies of Annex 9 – Real-life example of advance planning statements for all participants.**

Time

Approximately 15 hours and 30 minutes if the short option is chosen.
 Approximately 16 hours and 35 minutes if the long option is chosen.

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.

Introduction

Many persons with psychosocial, intellectual or cognitive disabilities continue to be denied the right to make decisions and choices for themselves – about their day to day life, their treatment, personal relationships, living arrangements, financial matters and so on - due to societal prejudices as well as guardianship, wardship or other substitute decision-making regimes that exist within all countries. This not only violates their rights but also disempowers and further marginalizes them from their communities.

The Convention on the Rights of Persons with Disabilities, or CRPD, makes clear that persons with disabilities have the right to equal recognition everywhere as persons before the law and that they have the right to “enjoy legal capacity on an equal basis with others in all aspects of life”. It adds that all States Parties must take measures “to provide access by persons with disabilities to the support they may require in exercising their legal capacity”. The CRPD aims to move the world on from viewing persons with disabilities as objects of charity, medical treatment and social protection towards viewing them as citizens with rights who are capable of claiming those rights and making decisions for their lives.

This training module aims to challenge existing misconceptions that underpin the denial of the right to exercise legal capacity for people with psychosocial, intellectual or cognitive disabilities. Through the training participants will gain an in depth understanding of what a supported decision-making looks like in practice, and how advance planning can help to ensure that people are able to exercise will and preference on an equal basis with others, in all aspects of their lives. Finally, the module shows how everyone can be an agent for change in order to enable persons with psychosocial, intellectual or cognitive disabilities to fully enjoy their rights.

Topic 1: Challenging the denial of legal capacity in mental health

Time for this topic

Approximately 4 hours and 50 minutes.



Presentation: Brief introduction to this module (5 min.)

The purpose of this brief introduction is to pre-empt the obstacles that participants grapple with in relation to promoting legal capacity and supported decision-making in challenging scenarios.

In this training we shall explore how to promote a person's right to legal capacity (i.e. the right to make one's own decisions and choices). It is important to acknowledge that upholding people's right to legal capacity can seem challenging in certain situations.

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 seem dangerous? What if refusing treatment means the person is going to get worse? What if someone is unconscious or otherwise unable to communicate and be understood? Is it really feasible to promote the rights of people to make decisions for themselves even in these types of scenarios?

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

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



Exercise 1.1: Confessions of a non-compliant patient (45 min)

Distribute to participants copies of Annex 2 (Confessions of a non-compliant patient by Judi Chamberlin). Explain to participants that Judi Chamberlin (1944–2010) was a survivor of psychiatry and a political activist. She is the author of *On our own: patient-controlled alternatives to the mental health system*.

Give the group approximately 15 minutes to read the text.

Once participants have finished reading, give them the opportunity to share their thoughts on the document. To prompt the discussion, ask:

How did the author feel when her thoughts and opinion were disregarded? How did she feel about not having control over her life?

Based on what you have read, do you think making decisions is important in recovery?

Then ask the group:

Do you think people with psychosocial, intellectual or cognitive disabilities should make decisions for themselves (e.g. decisions concerning treatment, housing, financial matters, daily activities)?

Why do you think people with psychosocial, intellectual or cognitive disabilities, as well as other people using mental health and social services, are often deprived of the possibility to make decisions?

In answering these questions, participants are likely to bring up a number of common misconceptions and negative stereotypes. The facilitator needs to be aware of these and should address them throughout the training. These misconceptions and negative stereotypes may not only be held by mental health and other practitioners but also sometimes by people with psychosocial, intellectual or cognitive disabilities themselves because they may have internalized the discrimination that they have experienced and therefore see themselves as incapable of fully exercising the right to legal capacity. The purpose of this part of the exercise is to challenge these misconceptions and stereotypes.

Make a list of the misconceptions and negative stereotypes raised by participants on the flipchart.

Possible misconceptions and negative stereotypes raised by participants may include:

People with psychosocial, intellectual or cognitive disabilities lack the ability to decide for themselves.

They cannot make good decisions because their condition gets in the way of logical thinking.

They are unpredictable.

They are dangerous to themselves and others.

They would always refuse treatment if they had a choice, and that would be bad for them.

They should not have the right to make decisions about financial matters.

They do not have the ability to start a family and care for their children.

They are unaware of or lack insight regarding their condition, and therefore they cannot make decisions for themselves.

If someone is delusional and wants to do something irrational such as, for example, giving all their money to the poor, clearly they cannot make decisions about their finances.

They need to be protected from people in the community who might hurt them or take advantage of them.

Mental health and other practitioners know best what is good for them.

Some people have confused ideas about reality, which will lead to bad decisions.

They suffer from “mental illnesses” that impair their judgement

Some people hear voices that can influence their actions with harmful consequences.

It is important to give time to people who disagree with these misconceptions and negative stereotypes in order to allow the facilitator and others to challenge such beliefs.



Presentation: Understanding the right to legal capacity (10 min.)

This presentation will briefly explain the difference between legal capacity and mental capacity and how misconceptions around mental capacity (i.e. ability to make decisions) have led to people being deprived of their right to legal capacity.

Legal capacity and mental capacity are two separate concepts but are often mistakenly seen as the same. The CRPD has helped to clarify and elaborate the differences (2):

- **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.

Both the misconceptions and lack of understanding about the term “mental capacity” have led to the frequent denial of the right to legal capacity for people with disabilities. Because of this confusion the terms “decision-making skills” or “ability to make decisions” will often be used in this module instead of mental capacity.

Status approach

The status approach is taken when people with psychosocial, intellectual or cognitive disabilities are automatically assumed to lack mental capacity (i.e. the ability to make decisions) by virtue of having a disability or diagnosis.

With this approach, “mental capacity” is often considered to be a stable and permanent status that people either have or do not have. These are misconceptions and negative stereotypes which are important to challenge.

Outcome approach

Often when a person with a psychosocial, intellectual or cognitive disability makes a decision that others do not agree with, it is assumed that the person is not capable of making the decision “due to their condition” and hence they are denied the right to make future decisions. This is called the “outcome approach”. This type of approach is often used by practitioners in mental health and social services and by family members, sometimes consciously and at other times unconsciously.

However, everyone at times makes decisions and choices in life that others do not agree with and this should not be a reason for denying people the right to make decisions.

Functional tests

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

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

“Functional tests” or “capacity tests” are generally carried out by mental health and other practitioners or capacity assessors.

However, the concepts of “mental capacity” and “functional capacity tests” are flawed because the way we make decisions cannot be measured scientifically. Sometimes we make decisions on the basis of very rational reasons and sometimes they are based on our emotions and feelings. There is no

universal process of decision-making and no right or wrong way to make decisions. All persons have their own process of thinking and it is not possible to fully know, understand or assess what is going on in another person's mind.

In any case, everyone has a right to make decisions at all times, including in crisis situations or extreme states, regardless of their ability to make or to communicate decisions.



Presentation: Challenging misconceptions and negative stereotypes in mental health (40 min.)

The purpose of this presentation is to challenge misconceptions and negative stereotypes based on concrete examples.

Ask participants to remember the misconceptions and negative stereotypes raised during Exercise 1.1.

Briefly compare them with the misconceptions and negative stereotypes that will be challenged during this presentation:

There are many misconceptions and negative stereotypes that are important to challenge in order to better understand how legal capacity can be realised for people with psychosocial, intellectual or cognitive disabilities.

Misconceptions and negative stereotypes often include:

- People with psychosocial, intellectual or cognitive disabilities make bad decisions.
- They sometimes have wrong ideas about reality, which lead to bad decisions.
- They should not decide about their treatment.
- They do not know what is best for them.
- Families and care partners know best what is good for them.
- Mental health and other practitioners know best what is good for them.
- They lack the ability to make decisions.
- They like to be told what to do and they are afraid to make decisions for themselves.

Challenging the misconceptions and negative stereotypes

After each concrete example below, invite the participants to share their opinions.

It is important that participants have the time and space to discuss and express any thoughts or concerns on this topic.

1. Misconception: People with psychosocial, intellectual or cognitive disabilities make bad decisions

- Different people can have very different views on what is a good decision. Just because you think that someone is making a bad decision does not mean that the person should be prevented from making it. This is true for all people.
- The opposite assumption – that people without psychosocial, intellectual or cognitive disabilities only make good decisions – is also not true.
- Even when people make a decision that has negative consequences it is still their right to do so.

Scenario - Elena

Elena has been diagnosed with an intellectual impairment. She used to find it difficult to manage her budget because she often forgot how much money she had already spent. Consequently, she always lacked money and did not have a sufficient budget for food. One of her friends informed her about an application she could download to her telephone to keep track of her expenditures. Elena's parents thought that the application was not going to work and that she needed a guardian to control her money. However, Elena searched for the app, and then decided to use it. Now, whenever she is not sure, she consults her telephone to see how much money she has left in her bank account and what she has already bought. She is even able to save some money every month.

In this example, Elena was able to find a solution to her problem with the support of her friend despite the disagreement of her parents. This example also shows how people's ability to make decisions can be maximized through a variety of supports, methods and tools.

2. Misconception: People with psychosocial, intellectual or cognitive disabilities sometimes have wrong ideas about reality.

- Just because a person has unique, unusual or different beliefs about life and reality, or for instance hears voices, this does not mean that they should be prevented from making decisions. Even in these situations, many people still know what is going on in their everyday lives.
- Different people in the general population have what may be considered by others very unusual beliefs, but this does not mean that they lack the ability to make decisions.
- Even if a person makes what is considered by others to be a bad decision, it is their life and their choice. As in the case of people without disabilities, it is normal for family and friends to feel and express concern about how a loved one's life is going. But they need to respect their loved one's independence and their responsibility for their own decisions and actions.

Scenario – Feng

Feng is a man who has heard voices since he was an adolescent. Most of the time, these voices describe his actions. However, when Feng is particularly stressed the voices can become threatening and order him to act in certain ways (e.g. saying that other people want to attack him and that he should attack them first to protect himself). Feng's family thought that because of this he could not have a normal life and that he would need a guardian. However, after years of experiencing voices, Feng has managed to live with them. He knows that sometimes they are communicating something very important about his emotions (e.g. that he is stressed, worried or tired) and whenever they suggest he must take action, he talks about this with key people in his life before making any decisions or taking action that causes him distress or which he believes is potentially harmful. He currently leads a full life and this year he has graduated from his university.

In this case we can see that Feng's ability to make decisions is not affected by the fact that he is hearing voices. Whenever a stressful situation occurs and he recognizes that he needs help to make decisions, he openly discusses his situation and thoughts with trusted people who support him.

At this point show the following video from Eleanor Longden: **The voices in my head**, Eleanor Longden, TED Talks <https://www.youtube.com/watch?v=syjEN3peCJw> (14:17) (date accessed 9 April 2019) Eleanor, who hears voices, talks about her experience and the things she has achieved in her life.

3. **Misconception: People with psychosocial, intellectual or cognitive disabilities should not decide about their treatment**

- When people refuse a specific type of treatment or prefer different care or support options, they generally have very good reasons for making this decision. It should be acknowledged that people with psychosocial, intellectual or cognitive disabilities are, like other people, experts about their own bodies, minds and lives.
- What is acceptable, preferred and effective differs from person to person and the decisions of people with psychosocial, intellectual or cognitive disabilities are as valid as the decisions of others.

Scenario – Amara

Amara has received a diagnosis of bipolar disorder and has been taking medication for several months. After reflecting for a long time, she decides to stop taking her medication. Everyone around her thinks it is a terrible idea because the previous times she stopped taking her medication she was admitted to hospital. However, Amara has stability in her life now and is confident that she can manage her life without this type of treatment. Her doctor advises her against stopping the medication and explains to her what the risks of doing so are. However, the doctor also provides Amara with resources concerning withdrawing from the medication. After listening to the doctor, Amara still maintains her decision, and the doctor respects this. They decide together that if Amara experiences difficulties with the withdrawal, she can contact the doctor to discuss the situation further. The doctor promises Amara that she will not treat her against her will or pressure her to take medication at any time. Both Amara and her doctor will investigate approaches that do not involve medication and where they are available in the local area (such as crisis respite), so that Amara has meaningful options from which to choose if she experiences difficulty with the withdrawal or at any other time.

In this example the doctor respects Amara's right to make decisions about her treatment. The decision may turn out to be good or not, but what is important is that Amara's will and preferences are respected which empowers Amara to have control over her life. It is important to note that her doctor continues to support Amara irrespective of disagreeing with her decision.

4. **Misconception: People with psychosocial, intellectual or cognitive disabilities do not know what is best for them**

- We all have knowledge of what we like, what we do not like and what does and does not work well for us, and this is also true for people with psychosocial, intellectual or cognitive disabilities. For instance, a person may know for certain that a particular medication makes them feel terrible.
- In addition, everyone has a right to make mistakes. People with psychosocial, intellectual or cognitive disabilities, as well as everyone else, need to learn through experience what works well or does not work for them.

Scenario – Lucas

Anna, Lucas' sister, goes with Lucas to a community-based mental health centre because he is experiencing a period of deep sadness that has left him unable to get out of bed and go to work most days. He has been experiencing such phases for quite a while now and has tried several treatments. He knows from past experience that most antidepressants make him feel irritated and lead to insomnia. He has had good results with interpersonal group therapy before, so he says he would be willing to receive this type of support and explains his reasons to the workers at the community-based mental health centre.

Here we can see that, although Lucas faces a really difficult period in his life, he is fully aware of the consequences that different treatments and support options have on him. He knows better than anybody else, including the staff of the service, what works best for him. His personal experience and expertise should be valued and respected and the requested support should be facilitated. He should not be forced or pressured to take medication.

5. Misconception: Families and care partners know best what is good for people with psychosocial, intellectual or cognitive disabilities

- Although families and care partners can provide invaluable support, they may sometimes act in what they think is the best interest of the person concerned and exclude the person from the decisions they make.
- This may be because they do not see the person as someone capable of making choices or because they want to protect them.

Scenario – Anna

Anna hears voices and sometimes responds to them out loud. She enjoys technology very much and would like to take formal studies in engineering. Her parents disagree and tell her that the classes are too expensive. The real reason is that they are afraid that people will make fun of Anna and that she will become isolated during her studies, especially as there are so few women in this field.

Here is an example of parents trying to protect their daughter from potential harm because they think Anna will not be accepted by others.

The engineering course may be very beneficial for Anna as it is likely to teach her new skills and allow her to meet different people, as well as increasing opportunities for employment in an area that she values.

Often when a family overprotects their relative, the family prevents them from gaining skills that may benefit and empower the person and make them more assertive and less vulnerable to abuse.

6. Misconception: Mental health and other practitioners know best what is good for people with psychosocial, intellectual or cognitive disabilities

- Practitioners can also provide very important support to people. However, they may often make decisions for people because they think they “know best”.
- People with psychosocial, intellectual or cognitive disabilities, like other people, have the right to make decisions about their own body and are able to do so, even during difficult circumstances.

Scenario - Eunice

Eunice is a woman diagnosed with major depression. During her pregnancy, for a time she experienced the inability to get up and go to work. She would also cry for most of the day. She therefore decided to go to a mental health service with her partner. During the consultation, the doctor ignored her and spoke directly to her partner, telling him that he would recommend an abortion since Eunice would be likely to become worse with the added pressure of looking after a child.

However, even though she was feeling unwell, Eunice did not allow the doctors to perform the abortion.

Now, Eunice and her partner have a 5-year-old lively daughter and are happy. The fact that Eunice was able to decide for herself about her own body, even when experiencing a crisis, was fundamental in her recovery.

In this example, Eunice is able to make an important decision even during a crisis. Undoubtedly, Eunice's life would have been negatively affected if others had made the decision for her.

Despite these damaging consequences, many women with disabilities are subjected to forced abortion with no respect for their decisions and choices.

The facilitator should emphasize that professionals have a technical knowledge which is undeniable. However, this knowledge needs to be used in a way that supports the rights, will and preferences of people using services. Sometimes professional knowledge and practices are based on stereotypes and may reinforce discrimination. It is therefore necessary that mental health and other practitioners take into account the experiential knowledge of people with psychosocial, intellectual or cognitive disabilities.

7. Misconception: People with psychosocial, intellectual or cognitive disabilities lack the ability to make decisions

- The ability to make decisions about all areas of one's life is not something that a person either has or does not have. In fact, everyone's ability to make decisions varies at different times in life, throughout our lives, and depends on the decision to be made as well as the context.
- There may be times when people find it easy to make decisions, and other times when they find it challenging.
- Similarly, the fact that people may need support to make decisions at some moments during their lives, or about some issues, does not mean that they are not able to make decisions in general.

Scenario – Tareq

Tareq is a young man with an intellectual disability. Three days a week he works in a grocery store. This means that for the remaining days of the week he does not have any structure for his day which makes him feel frustrated and insecure. Fortunately, Tareq was able to get the support of a personal assistant who can help him to structure his free days on weekly basis. Most days Tareq has several ideas about what he would like to do and makes plans himself – such as visiting a neighbour, making lunch, and riding his bicycle to the city centre to meet a friend. On other days he has more difficulty deciding what he wants to do and on these days his personal assistant is really helpful in proposing options for things Tareq can do during the day. Sometimes, Tareq will call his personal assistant several times during the day to ask questions when things do not go to plan. The assistant listens to him and suggests options when he asks.

8. Misconception: People with psychosocial, intellectual or cognitive disabilities need to be told what to do and they are afraid to make decisions for themselves.

- Because of negative perceptions and discriminatory reactions from people around them, some people have lost confidence in their decision-making skills and defer to others who take responsibility to make decisions for them.
- Instead of being denied the opportunity to make decisions, people should be supported to regain confidence in their decision-making skills.

Scenario – Gavin and Michael

Gavin and his partner Michael are working together to make decisions related to finances and avoid the kind of problems they experienced earlier when Gavin would make impulse purchases. One thing Michael learned quickly was to ask Gavin what he wanted to purchase and why, rather than telling him what he should or should not do. When Michael was able to engage with him in this way, they would have more productive conversations about what he wanted to spend money on and why, and Michael could understand the emotional needs he was trying to fill with purchases at certain times in his life. These conversations also allowed Gavin to understand and consider other possible ways for his needs to be met.

The right to legal capacity in the CRPD

If necessary, recap the following:

The UN Convention on the Rights of Persons with Disabilities (CRPD) is an international treaty adopted by countries to ensure that **people with disabilities all around the world enjoy their rights on an equal basis with other persons in all aspects of life**. The CRPD was drafted in 2006 with the substantial involvement of people with disabilities, including people with psychosocial, intellectual or cognitive disabilities.

The Convention aims to protect the human rights of people with disabilities, fight discrimination, stigma and stereotypes and promote inclusion and participation. It recognizes that people with disabilities must be able to achieve their potential on an equal basis with others.

Provide the group with copies of article 12 of the CRPD and of the General Comment on this article (Annex 3 and Annex 4).

Read with the participants the content of article 12 and remind them that there is simplified text beneath each paragraph of the article in the hand-out.

According to article 12 of the CRPD, the right to legal capacity can never be taken away from people. Everybody has the right to legal capacity irrespective of their decision-making skills. A psychosocial, intellectual or cognitive disability can never justify denying people the right to legal capacity.

- The right to legal capacity is guaranteed to all people, no matter what their support needs are. Therefore people who have significant support needs (e.g. those who do not communicate in traditional ways, or who may be perceived by others as not able to communicate at all, those who are extremely isolated, those who have no existing support network or those who are at risk of abuse and exploitation) are protected by the provisions of article 12 (3).

Let participants know that they will have the opportunities to explore these situations later on in the module.



Presentation: - Formal and informal decision-making (10 mins)

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

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

In the case of informal decision-making, many of the day-to-day decisions that people with psychosocial, intellectual or cognitive disabilities may face in all aspects of their lives are also often made by others – particularly by families or care partners. Examples of these decisions include how to spend money, living arrangements, personal relationships, choosing which clothes to wear, choice of food and daily routines. This is particularly the case when people are admitted to mental health and social services.

Women with disabilities may face multiple discriminations and be more at risk of being subjected to denial of the right to legal capacity. For instance, in some countries they may be prevented from making decisions about their sexual and reproductive rights, which results in further human rights violations (4),(5).



Exercise 1.2: Examples of denial of the right to legal capacity (20 min.)

Read with participants the two scenarios below:

Scenario - João

João was diagnosed with schizoaffective disorder and was told that he has anosognosia which, the staff of the service explained, means “lack of insight” or “lack of awareness”. He is told the reason he thinks he does not need medication is because he does not know how truly ill he is and the belief that he does not need medication is just a symptom of the illness. He is told that if he refuses to take the medication they will need to re-evaluate his ability to make other important decisions in life, like returning to work.

Scenario – Rania

Rania has an intellectual disability. She works at the local library four days a week. Thanks to this job, she is able to save some money. She would like to go on holiday to visit her cousin in the south and use this money to buy a train ticket. However, her father is her legal guardian, and he thinks that it is unsafe for Rania to travel, so he does not allow her to go out to buy a train ticket.

For each example, ask participants:

What are the reasons why the person is denied the right to make decisions in this example?
Do you think that these reasons are valid? Why?

Give participants the opportunity to discuss the examples above.



Presentation: Settings where the right to legal capacity is denied (10 min.)

The denial of the right to legal capacity happens:

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

At home, people are in some cases denied the right to make decisions about their own lives and daily activities. Family members may make all these decisions for them. This is sometimes a consequence of their desire to (over)protect their relatives from potential harm and from communities which are not yet inclusive. Often, families 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 is systematically violated.

- This is particularly true when people are involuntarily detained and treated because staff have (legal) authority to make decisions for them.
- Involuntary admission to mental health services denies people the right to exercise free and informed consent to health care and therefore denies them the right to legal capacity.
- Legal capacity is also denied to people who are not involuntarily admitted and treated because even in these cases staff assume that people who are using the service cannot make decisions for themselves and that mental health and other practitioners are in a better position to decide.
- The simple threat of involuntary admission and treatment may result in the acceptance of unwanted treatment by some people.
- Staff often also make decisions for people using the service because they think it is quicker, more convenient and less time-consuming.

The result is that decision-making power (e.g. about their treatment, about what medicines they wish to take or not take, about whether or how long they feel they need to stay in the service etc.) is taken away from people without talking or listening to them.

The more the service is institutional in its nature, the more it deprives people of their right to make decisions. Thus mental health services may foster dependency and increase isolation and risk of exploitation.

In addition, people in their community may face denial of their right to legal capacity on a day-to-day basis (e.g. bank staff may refuse them access to their money without a guardian/family member present, social services may refuse to provide them with the paperwork they need to access support).



Exercise 1.3: Everyday examples of decision-making (25 min.)

Provide the participants with copies of the table below (Annex 5). Please note that the examples in italics below are just some ideas; the participants should try and come up with their own examples. You can also draw the table on the flipchart.

Invite the participants to provide concrete examples of decisions made for people with psychosocial, intellectual or cognitive disabilities in mental health and social services or at home. Then ask them who currently decides and why.

	How are decisions made?		
	Issues	Who decides?	Why?
In the service	<i>e.g. bedtime</i>	<i>e.g. the staff</i>	<i>e.g. to make the service easier to manage for the reduced staff presence at night</i>
At home	<i>e.g. drinking sugary soft drinks</i>	<i>e.g. the person's mother</i>	<i>e.g. because she thinks the person needs to lose weight and does not want the person to develop health problems</i>
	<i>e.g. going out</i>	<i>e.g. the family</i>	<i>e.g. because they think the person needs to be protected from possible harm in the community</i>

After completing the table, ask participants the following questions:

Do you think that people are encouraged or discouraged to make their own decisions and choices? In what ways do these arrangements help/hinder recovery?

Looking at examples from the table. What changes could be made so that people are able to make their own decisions and choices?



Presentation: The consequences of denying the right to legal capacity (15 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 you were deprived of your right to legal capacity? For people who have experienced this, how did it make you feel when you were deprived of your right to legal capacity?

Potential answers from participants may include:

It decreases self-esteem.

It can have a negative impact on people's mental health.

It furthers social exclusion and discrimination.

It prevents people from participating fully in society.

It prevents people from taking control and responsibility for their lives.

It prevents people from learning from their mistakes.

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, highlight the following:

The right to legal capacity is fundamental to human personhood and freedom, dignity and autonomy (i.e. the ability to take charge of and to control one's own life).

Any system that denies a group of people the right to legal capacity undermines people's places in the community and society.

The negative effects of not allowing people to make major life decisions are very significant but it can be similarly harmful to consistently deny people the opportunity to make the small daily decisions which in effect shape their identity and world. In many cases, the small decisions people make in life – such as what drink to buy, what shirt to wear or what to eat, make up an individual's personality and contribute to their role and identity in society.

Consistently taking away people's right to make decisions – both big and small – can be profoundly disempowering and can foster helplessness, dependence and nonparticipation.

Without the right to make decisions, people have very little or no control over their lives and are at higher risk of experiencing abuse and exploitation.

Furthermore, making decisions helps people to take responsibility for their lives and to address barriers to their well-being. Making decisions enables them to become less dependent on others, which in turns means that they are more able to develop positive and equal relationships with others.

In summary, making one's own decisions is very important because:

- It shows that we are equal to other members of our community.
- It helps us develop relationships with others as equals.
- It allows us to be responsible members of our community.
- It allows us to defend ourselves against violence, exploitation and abuse.



Exercise 1.4: Decision-making as a means for empowerment (50 min.)

Ask the group to read Rory Doody's personal account of his experience of decision-making (6). Provide the group with copies of Annex 6 and give them sufficient time to read the text.

"Eventually, I met a peer. I met somebody after coming out of the hospital, I met somebody in the community and we became great friends and eventually this man asked me "What are you going to do?" and it totally took me aback. I said "What do you mean? I'm going to take my tablets, I'm going to go to the outpatients' department and ... I'm better" and he said "No, no, no, what are you going to do?"

What that did for me was, although I did not know this at the time, that was the start of a journey of empowerment, and it was the start for me of taking responsibility for my own life. I really and truly had handed over my life and my will to the institution of doctors, psychiatrists, psychologists, occupational therapists and nurses and I did it willingly. There were many times that I begged to be put into hospital. I was so afraid of where I was in my life.

When I was asked that question – "What are you going to do?" – it took me aback in a big way. As I said, it was the beginning of a journey, a very slow and painful journey that brought me to the realization that there were things that I could do in my life and that there were choices that I could make that would have an impact on my life, that I didn't have to leave it up to others.

One of those choices – one of the consequences of those choices – I presented to my doctor one day. At this stage I had gotten married and I didn't exactly get the reception where people threw their arms around me and congratulated me for getting married but I do remember the day that I told my doctor that my wife was pregnant and the poor man his eyes fell to the floor. They fell to the floor and he just couldn't work with it like, he just couldn't accept it. I know he is a nice man and he is caring but all those good things, he didn't want it for me; he didn't think it was right that I would be able to handle it and do well with it. He is not my doctor anymore and I have four kids now. Maybe I should have come back to him!"

Mr Rory Doody, Area Lead for Mental Health Engagement, Cork Kerry Community Healthcare

Provide the participants with the opportunity to comment on this text. Ask the participants to make a list of key words or sentences relating to Rory Doody's life before and after he was asked what he was going to do.

Key words or sentences relating to his life before his encounter with a peer include:

I'm going to take my tablets.
I'm going to go to the outpatients' department.
I really and truly had handed over my life and my will.
I was so afraid of where I was in my life.

Key words or sentences relating to his life after his encounter with a peer include:

The community.
Empowerment.
Taking responsibility for my own life.
We became great friends.
The beginning of a journey.
They were things that I could do in my life.
They were choices that I could make that would impact my life.

I had gotten married.
I have four kids now.

Ask the participants:

What impact did supported decision-making have on Rory Doody?

Possible responses may include:

He takes charge of his life and his treatment, and he feels empowered and more confident.
He develops and maintains relationships (he makes a great friend).
Positive changes happen in his family life (he gets married and has children).
He is able to live his life in a way that is meaningful for him.

You can also show participants Rory Doody's full speech: Amnesty International Ireland, Rory Doody on his experience of Ireland's capacity legislation and mental health services, (35:36) Date accessed 9 April 2019, <https://youtu.be/63vK2F1ok7k>



Presentation: The benefits of making decisions – summary (5 min.)

The presentation briefly outlines the benefits of supported decision-making.

In summary, the benefits of making one's own decisions are as follows:

- Improvement of decision-making skills.
- Increased self-esteem, self-confidence and autonomy.
- Personal empowerment.
- Personal development as human beings and citizens.
- Widening of people's networks.
- Feeling supported, respected and valued.
- Enhancement of people's relationships.
- Enabling others to view and treat the person with the respect they deserve, thus helping to combat stigma and discrimination.



Reflective exercise (5 min.)

This reflective exercise will give participants an opportunity to think further about what has been learned on this topic.

Ask the participants to think about the following questions:

Has your opinion about the ability of people with psychosocial, intellectual or cognitive disabilities to make decisions changed?

Even if your opinion has not changed, do you think that people nevertheless have a right to make their own decisions?

Are you aware of some practical ways to respect people's right to legal capacity (i.e. their right to make decisions)?

Changing people's opinions on this topic is not easy. It will take work and time. It requires a paradigm shift from models which, for many decades, have influenced individuals' attitudes and the approach of mental health and social services. However, it is important to emphasize that, even when someone's personal opinion has not changed, they still have a responsibility to respect human rights.

Topic 2: Substitute versus supported decision-making

Time for this topic

Approximately 4 hours and 45 minutes if the short option is chosen. Approximately 5 hours and 50 minutes if the long option is chosen.



Exercise 2.1: Meaningful support (20 min.)

The purpose of this exercise is to engage participants in a general discussion about the meaning of helping and supporting someone.

1. You may want to start the exercise by discussing a simple, everyday example that has no major impact on people's life, such as buying a coffee for someone.

In most cases the person will appreciate the effort and will gratefully accept the coffee. But what if the person does not like coffee and prefers tea or hot chocolate? As a result, the person may feel embarrassed by what was intended to be a positive action.

Generally it is better to make sure beforehand that the person likes coffee. You may have observed what they usually drink or you may ask them directly what their preference is.

Ask participants the following:

What are some of the simple everyday actions that you may take in trying to be helpful and kind to someone?

Let's propose, for example, that your colleague buys you coffee every morning.

- How many people would appreciate having a coffee brought to you every morning?
- How many people don't like coffee and prefer tea?

It is important to make clear to participants that:

- Sometimes good intentions do not actually help people. The fact that you think you are doing the right thing for someone does not mean that you are, or that the person will perceive it that way.
- Support may be felt by people as an unacceptable intrusion into their life and may even be harmful. This will depend on how the person subjectively views the help, and the context and culture in which it is given.
- That is why the slogan "Nothing about us without us" is so strongly emphasized by people with disabilities – including people with psychosocial, intellectual or cognitive disabilities.

Now let us take a more complicated example.

- You are feeling really distressed and in order to be supportive, your partner books a weekend away together without having discussed this with you.
 - What are the different types of reactions that people may have depending on their particular context?

Encourage participants to express how they feel when they receive unwanted support.



Presentation: Why substitute decision-making is not a good model (40 min.)

As discussed previously, people with psychosocial, intellectual or cognitive disabilities are often deprived of the right to legal capacity and are not given the opportunity to make decisions.

Substitute decision-making is the prevailing model in many countries. It means that people are deprived of the right to make decisions and, instead, decisions are made for them by others. Substitute decision-makers may be members of the family, mental health and other practitioners, or people appointed by a court.

Sometimes substitute decision-making is a formal process (e.g. someone is appointed to be a “guardian” by law).

At other times, substitute decision-making happens informally, with family members or practitioners automatically and systematically taking over all decisions for the person concerned.

In yet other circumstances, laws allow others (e.g. a court, or the director or manager of a mental health or social service) to make decisions for people, even when a guardian has not been appointed.

Why is substitute decision-making often used?

- People may think it brings clarity to the decision-making and to the person who makes the decisions.
- People may think this is the only way in which important decisions can be made for people who are assumed to be incapable of making these decisions.
- It may seem more convenient for care partners and families to make decisions because they feel that they know what is best for the person, especially if the person is in a crisis.
- People may think that it is less time-consuming.
- People may think that the decisions made are necessary and good for people – in other words “in their best interest”.
- Practitioners may feel they have to take responsibility for the person’s recovery.

Problems with substitute decision-making

Substitute decision-making is often based on misconceptions and negative stereotypes about people’s decision-making abilities.

The problem with the substitute decision-making model is that it is a violation of people’s right to legal capacity.

In addition, it does not respect the person concerned as a decision-maker. People’s decisions are part of who they are and define who they become. To remove decision-making from a person means that

their life becomes something that happens to them instead of them having the dignity and responsibility to drive their own life.

At this point of the presentation, ask participants the following questions:

- What are your thoughts on this?
- What could be the impact on people when their decisions, will and preferences are not respected?
- Can people develop the skills to live independently without being provided with the freedom to make choices?

It is important to bear in mind that a substitute decision-maker may make decisions which not only go against the person's will, but which are also bad for them. They may sometimes take advantage of the person, or further limit a person's opportunity to make decisions. For example, a substitute decision-maker may decide to sell a person's house while they are in hospital.

Substitute decision-making results in a vicious circle: if people are deprived of the opportunity to make decisions, they can lose confidence in their ability and they stop trying. That is why some people who have never had a right to make decisions may sometimes prefer to defer this responsibility to others. Conversely, the more people exercise decision-making skills, the more confident they become in those skills. This is true for all of us: decision-making is like a muscle that you need to exercise in order to strengthen it!

People with psychosocial, intellectual or cognitive disabilities can and want to make decisions about their lives, and research has shown that having the autonomy to make decisions for oneself has a substantial impact on well-being (7),(8),(9).

Yet despite the negative consequences and the huge potential for abuse, substitute decision-making continues to be the predominant practice in most countries.

To illustrate this topic you can show to participants the following video: Global News: **Incompetent Persons Act declared invalid**, Landon Webb's parents removed as guardians (01:58)

<http://globalnews.ca/news/2791115/incompetent-persons-act-overhauled-landon-webbs-parents-removed-as-guardians/> accessed 9 April 2019.



Presentation: Supported decision-making, a new approach to decision-making (50 min.)

At times, we may all need support to make decisions in different areas of life. There may be times in life when we all may find it difficult and challenging to make decisions on our own.

At times like these it can be useful to turn to trusted persons who can provide support in the process of making decisions. In fact, at times everybody uses support from others when making decisions and choices.

In acknowledgement of this fact, article 12 of the CRPD introduces the concept of **supported decision-making**. The article states that people must have access to a variety of support options, including the support of people they trust (e.g. family, friends, peers, advocates, lawyers, personal ombudsperson,

etc.). The CRPD 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 information, weigh up different options, understand the possible consequences of different options and communicate their decisions to others (e.g. banks, utility companies, restaurants, health workers).

- For example, in the context of a mental health or social service, a peer supporter can support a person to 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 in asserting and communicating their choices if the person has difficulty in doing so.

Some people are isolated and do not have trusted people in their lives. Examples include people who have been institutionalized for long periods of time and have been denied the opportunity to develop supportive relationships, people whose families have deserted them and people who have experienced repeated violence and abuse. In addition, some people who may not be completely isolated still lack people around them who they trust sufficiently. Therefore, supported decision-making might also involve providing the opportunity for people to form relationships of trust where these are absent in their lives. For instance, if the person is open to creating a new support relationship, an "advocate system" can be put in place in which a designated person takes on the role of supporter until the person concerned is able to build their own social network.

When persons have difficulties in expressing their will and preferences, they may want supporters to help others realize that they are persons with a history, interests and aims in life – persons who have the right to exercise their legal capacity (10).

It is important to note that support needs to be tailored to the individual. Furthermore, decision-making skills, and hence the level of support required, can vary at different stages in a person's life.

At times people may not need any support at all, at other times low-level support is sufficient, and sometimes more intensive support may be required. For example, a person in the early stages of dementia may need minimal or no support at all, whereas in later years they may need more intensive support. In addition, some people may 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 be accepted as having the right to make their own decisions.

Supported decision-making in mental health and social services

The unequal power dynamics between mental health and other practitioners and people using services act as an important barrier to supported decision-making in these settings. To a large extent, laws allowing for involuntary admission and treatment in mental health and social services contribute to this power imbalance.

People using services often hold the belief that practitioners are able to do what they want because of their position and their level of authority while service users themselves have little influence on their own care (11). It is important to address and change power dynamics in order to respect people's right to legal capacity in that setting. For more information on power dynamic see the guidance on *Transforming services and promoting rights in mental health and social services*.

Mental health and other practitioners are not “supporters” due to the risk of conflict of interest and undue influence. However, they must adopt a supportive approach and use their professional skills in considering whether they are able and willing to provide what a person asks for.

Sometimes practitioners have a strong commitment to the idea that they are already implementing such an approach. However, very often they are not doing this: they identify a need, make a suggestion, ask for agreement from people using the service and then record and act on this. Directing the flow of information in this way is **not** considered to be a supportive approach.

In addition, mental health and other practitioners often fail to account for the power differentials that exist between them and people using the service. By identifying needs and suggesting limited options, practitioners (sometimes even unconsciously) control the discussion and provide little opportunity for disagreement.

It is necessary to overcome these barriers and to promote a new approach centred on support in which:

- People are empowered and provided with comprehensive information which enables them to make decisions about their lives, including about their care and treatment.
- Power imbalances can be counteracted if practitioners pay attention to the values, expectations, will and preferences of the people they are working with, understanding their interpretative system and acting accordingly.
- Practitioners’ self-reflection about how their assumptions or behaviours may unintentionally be a barrier to decision-making by service users is also necessary.

Respect for the right to legal capacity also involves respecting people’s right to consent to or refuse treatment. This requires actively facilitating supported decision-making by ensuring that people are able to invite trusted persons to accompany them to the service to support them. Mental health and other practitioners can also facilitate contacts between a person and formal support services such as supported decision-making NGOs or peer workers who can act as supporters if this is what the person wants.

[Distribute to participants copies of Annex 7 \(reproduced below\).](#)

The following box (12) is a useful checklist tool for supporters initiating a supported decision-making approach. However, additional steps will need to be included on a person-by-person basis.

Supported decision-making checklist

Do you do the following?

- Provide relevant information:
 - Give the person all the relevant information they need to make a particular decision.
 - Give the person all the information they asked for.
 - Give the person information on all the 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 whether the person accepts this help.
- Make the person feel at ease:
 - Identify if there are particular times of the 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 delayed 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.

Differences between supported decision-making and substitute decision-making

In supported decision-making, a support person never makes decisions for/on behalf of/instead of another person. With supported decision-making, all forms of support, including the most intensive, are based on the **will and preferences** of the person concerned.

It is important to note that a person's will and preferences are different from what others may perceive as being in a person's "best interest".

- In many countries, the standard for making a decision for a person perceived as lacking decision-making skills is generally based on the "best interest" (i.e. when others determine what is the best decision or course of action for a person).

As explained in a previous exercise, even if substitute decision-makers have good intentions and think they are doing the right thing for a person, it does not mean that they are or that the person will perceive the situation in that way.

Unwanted or inadequate support may be felt by people as an unacceptable intrusion into their lives and may even be harmful. This will depend on how the person subjectively views the help, and the context and culture in which it is given.

Therefore, the “best interest” approach needs to be replaced.

Best interpretation of their will and preferences.

When the person is still unable to communicate their will and preferences even after significant attempts have been made to communicate, decisions must be made on the basis of the **best interpretation of their will and preferences**. These can be determined, for example, by:

- referring to what is already known about the person (e.g. their views on different matters, beliefs, values in life, etc.);
- referring to advance planning documents which contain information about the person’s will and preferences (this will be discussed in more detail later).

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 in which the person always has the final say because decisions are made according to their will and preferences or the best interpretation of their will and preferences.

Finally, unlike most forms of substitute decision-making, 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.

Supported decision-making also means that people can make real choices between acceptable options and are not coerced into making any specific decision. For instance, asking a person if they prefer to take their medication or to be detained in a mental health or social service is not respectful of their right to make decisions. There must be no threat of coercion or punishment for exercising the right to make decisions.

Many people, particularly family members, as well as mental health and other practitioners, have expressed 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 on a person can itself cause harm either immediately or later on. The harm caused to the person can take many forms, including trauma, humiliation, physical injuries, etc.

In addition, respecting people’s choices should not be used as an excuse to neglect or ignore someone in distress. The CRPD requires that supporters meaningfully engage with the person and provide options that are acceptable (13).

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

It is important to acknowledge that:

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

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



Presentation: Moving from substitute decision-making to supported decision-making (10 min.)

The following table (14) summarizes the shift from substitute decision-making towards supported decision-making. To make this shift it is necessary to move from the left column of the table to the right column.

From	To
An assumption that people with psychosocial, intellectual or cognitive disabilities do not have the mental capacity/ability to make their own decisions	An assumption that people with psychosocial, intellectual or cognitive disabilities can make decisions by themselves and for themselves, with accommodations and/or the assistance of their supporters if desired.
Some people have the right to make all decisions for themselves and others do not	Everyone has the right to make decisions at all times, including decisions about whether to use support in making decisions.
Assessing deficits in mental capacity (ability to make decisions)	Exploring the type and level of support that may be required to make decisions.
Detention in mental health and social services	Exploration of support alternatives in the community, if desired by the person concerned.
Best interests (where others determine what is the best decision or course of action for a person)	Will and preference (where all decisions are made by the person based on their own will and preferences and the best interpretation of their will and preferences is applied where, despite significant efforts, it is not possible to determine their will and preferences).
Substitute decision-making and appointment of substitute decision-makers (where other people make decisions for a person according to their own standards and not the person's will and preferences)	Supported decision-making (where people make decisions for themselves and by themselves with the support of others when desired).



Exercise 2.2: Understanding support in decision-making (20 min.)

The purpose of this exercise is to demonstrate that supported decision-making is not a new concept and that everybody needs support from others in making decisions about different areas of life. People do not always have sufficient knowledge, experience or time to make every kind of decision on their own.

Ask the group the following questions and make a list of their ideas on the flipchart:

Can you remember being helped by someone to make a decision?

For example, a decision about whether to enter a new relationship, what purchase to make, how to organize for children to go to school, where to live, what training to undertake, what career path to choose etc?

Did you find this support helpful?

If yes, why?

Possible responses from participants may include:

The support person helped me to find the relevant information.
I trusted the person whose opinion I sought.
The support person connected me with people who previously experienced the same situation.
The support person had themselves experienced the same situation.
The support person provided an external point of view which I had not thought about.
The support person helped me to weigh the pros and cons and to organize my ideas.
The support person helped me to identify the real problem.
The support person reminded me of my previous experience(s) which were relevant to the decision to be made.
The support person helped me to make a decision in line with my personal objectives and values.
The support person made me feel that it was going to be OK, no matter what decision I ended up making.

If not, why not?

Possible responses from participants may include:

The support person did not know about the issue.
The support person did not provide the appropriate information.
Even if the information was accurate I was not able to understand it.
The support person already had a strong position on the question.
The support person told me what they would do in this situation (rather than focusing on what I would like to do).
The support person encouraged me to make a decision to please them, not to please me.
The support person finally made the decision on my behalf or against my will.



Presentation: Different forms of support (70 min.)

The following presentation will provide examples of different models of support that can be offered to enable people to make their own decisions.

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

Providing full and complete information

The first form of support is to provide full and complete information in a format that the person understands.

Many people – including (but certainly not limited to) people with psychosocial, intellectual or cognitive disabilities – do not have enough information (e.g. about treatments, care and support options, rights, legal issues, etc.) to be able to make decisions. In order to make decisions, people must first be given all relevant information concerning the area or issue about which they want to make a decision.

Supportive communication skills

Communication skills are necessary to accommodate and understand people using diverse styles of communication and/or experiencing communications difficulties.

Supporters or people adopting a supportive approach, including mental health and other practitioners, should learn how to listen to people actively and attentively. They should build their understanding of a person's needs by listening and checking with the person to see if they understand what the person is saying. These listening skills should also include helping the person to relax and giving the person breaks (i.e. not conducting an interrogation of the person). They should also respect how much or how little the person wants to share.

Communication skills in relation to people with diverse styles and limitations might include:

- Understanding indirect or unusual communication styles.
- Understanding the person's values that underlie the communication, which can be different from the listener's values.
- Assuming that communication always has meaning even though it may seem meaningless to others.
- Understanding that you might not be able to understand someone because of your own limitations.
- Considering the issue from the other person's point of view.

Making reasonable accommodations

As part of the requirement to provide full and complete information during the support process, reasonable accommodations may be required.

The term "reasonable accommodation" refers to measures that need to be taken (by governments, service providers or others) in order remove the barriers that persons with disabilities face, and to

ensure that they are able to exercise their human rights on an equal basis with others and that they are not discriminated against in the exercise of their rights.

- Article 5 of the CRPD requires that people with disabilities are provided with reasonable accommodation in exercising and enjoying the rights in the CRPD. This includes the right to legal capacity, and means that other people – such as mental health and other practitioners, personnel in financial institutions and employers – must accommodate the person’s requirements in decision-making and recognize the person’s potential need for supports in the decision-making process.

Reasonable accommodation can include, for instance, providing people with information in a way that enables them to understand it. This might involve providing a person with easy-to-read or plain language formats, reading assistants, assisted/adaptive communication tools, visual aids, or interpreters (including sign language interpreters).

Making reasonable accommodations may also involve mental health and other practitioners accepting formal or informal assistance from family and friends or taking more time to talk with the person in order to communicate information relevant to the decision.

Reasonable accommodations can be relevant whenever an individual interacts with other people (e.g. doctors explaining the risk of a medical procedure, bank employees opening an account, etc.) and should be individualized and tailored to the needs of the person concerned.

Making decisions with the support of others

Support can take many forms and can involve one trusted person or a network of people. It can also be informal or formal.

- Informal support, mostly provided by family and friends, is used by everyone in everyday life. As far as possible, informal support should be encouraged to limit formal intervention in people’s lives and to allow people with psychosocial, intellectual or cognitive disabilities to make decisions in a way which is similar to that used by people without disabilities.
- However, formal support may sometimes be necessary for making complex or important decisions when informal support is not sufficient and/or when the person has important support needs.

When people decide to nominate their supporter(s) formally, they may nominate a relative that they trust. However, a person may sometimes nominate someone who is independent (e.g. an advocate). This may be, for example, because the person is isolated or has experienced abuse in their family.

Formal support

- **The Swedish Personal Ombudsperson (PO) (15)**

Ask the group to watch the following video on an innovative policy, **Personal Ombudsperson System** (13:50):

<https://youtu.be/63vK2F1ok7k> , accessed 9 April 2019.

- The Personal Ombudsperson (PO) system in Sweden is one model of supported decision-making. The service is generally offered by NGOs.
- POs are skilled persons who work at the request of the person needing services. They help clients with a range of issues: family matters, health care, housing, and accessing services or employment. POs only do what their client wants them to do.
- The model is based on a long-term relationship of trust. It is designed mainly for people who are hard to reach, isolated or left without support.
- To avoid burdensome administrative processes and paperwork there is no written agreement between the PO and the client.
- POs have flexible schedules, adapted to the needs and wishes of their clients. They do not have an office, as coming to an office could deter clients from taking up the service by creating the impression that POs are in a position of power. POs work from their own homes with the help of a telephone and the Internet; they meet clients in their homes or at neutral places such as a cafe. They are required to have the skills to argue effectively for the client's rights in front of various authorities or in courts.
- Sweden has a system of partial guardianship, generally used for financial matters, but the POs are not seen as an alternative to guardianship by the government. The two systems are not connected and have developed separately. Therefore, a person might have a PO and a guardian at the same time. In practice, the person often wants a PO to help them end the guardianship measure. Frequently they do so successfully.

The Swedish system has shown very positive results and benefits (16):

- In 2014, 6000 persons were supported by a PO in Sweden.
- 84% of Swedish municipalities included POs in their social service system.
- Individuals with disabilities who are supported by a PO require less care and their overall situation improves.
- In the long term the PO system reduces costs for the social system.
- **Independent Advocacy (Scotland, United Kingdom) (17)**

Show participants the following video: Independent Advocacy, James' story (4:33) (the video is available in several languages):
<https://youtu.be/SSvorQMSn8Q> (accessed 9 April 2019).

- Independent Advocacy is a way to help people, including people with psychosocial, intellectual or cognitive disabilities, to have a stronger voice and to have as much control as possible over their own lives.
- Independent Advocacy organizations are separate from organizations that provide other types of services.
- An independent advocate will not make decisions on behalf of the person/group they are supporting. The independent advocate helps the person/group to obtain the information they need to make real choices about their circumstances and supports the person/group to put their choices across to others.
- Independent Advocacy is:
 - about standing alongside people who are in danger of being pushed to the margins of society;
 - about standing up for a person and taking their side;

- listening to someone and trying to understand their point of view;
- finding out what makes them feel good and valued;
- understanding their situation and what may be stopping them from getting what they want;
- offering the person support to tell other people what they want or introducing them to others who may be able to help;
- helping someone to know what choices they have and what the consequences of these choices might be;
- enabling a person to have control over their life but taking up issues on their behalf if they want you to.

- **Open Dialogue (Finland) (18),(19),(20)**

Participants can watch the following videos about Open Dialogue:

Short option: Daniel Mackler, **Jaakko Seikkula Speaks on Finnish Open Dialogue, Social Networks, and Recovery from Psychosis** (8:24) : https://youtu.be/b5_xaQBgkWA , accessed 9 April 2019.

Long option: Daniel Mackler, **Open Dialogue: an alternative Finnish approach to healing psychosis** (complete film) (1:13:59): <https://youtu.be/H-ontu-Ty68> , accessed 9 April 2019.

Open Dialogue is a Finnish alternative to the traditional mental health system for people diagnosed with psychosis such as "schizophrenia". This approach respects the decision-making power of the person concerned and engages the person's network of family and friends.

The Open Dialogue team provides immediate help within 24 hours of the first contact. They seek to engage social networks, rebuild relationships and, if possible, avoid medication and the alienating experience of hospitalization by bringing together people from 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. Also, the place of the meeting is jointly decided. In order to counter stigma, the meetings can take place at the home of the person seeking support.

In Open Dialogue, the person seeking support identifies the family and care partners to be invited to participate alongside the open dialogue team 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.

Language is an important part of creating an open dialogue. Open Dialogue team members do not interview the participants or use medical language. In addition, they do not seek to find solutions or to make decisions about treatment on behalf of the person concerned. On the contrary, the team members follow the themes and issues raised by the person and their family members or supporters. Open Dialogue explores how they understand the situation and how, in their own language, the person and their support network have named and described the person's distress. By speaking openly at all times, everyone understands what is going on and what is being talked about. Consequently, a shared language is created and the participants build up a new understanding between them and a stronger basis for collaboration.

A follow-up study on first-episode psychosis has shown that, after five years, 82% of persons supported through this approach had no remaining psychotic symptoms, 86% had returned to their studies or a full-time job, and only 14% were on disability allowance. Only 29% had used neuroleptic medication in some phase of the treatment. In comparison, a 5-year follow-up study (21) on people experiencing a first psychotic episode treated in Stockholm from 1991 to 1992 (before the development of a psychosocial programme in the area), reported that during the 5-year period, the mean length of hospitalization was 110 days, and neuroleptic medication was used in 93% of cases. As an outcome, 62% of the patients were living on a disability allowance after five years.

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 nonexistent or weakened, it is very important to support the person to rebuild and/or consolidate these networks.

It may also be necessary to advocate for a more formalized form of support networks for people who need and want them.

Informal support

- **Support network**
- E.g. Circle of support (UK, Australia) (22):

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

Circle of Support (sometimes called a Circle of Friends) is a group of people who meet together on a regular basis to help a person (the focus person) accomplish their personal goals in life. The circle acts as a community around the person concerned, providing them with support to achieve what they want in life, if desired.

The person who is being supported is in charge, both in deciding who to invite to be in the circle, and also in the direction that the circle's efforts should be employed, although a facilitator is normally chosen from within the circle to take care of the work required to keep it running.

Members of the Circle of Support may include family, friends and other community members and are involved because they care about the person and are willing to give time and energy to support them. No-one is paid.

- **Personal assistance (23)**

Personal assistance refers to person-directed/user-led human support delivered to a person with disability. It is an important tool to promote independent living. Personal assistants can also play a key role in supported decision-making. As trusted individuals they can talk through options with the person, support the person in communicating their will and preferences to others, etc.

Although definitions of personal assistance may vary, there are certain elements which distinguish it from other types of support:

- The funding is to be controlled by and allocated to the person with disability with the purpose of paying for any assistance required.

- It is based on an individual needs assessment and the person/user's life circumstances. The personal assistance service is led by the person with disability, meaning that he or she can either contract the service from a variety of providers or act as an employer.
- Persons with disabilities have the option to custom-design their own service – i.e. decide by whom, how, when, where and in what way the service is delivered.
- Persons with disabilities who require personal assistance can freely choose their preferred degree of personal control over service delivery according to their requirements, capabilities, life circumstances and preferences.
- Even if the responsibilities of the employer are contracted out, the person with disability always remains at the centre of the decision-making processes concerning the assistance.

Show participants the following video: What is the role of a Personal Assistant? (12:10) <https://youtu.be/Wdx9iTMsGyE> , accessed 9 April 2019.

- **Peer support**

Peer support refers to the idea that people with psychosocial, intellectual or cognitive disabilities can help each other. The support can come from an individual or a group of people with “lived experience” of similar issues and who have acquired the knowledge and expertise to support others going through difficult moments in their lives. Peer support can be provided formally or informally. Peers can provide the person with valuable information about a wide range of issues and therefore enable them to make informed choices. Peer support also has a positive impact on agency and autonomy and therefore supports the right to legal capacity (24). Peers may offer particularly relevant support as they know what kind of challenges the person may face. Whether or not they carry out their role formally within mental health and social services or outside these services, peer supporters should always be independent.

- **Support from family and friends**

For many people, the support and understanding of their family and friends when they go through difficult times in their lives is extremely important. Families and friends know a lot about the person concerned and often provide the most direct support to their loved ones. They are generally aware of the everyday life of the person, the decisions they make on a day-to-day basis and the person's usual choices and preferences. In addition, family and friends are more likely to be on hand to encourage and support the person to exercise their right to legal capacity (e.g. offering to help people to engage in activities they like or providing support on how to manage a budget).

Family and friends can also be a great source of information to enable others to understand the background of the person, their values and objectives in life, or their previous experience(s) of mental health and social services.

However, there are also several potential conflicts of interest and attitudinal barriers that can impede support provided by family members and friends. These include:

- Making assumptions about what is in the best interest of the person.
- Being emotionally over-involved, stressed, or lacking patience.
- Feeling guilty about the person's situation and addressing this guilt by overwhelming the person with support.
- Lacking knowledge about the person's values and preferences.
- Being unrealistic or having low expectations about what a person can achieve.

- Underestimating the person’s decision-making skills or continuing to treat them as children even when they have reached adulthood.
- Fearing potential consequences for themselves as a result of challenging situations involving the person.
- Being overprotective of the person.
- Feeling entitled to share part of their family member’s story with others when the person may not want the information to be shared.
- **Communities of support**

A lot of people who may appear to lack other kinds of support such as close friends or family may in fact find a lot of support in certain communities or community spaces and create a “family of friends”. These can include online communities, religious or cultural groups, political activist communities, groups focused on activities such as music or art work or communities based on for example, gender or sexual orientation. It is important that services recognize and take into account these forms of support even though they may be different from traditional support networks.



Exercise 2.3: Scenario – Understanding support in supported decision-making (30 min.)

Explain to participants that this is a simple scenario, not a challenging one, which aims to explain the concepts clearly. Encourage the group to focus on the issues being discussed and not to be distracted by the complexities participants may have seen in their personal or professional experience. More challenging scenarios will be addressed in a subsequent exercise.

Read to participants the scenario below.

Scenario – Sunita (1)

One morning Sunita has her first consultation at the mental health unit of a teaching hospital. She appears to be very agitated and explains that she is feeling very down. She subsequently receives a diagnosis of depression.

The medical officer insists that she immediately starts to take antidepressants although she says she does not want to take medication. She reluctantly starts the treatment, but she becomes increasingly nervous, irritable and agitated on the medication. She returns to the service and the medical officer in charge at her first appointment prescribes her benzodiazepines to manage her agitation.

The sedating effect of the medication makes it difficult for her to interact with other people and after several weeks she becomes isolated, loses confidence in herself and feels even worse. She also decides to take herself off the medication but she experiences withdrawal symptoms, including severe headaches, nausea and insomnia. She never had an opportunity to talk about what was troubling her.

Then ask the group:

Considering what we have previously discussed, what went wrong in this case? How could things have been done differently?

Possible responses as to what may have gone wrong include:

Sunita was deprived of her right to make decisions about what treatment she should receive because her free and informed consent was not sought before giving her medication.

She was not listened to and her opinion was ignored.

Staff of the service made the decision on her behalf.

The immediate response was to put her on medication. Nobody took the time to talk to her.

The following could have been done differently:

Staff could have tried to understand why she was feeling depressed.

They could have made efforts to get to know her as an individual and to understand why she did not want antidepressants.

They could have asked her what type of treatment, care and support she wanted.

They could have offered her different care and treatment options, including individual psychotherapy, group therapy, counselling or peer support.

They could have explained to her the likely benefits and side-effects of each treatment option in a language that was clear and understandable to her.

They could have offered her the possibility to contact someone she trusts (e.g. a family member or friend) who could support her in making treatment decisions, help her understand the different options available to her, support her in communicating her preferences and ensure that these were respected.

They could have accepted her decision and respected her choice of care options other than medication.

Now read a different version of Sunita's story, in which the medical officer adopted a supportive approach and in which she was able to involve her friend as a supporter:

Scenario – Sunita (2)

One morning Sunita has her first consultation at the mental health unit of a teaching hospital. As she seems distressed and agitated, the medical officer in charge suggests to Sunita that they go to a quiet room in order to discuss what is troubling her. The medical officer asks Sunita if she would like to share her feelings with her and tell her a little more about her situation.

Sunita explains that she has been feeling very down during the past months to the point that she was neglecting herself: she has not been washing regularly, and her eating and sleeping have become irregular. Sunita is reluctant to go into the details of why she is feeling distressed and agitated.

She says she would like care and support but does not want antidepressants as her experience with these in the past was not positive. The medical officer says there are different types of medication which she could try. She also explains that there are alternatives to drug treatments such as individual psychotherapy, group therapy or counselling sessions which might be helpful to Sunita. She also suggests that Sunita could explore and engage in activities available in the community that might make her feel better, such as relaxation yoga classes.

She offers to schedule an appointment with the psychiatrist, the peer support worker, the psychologist and the occupational therapist to discuss the different options. She asks Sunita if she would prefer to have a brief stay at the mental health unit or to go home and receive support there. She also asks if there are people who Sunita trusts and whom she would like to contact to support her.

Sunita knows and values a good friend of hers who has had similar experiences with depression with whom she has been spending time recently. She feels that her friend can help her weigh up the pros and cons of different treatments, care and support options, and help her to make a decision. The medical officer says that Sunita could nominate her as a supporter and involve her in the formulation of her recovery plan.

Sunita now feels more comfortable with the medical officer and about the support she will receive. She opens up to the medical officer that things are really difficult for her at home and that her husband is abusive. The medical officer says that there is a very good NGO which supports women in her situation and shelters women who are in danger. She offers to give her the contact of the organization.

Give participants an opportunity to comment on this alternative scenario.

Topic 3: Supported decision-making in practice

Time for this topic

Approximately 1 hour and 10 minutes.



Exercise 3.1: Scenarios – Deciding on supporters and support options (30 min.)

Explain to participants that this is a simple scenario, not a challenging one, designed to explain the concepts in a clear way. Encourage the group to focus on the issues being discussed and not to be distracted by all the complexities participants may have seen in their personal or professional experience. More challenging scenarios will be addressed in a subsequent exercise.

Read the paragraph below to the participants.

Scenario – Ximena (1)

Ximena is a 79-year-old woman who lives on her own in a small apartment. She is separated from her husband of 30 years with whom she has very little contact. They have two children, both of whom live in different parts of the country. She has a few close friends who live near to her.

Ximena has noticed that she has been forgetting important appointments, forgetting to make payments, getting confused about where she is and how she got there, and not being able to distinguish between dreams and real activities. She thinks this might be because she is withdrawing from some medication that she has been taking for years. She sees her doctor who refers her to specialized testing, after which she receives a diagnosis of vascular dementia. She is devastated to hear about the diagnosis, fears for her future and what will happen to her and that she will end up in a nursing home isolated and neglected and not able to do the things she enjoys with her friends who live nearby in the local neighbourhood.

Then ask the group:

1. On the basis of this context, who do you think should be Ximena's main supporter?

Possible answers may include: Her husband or children because they are family, or her friends because she is close to them. However, it might be that she may not feel comfortable with either of these solutions for many emotional and personal reasons. It should be clear after this discussion that Ximena is the person who knows what is best for her and she should be asked the question about who could provide support.

Once the participants have had the opportunity to discuss the first question, you may ask:

2. What type of immediate and longer-term support might Ximena benefit from on the basis of the scenario described above. What are the options for how this could be provided and by whom? Describe how you might explore the options.

Make clear to participants that they should think about solutions that respect Ximena's right to legal capacity. Therefore solutions should not involve substitute decision-making (such as placing Ximena under a guardianship order).

Possible options might include:

Immediate support needs could be identified through discussion with Ximena to identify the most important challenges and how they affect her life, and exploring multiple possibilities in order to select the solutions that best meet her hopes, expectations and lifestyle. For example:

- For remembering to take medication, it might be useful to make use of simple assistive technology (e.g. a weekly medicine container to keep track of medications, and regular reminders through her smartphone).
- For the challenges with making payments, automatic payments could be explored, or alternatively she could contract an accountant to deal with the basic management of payments.
- It could be arranged for a support person to check in once or twice a week according to needs that could be varied over time.

Longer-term support: The idea of developing an advance plan should be raised and discussed as a means for planning options so that Ximena's preferences would be respected in all areas of life.

Once the second question has been discussed, read the outcome of the case study:

Scenario – Ximena (2)

Ximena acknowledges that she does need some support but at this stage preferred to limit this to a small range of informal supports. She has automated all regular payments that need to be made, and she has automated reminder messages for routine tasks and appointments that need to be carried out. She has discussed her situation with her friends and they are more than happy to provide additional support to accompany her to appointments and to help her keep track of them. After several discussions with a social worker, she has planned an advance directive that specifies her wishes for the long term. She has discussed this with her family and friends, which has brought a great deal of relief and reduced her anxiety about some aspects of the future. Ximena maintains a good relationship with the social worker who helped her to initiate an advance directive and who visits her once a month to see if everything is going well. Ximena knows that she (and her family and friends) can call the social worker at any moment.

Read the story below to the participants:

Scenario – Jack (1)

Jack is a young man with two children whose experience of low moods sometimes makes it challenging, and even overwhelming, for him to raise his children on his own.

At times, Jack finds it extremely difficult to manage the emotional and financial needs of the family as well as the logistics of the home. He really wants his children to have a good life because his own parents were unable to take care of him properly when he was a child, and he does not want his children to experience the same hardships.

Jack would like support in managing certain aspects of his home and family life. He gets on very well with his brother (Marlo) as well as his best friend Jane and approaches them to explore the possibility of supporting him.

Ask the group the following question:

In what ways might Marlo and Jane offer to help Jack with managing certain aspects of his home, family life and parenting concerns?

Many answers are possible here. For example, they could help Jack to contact family support services. They could also take care of the children from time to time when Jack finds it hard to cope with the situation. They also may offer to make themselves available when Jack needs advice.

The participants may come up with other ideas for how to help Jack.

Now read the end of Jack's story, making clear to participants that different outcomes are possible and that the end of the story below is just one among many possible solutions.

Scenario – Jack (2)

Jack contacts Jane and Marlo and tells them he would like them to attend a couple of his counselling sessions during which they could discuss parenting issues. Once they have met with the counsellor, they agree on a plan:

- His friend Jane will check in on him on a regular basis in person or by phone.
- Marlo says he will look into family supports that may be available for Jack and will help him fill in any forms that may be required or accompany him if any visits to social services are necessary.
- The brother and friend will sometimes take the children for the weekend if Jack is feeling overwhelmed.
- They also agree to be available to discuss any big decisions concerning the children (e.g. schooling, holidays, etc.).

Counselling sessions will also be organized for the children to help them understand the situation, to support their relationship with their father, and to make sure that they don't feel abandoned or neglected when their father feels unwell.



Exercise 3.2: Scenarios – Challenging situations (30 min.)

This exercise should allow participants to consider different options they could use to respect people's right to legal capacity, even in the most challenging situations.

Ask participants to split into three groups. Assign one of the examples below to each group and distribute the relevant examples (Annex 1).

Scenario - Claudia

Claudia is a young woman and has always wanted to have a child. She has a boyfriend with whom she plans to marry. Claudia lives with her parents and they support her in her daily life. Her parents have told her that they do not give permission for her to marry or have a child and have placed limitations on Claudia seeing her boyfriend. They believe there are too many risks involved and that she would not be able to care for a child on her own due to her having an intellectual disability. Her general practitioner has also told her that it would be irresponsible for a person with an intellectual disability to have a child.

Scenario - Nasima

Nasima is a woman who has been bullied and teased by others since she was a child. Even as an adult, her parents decided it is better to keep her at home where they believed she will be more secure and less likely to be harmed by the bullying. They also stop her from going to the market and participating in community festivals – activities which she loves. Since Nasima completed school, she has not been eligible for entitlements and community supports. She desperately wants to find a way to have her own money. However, she has great difficulty finding a position that accommodates her needs and requirements.

Scenario - Christopher

Christopher is a young man who has suddenly and drastically changed the direction of his life. Recently, he started to have many different ideas about a career for himself but has been moving quickly from one idea to another. Most recently, he has decided to pick up dogs and cats from streets in order to save them. He has decided that the garden of the mental health service is the place most suitable for them, so he comes to visit the service in order to ask staff their permission to create an animal shelter there. He tells them that he wants to sell his personal belongings in order to invest more money in his project.

Then ask each group:

Considering what has previously been discussed on the right to legal capacity (the right to make decisions for oneself) and supported decision-making, what would you do in this case?

Could you suggest positive actions that could be taken in these situations that respect the right to legal capacity?

Ask the three groups to nominate a spokesperson at the end of the group discussion to present their findings to the rest of the participants.

After each group's presentation, allow for discussion in plenary on each scenario.

Emphasise for all scenarios how people's right to exercise legal capacity should always be respected, protected and fulfilled, even in challenging circumstances (such as the ones depicted in the case studies presented). Alternatives should always be sought in order to respect, protect and fulfil people's right to make decisions.

Possible responses respecting people's right to make decisions for each scenario include:

Scenario: Claudia

Arranging a meeting with her family to discuss how they can respect Claudia's right to marry and have a family.

Discussing and providing the support that Claudia and her partner might need to start a family and to help her in other areas of her life.

Ensuring that Claudia has access to health care (i.e. prenatal and reproductive) in a way that is understandable to her.

Looking for and linking Claudia to community resources (i.e. parenting classes, Circle of Support) to support her in raising a child.

Scenario: Nasima

Connecting her to counselling services where she can seek assistance to address the bullying she has experienced.

Encouraging and supporting Nasima to identify her strengths and interests in order to explore meaningful job opportunities.

Discussing the positions that most interest Nasima.

Linking Nasima with community services in order to build any new skills to help her find the job that she wants and to increase her confidence.

Supporting Nasima to discuss accommodation measures with future employers.

Scenario: Christopher

Trying to understand what Christopher values in the project and what he is trying to achieve.

Talking with Christopher to encourage him to think longer before spending his savings on this project, and to consider carefully other projects or opportunities for a business.

Trying to facilitate the creation of a small experiment to see if it meets Christopher's expectations.

Asking Christopher if there is anyone he trusts who can give advice on his project.

Encouraging and supporting Christopher to work out the pros and cons of spending all his money and selling his house, which would leave nothing for him to live on and which would in effect make it difficult to care for the stray cats and dogs.

Linking him to peer supporters or peer support networks in the community.

Encouraging him to identify what his financial needs are for daily living and to put that money aside so that if the project does not work out he still has sufficient money to live on.



Presentation: System failures in supported decision-making (10 min.)

These cases depict challenging situations. Sometimes, in some situations, it seems impossible to find alternatives to substitute decision-making. It is even more complicated when it is necessary to protect the rights and well-being of others (e.g. partner, children, parents). In such situations people often resort to making decisions instead for the person rather than trying to find alternative solutions that respect the person's wishes.

It is very important to make sure that challenging situations are not used to justify substitute decision-making. Mental health and social services need to put in place clear processes to determine a person's

will and preferences. If this is not possible, after serious attempts have been made, decisions should be made based on the best interpretation of the will and preferences of the person.

Making decisions on behalf of other people is not acceptable. It is a violation of the individual's human rights and also a system failure. Most of the time, this would not have occurred if support had been provided earlier before the situation escalated or deteriorated.

Support should also be provided to relatives who may also suffer adverse consequences in difficult situations. These support mechanisms should be discussed and agreed upon by all the people concerned.

Each failure to respect people's right to legal capacity should make everyone involved – mental health and other practitioners, families and others – review and question their current processes, practices and strategies, in order to understand what went wrong. A meeting can be organized with all the stakeholders, including the person concerned, to discuss ways to avoid the same situation in the future.

Topic 4: Nominating a person to communicate best interpretation of will & preferences

Time for this topic

Approximately 20 minutes.



Presentation: The role of nominated persons (20 min.)

A nominated person is a specific supporter who is trusted to communicate a best interpretation of the person's will and preferences in future situations where it may be impracticable, after significant efforts have been made, to determine the person's will and preferences directly. People may or may not find it useful to have a nominated person.

One specific person can be nominated or, alternatively, a group of people can be nominated who can collectively determine and communicate their best interpretation of the will and preferences of the person. It is also possible to nominate different people for different issues that may require decision-making (e.g. health, finance). The person can indicate, if they wish, that among a group of people to be consulted the opinion of one particular person of their choosing should prevail.

The best interpretation approach might need to be used, for instance, when a person becomes unconscious, unresponsive or has very severe and profound communication impairment.

The best interpretation of a person's will and preferences should be made according to what the person has told the nominated person in the past or what the nominated person understands the person would want on the basis of many discussions or close knowledge of the person. Nominated persons, in this sense, are **not** "substitute decision-makers". They should not make decisions "instead" of the person. Nor should they make decisions according to what they *think* is in the "best interests" of the person concerned.

Before using the best interpretation approach, supporters should find out whether assistive technology or other forms of accommodation could help to determine the person's actual will and preferences. If no accommodation can enable the person to communicate directly, then the nominated person should communicate their best interpretation of the will and preferences of the person concerned.

Nominated persons can also play an ordinary support role in situations which do not require a best interpretation of will and preferences. They can help to clarify the person's will and preference when others may not understand the person's communication. They may also support the person in asserting their choices towards others and can make sure that these choices are respected.

Nominations of representatives can be included in advance plans or directives (which will be discussed in the next session) or can be stated in a separate document (e.g. in the person's care and treatment plan and medical records). When nominating someone to communicate one's wishes and preference, it may be helpful to include an alternative nominated person in the advance plan in case the preferred person is unavailable for any reason.

The nominated person should:

- **Be a trusted person:** This should be someone who knows the person well and is able to respect the person's rights and will and preferences, including their values and beliefs, when a decision is called for.
- **Be available:** It is important to choose someone who can make themselves available when necessary. For example, someone whose job requires them to be far away from home or someone who has too many family or other obligations may not be the best person to choose.
- **NOT be a mental health or social service staff member:** This is to avoid any conflict of interest since staff may sometimes favour practices that are not necessarily what the person would have wanted (e.g. keeping the person at the hospital against the person's will).
- **Be revocable:** The nomination should be revocable at any time and the person should have the possibility to change their mind and to choose another person instead.
- **Be subject to accountability mechanisms:** Safeguards should be in place to check on how nominated persons are applying the "best interpretation" approach and to ensure that they do not abuse their role.

In addition, it may also be useful to nominate a person who is able to navigate the medical and/or social system and who is thus in a good position to ensure that the will and preferences of the person being respected.

Sometimes, little is known by service staff about the person's will and preferences (for instance, a person comes to a service alone and clearly distressed but then does not communicate and it is not possible to identify immediately any supporter in the person's life). If the person has come to the service, this would seem to indicate that the person is seeking support. It is important to give people time to express what kind of support they want. The fact that they have come to the service is not a reason to decide for them what treatment or support should be given or what action should be taken.

If no supporters can be identified, an independent person (e.g. an advocate) should be appointed. The appointed person should make every effort possible to identify the person's beliefs and values and to make decisions that are the best interpretation of the will and preferences of the person concerned.

However, because little is known about the person so far, the advocate's best interpretation may not be completely correct. Such situations must only be temporary. The appointed person has a duty to take steps to get to know the person better and to help them to build a social network, so that the person can personally choose a supporter.

Topic 5: Positive steps to adopt a supported decision-making approach

Time for this topic

Approximately 45 minutes.



Presentation: Key principles of supported decision-making (5 min.)

Recap with participants the key principles of supported decision-making:

1. Everyone has a right to make decisions.
2. People should be offered opportunities to receive support to make decisions.
3. People have a right to decline support that may be offered to them.
4. People should be able to receive support from persons they choose and trust and who can understand their values, wishes and background and can respect their will and preferences.
5. The level of support required depends on the complexity of the decision and the situation of the person who is making the decision.
6. People have a right to learn from experience and to make bad decisions.
7. People have a right to disagree with others.
8. People have a right to change their minds, including the right to terminate support if it is no longer desired.
9. Others must respect the will and preferences of the person at all times, including in crisis situations.
10. When it is not practicable, after significant efforts, to determine the person's actual will and preferences, a best interpretation of their will and preferences should be determined in order to respect their right to legal capacity.



Exercise 5.1: Personal action to promote supported decision-making (15 min.)

This brainstorming exercise is intended to encourage participants to discuss how they can personally implement and promote supported decision-making. This is meant to encourage the participants to commit to respect and strengthen people's autonomy through personal action.

Start by brainstorming with the participants a list of possible personal actions. Write ideas on the flipcharts. Ask the participants:

What action could you take personally to support people to make decisions?

Some examples may include (but are not limited to):

Get to know people as individuals. Get to know their opinions, their background, their social context and their supporters.

Take time to ask about and learn people's opinions, preferences, likes and dislikes, and do not assume that you know what they want.

Acknowledge the fact that you may not always agree with a decision, but you still want to support and respect the person and the decisions that they make.

Acknowledge the fact that people can change their minds.

Provide people with clear information.

Help people to find the information they need – if necessary, in a relevant format that they understand.

Give people time to reach a decision.

Do not dismiss someone's view even if it seems unrealistic to you.

Enable people to contact their friends, relatives and supporters when they need advice.

Provide people with opportunities to discuss choices in an informal way.

Help people to identify support persons around them.

Talk with the person concerned about the option to receive support in settings different from the mental health or social service (e.g. at home, in the community, at a friend's place, etc.).



Presentation: Tips for supporters (5 min.)

- Take time to listen and to learn from the person to understand what they want: some people may require more time to formulate what they want to say. Use active listening to encourage communication without pressing for immediate answers.
- Get to know the person that you support as well as their social context (e.g. what they like or dislike, what their goals in life are, and so on).
- Take time to discuss with the person the types of support they need and want, the decisions that are difficult for them to make, and the type of advice the person would like.
- Give people sufficient time to reach a decision on their own.
- Remain engaged with the person over time since their will and preferences may change.
- Pay attention to what might help or hinder a person to make certain decisions – e.g. are there barriers within services, in their family, or in the community?
- Remain aware that other people may try to influence you. Always keep in mind that the person you are supporting is driving the decision.
- Find information about individuals, networks or services providing extra support and advice.
- Find support for yourself, identify people or services that can help you in your role as a supporter.
- Learn how to cope with frustration. Sometimes it can be frustrating and even painful to respect the decisions of people we care about when we think they are wrong or that they might harm themselves. It is important to learn strategies for overcoming this kind of frustration.



Exercise 5.2: Action to promote legal capacity and supported decision-making at the level of mental health and social services (20 min.)

Invite participants to brainstorm together a list of changes that need to be implemented in mental health and social services in order to adopt a supportive approach, including the specific actions that need to be taken in order to implement those changes.

Ask participants the following question:

What could be implemented to facilitate supported decision-making in a mental health or social service?

Participants may think about a service they use or have used in the past, that they are working in, or that they have visited or have heard about. Then show possible responses to this question and ask the participants to comment on and discuss the different propositions:

- Develop and adopt service-level policies that promote legal capacity and supported decision-making.
- Provide the staff with information to understand the right to legal capacity and supported decision-making.
- Encourage staff to develop their communication skills.
- Systematically ask about and respect the will and preferences of people using the service.
- Promote training sessions and discussions on supported decision-making.
- Appoint information champions/mentors to promote the use of supported decision-making.
- Make sure that people using the service have access to the relevant information to make informed decisions – in an appropriate format if necessary.
- Involve people using the service in all mechanisms related to the organization, oversight and evaluation of the service to help develop a supportive approach.
- Regularly provide people using the service with the opportunity to connect with sources of support outside the service (e.g. independent advocacy organizations, peer support workers or groups, etc.).

Topic 6: What is advance planning

Time for this topic

Approximately 1 hour and 20 minutes.



Presentation: What is advance planning? (60 min.)

As we have seen in the previous session, supported decision-making can ensure that people take charge of decisions about their lives. Advance planning is one of the tools that can be used to ensure that the will and preferences of the person are considered and respected.

Advance planning refers to the process of making a person's choices and preferences about future situations known when the person experiences difficulty in making their will and preferences known to others and where a response may be needed. Other people (e.g. supporters, general health or mental health practitioners) can refer to the person's advance plan to make sure they follow the person's directives and respect what the person wants. Advance plans may prove particularly useful for persons who may be distressed, who experience psychosis or dementia, or who simply may want to specify their wishes in advance should they be unable to communicate them in the future.

Advance plans are sometimes called living wills or advance directives. These are generally written documents. However, people who are unable to write should have the possibility to record their will and preferences in audio or video formats or to receive support in writing them down.

In some communities and cultures, people may not have a tradition of writing documents (such as wills, contracts, etc.). However, this does not prevent people from expressing verbally or in other informal ways their choices about care, treatment and support.

People may develop an advance plan for crisis situations as part of a recovery plan. A recovery plan is a document written by a person (on their own or in collaboration with others) that helps to guide their recovery journey. It is a tool designed to help people to live the life they want and to achieve their goals. Advance planning is very useful in the context of a recovery plan because it helps people think through the things that they like and want and the things that they do not. It also provides guidance to others (e.g. health workers, families, friends, etc.). For more information on recovery plans, see the QualityRights module *Recovery practices for mental health and well being*.

People should always have a choice on whether or not to make advance plans. It should not be a requirement imposed by a mental health or social service or by a service staff member.

In some countries, the law makes advance plans binding. This means that other people (e.g. service providers, family and friends, etc.) are legally bound to respect the directives stated in the advance plan. In many cases, laws also outline situations when binding advance directives can be overridden (e.g. lifesaving emergencies, incompatibility with the known wishes and preference of the person).

- For instance, in the United Kingdom people can make binding advance plans but situations where they can be overridden include when the person requests something that is illegal (e.g. assisted suicide).

Content of advance plans

People can include as much or as little information as they want in their advance plan. However, the more details that people provide in the advance plan, the more likely it is to be implemented in the way that they want. In addition, thinking about and elaborating scenarios that people are likely to encounter can bring clarity to decision-making.

- **Nominated persons**

For many different reasons, some people may not want to write an advance plan. For instance, they may be confident that, if they are unable to communicate their decisions in the future, their partner, family members and/or friends will make a decision which is based on their will and preferences and which reflects their beliefs and values in life.

Even in these cases, an advance plan can still be useful to indicate who should be consulted. As explained earlier, the person can nominate one person or a group of people who would discuss in order to establish what is the best interpretation of the will and preferences of the person concerned.

Scenario – Yasmin

When a decision needs to be made in Yasmin's family, people generally come together to discuss and find a solution which everybody agrees on. Yasmin does not think that she can anticipate all the decisions to be made if she becomes unable to communicate her choices in future. In the area of health, she also thinks that science and medicine are constantly evolving and new treatments may become available. Therefore, she writes an advance directive stating that if one day she becomes unable to communicate her health decisions, she wants her husband, parents, brothers and sisters to gather and reach a decision based on what they think she would have wanted in these circumstances.

- **Directive for care, treatment and support for health-related needs**

Regarding health and mental health-related needs, people can specify:

- which treatment, care and support options they want
- which treatment, care and support options they do not want.

It is important to note that advance refusal of a support, care or treatment option is different from advance consent to a support, care or treatment.

- Advance refusal guarantees that a person will not be given that specific form of support, care or treatment.
- However, advance consent does not guarantee that the person will be given that form of treatment. Reasons why the person might not receive this support, care or treatment option may include, for instance, that the service does not offer this option or that resources do not allow for this type of treatment.

It is important to note that people may want to develop and implement their advance plan outside the context of mental health or social services and may wish include forms of support which are not related to health care (e.g. personal assistance, peer respite, etc.).

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

Planning ahead – living with younger onset dementia: (5:08) Original video produced by Office for the Ageing, SA Health, Adelaide, Australia
<https://youtu.be/8sVCoxYbLlk> , accessed 9 April 2019.
Acknowledgement: Kate Swaffer, Co-founder, Chair & CEO of Dementia Alliance International
www.infodai.org.

- **Directive for support in other areas of life**

In their advance plan, people may also want to specify their wishes about other aspects of their lives. For example:

- care of the children
- home
- bills and property
- taxes
- pets.

- **“Ulysses clauses”**

Advance plans should not prevent people from changing their mind and people should generally be able to revoke their plans at any time.

However, some people may wish to anticipate a situation in which they may express or state a wish or preference which is not in accordance with their values and long-term will.

In this case, they can **explicitly** specify that what they have stated in their advance plan should take precedence over their stated wishes and preferences during specific future events. This mechanism is called a “Ulysses clause” in some jurisdictions.

This measure should be used with caution, especially if it authorizes others to use force to override one’s will and preferences in the specified future event. An additional safeguard could be to have a group of supporters confirming that the Ulysses clause reflects the long-term will and preferences of the person and is consistent with what is written in the advance plan, despite the fact that the person is expressing contrary preferences at that moment.

After the situation has occurred, the person should carefully review the Ulysses clause, with the support of others if they want, to make sure that the course of action taken was helpful and consistent with their values and long-term will.

Examples of the use of Ulysses clauses:

1. *Kwame has been diagnosed with bipolar disorder. He knows that a particular type of medication has extremely negative effects on him. It is very clear to him that he does not want this type of medication. However, he is concerned that when he feels really low, he would not be assertive enough to object to whatever medication staff might offer him. Therefore, he decides to write in his advance directive that he does not want to be given this type of medication in any circumstance, even if he agrees to it during a crisis.*

2. *Li-Ming knows that at some time in the future she will find it increasingly difficult to make decisions about her life due to the progression of Alzheimer’s disease. She trusts her cousin who knows her very well and is always supportive of her decisions. However, she does not want her brother involved in decisions related to her life because he is likely to overrule her will and preferences since he often thinks he knows what is best for her. She therefore develops an advance directive indicating who can communicate her will and preferences (i.e. her cousin) if she is unable to communicate them, and also specifying some of her choices for her future that she can already identify – e.g. she wants to live at home and receive support there rather than go into a retirement home, she specifies how her money can be spent, who can have keys to her house, what medical conditions she needs medication for, which medications she is not prepared to take etc.*

When should advance plans come into effect (25)?

Currently, in most countries which have introduced advance planning mechanisms:

- Advance plans come into effect when people are assessed as not having mental capacity (i.e. the ability to make decisions). In this situation, once the advance plan comes into effect, the person is no longer allowed to make their own decisions directly or to change their mind.
- The law requires that people have “capacity” in order to make a valid advance plan. This means that people under guardianship cannot make a legally valid advance plan. It also means that advance plans will not be legally valid if they are made during crisis or other situations in which the person is not considered to have the ability to make decisions.
- Advance plans will sometimes not be considered as having effect in situations where a person is involuntarily admitted to a mental health or social service. Therefore, a person who is detained involuntarily can also be given treatment against their will despite the existence of an advance plan.

Although these types of advance documents can allow people to assert a degree of control and to negotiate about proposed support, care or treatment options, the legal restrictions placed on their implementation reduces their compliance with the CRPD.

The CRPD requires a completely different approach:

According to article 12 of the CRPD, people have the right to legal capacity **at all times**. Therefore, people should retain their right to make decisions directly and to change their mind, even if an advance plan has been drafted. The fact that people develop advance plans does not mean they are “legally incapable”.

People may find it useful to make their advance plan binding for situations in which they could be unable to communicate their will and preferences directly.

- This guarantees that others respect the directives stated in the plan.
- In these cases, the person should specify the situations or criteria in which the supporter can start to put the plan into effect, as well as the situations and criteria concerning when they should stop implementing the plan.
- The implementation of an advance plan should not prevent supporters from trying regularly to engage and communicate with the person directly in order to see how the person reacts to any action being taken, if they can communicate their will and preferences directly again and if these have changed.

When persons can communicate their will and preferences directly, advance plans can be useful **communication tools** to structure discussions:

- They are useful for exploring and discussing with supporters the possible scenarios requiring decision-making, the pro and cons of decisions, etc.
- They can help supporters to feel at ease with the plans and feel confident in putting them into practice.
- They can be used as a reference point for the will and preferences of the person. Supporters can remind the person of what they discussed and set down in the advance plan, but they should accept that the views of the person can evolve and that persons can change their mind.

Advance planning in countries

Example: German law (2009) (26)

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 vis-à-vis the practitioner.

The law adds that if the person does not have an advance directive, the person's presumed will and preference concerning treatment must be determined on the basis of concrete evidence such as previous oral statements.

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

Even when countries do not legally recognize advance plans, this does not prevent supporters, as well as mental health and other practitioners, from developing and implementing them.

Mental health and social services can:

- Put in place a policy to respect individuals' decision-making at all times.
- Inform people using services about the opportunity to create advance plans and can make necessary resources available to support them in developing their plan.
- Encourage people to make advance plans to anticipate future needs and scenarios and to nominate supporters.
- When the situation requires their use, respect the directives stated in a person's plan.

Advance plans do not replace the need and duty to respect a person's autonomy and right to legal capacity at all times. It involves respecting people's support, care and treatment choices, including in crisis situations.

The benefits of advance planning for service providers

Advance planning can also help service providers in their practice. Often, mental health and other practitioners are concerned that, if people refuse treatment, care or support, and if they do not use coercive measures to admit and/or treat people, they will be held responsible or liable for any bad outcomes that may occur.

The law should make sure that practitioners are not held responsible if they follow the instructions stated in the person’s advance plan.

This will help to remove barriers that may prevent practitioners from adhering to advance plans and from respecting people’s choices

Examples of advance plan templates

1. In this box, you can find an example of what a completed advance planning document might look like.

Advance PLAN Example Template

What are important to me in my life – my will and preferences:

- I value my independence above everything, and this should be the primary consideration in all issues affecting me and decisions communicated for me.
- I would like to receive my usual support and care at home but not at the mental health service.
- I am happy for my mother and best friend to be kept involved in supporting me but I do not want my father involved as I did not grow up with him and he does not know me well enough.

2. Current health issues should be included with directions about your preferences for how these should be managed and why.

HEALTH ISSUES including mental health issues, indicating what has helped and what has not helped

Health issue 1:

Management preference

Helpful:

Not helpful:

Health issue 2:

Management preference

Helpful:

Not helpful:

Health issue 3:

Management preference

Helpful:

Not helpful:

Health issue 4:

Management preference

Helpful:

Not helpful:

3. Consent or refusal for medical treatment, including “do not resuscitate” clauses.

I consent to the following medical treatment in (specify treatment and the specific circumstances for that treatment and reasons why)

I refuse the following medical treatment (specify treatment that you refuse, the specific circumstances and reasons why)

4. Unacceptable health outcomes after medical intervention, including high levels of dependency and care, not being able to communicate my wishes and preferences.

Health outcomes resulting from medical intervention that are unacceptable to me

5. Preferences and directives regarding related non-health issues.

This information enables supporters to get to know and understand a person's will and preferences and helps to ensure that these are respected. It provides important information about who the person would like to take care of children and pets if the person is temporarily unable to do so, and also information about the activities that the person likes to do.

Children, Accommodation, Keys, Pets, Garden, Relationships, Social ties, Work

6. People to consult on different areas of my life (e.g., finances, relationships, daily tasks, health matters).

Important aspects about me that I would like people supporting me to know about (e.g. interests, daily routines, life history, etc.)

About me

Finances

Relationships

Daily routine tasks

Health matters

7. If I am dying the following things are important to me.

If I am dying, the following things are important to me



Exercise 6.1: planning ahead (15 min.)

The aim of this exercise is to encourage participants to think about the type of information they would need to consider in order to prepare an advance plan.

Ask the participants the following question:

What information do you need to gather or consider before drafting an advance plan?

Possible responses could include (but are not limited to):

What is important to me in my life?

What are my preferences for treatment and support in relation to different health conditions (e.g. terminal illness, mental health crisis, coma, dementia, chronic health issue)?

Do I want to include a “Do not resuscitate” clause in my advanced plan?

What are the different treatment, care and support options that can help my recovery in relation to health and life challenges?

Are there specific people that I would like to support me to make decisions in different areas of my life? Who are they?

How do I want others to respond to me if I am unable to communicate my decisions and choices?

Where would I like to be supported?

What are the pros and cons of the different treatment, care and support options for my health condition, and of having none of these?

Who can help me with daily life obligations (e.g. bills, children, pets)?

What are my rights concerning treatment, care and support (e.g. my right to refuse treatment and my right to choose one practitioner or health-care provider over another)?

Topic 7: Making advance planning documents

Time for this topic

Approximately 2 hours and 10 minutes.

Now that the purpose and prerequisites of advance planning are understood, it is important to look at the process of making advance planning documents. The following presentation will describe different steps that may be helpful in doing so. Each step will be different for everyone. Some people may need to spend more time on a particular step while others will already have a very clear idea of what they want.



Presentation: Steps for making an advance plan (30 min.)

It is important to remember that no-one should be forced to make an advance plan. In addition, remember that an advance plan should reflect the will and preferences of the person, not those of other people.

Mental health and other practitioners, family members and care partners are strongly encouraged to develop their own advance plan in order to be familiar with and support more effectively others undertaking this process.

Step 1: Think about it

The first step is to think about how to approach advance planning. Some aspects to consider include:

- Do I want to prepare the advance plan by myself or involve other people?
- What is important to me in my life?
- What are my preferences for treatment and support in relation to different health conditions (e.g. terminal illness, mental health crisis, coma, dementia, chronic health issue)?
- Do I want to include a “Do not resuscitate” clause in my advanced plan?
- What are the different treatment, care and support options that can help my recovery in relation to health and life challenges?
- How do I want others to respond to me if I am unable to communicate my decisions and choices, or if they think I am experiencing a mental health crisis, and where would I like to be supported?
- What are the pros and cons of the different treatment, care and support options for my health condition, and of having none of these?
- Who can help me with daily life obligations (e.g. bills, children, pets)?
- What are my rights concerning treatment, care and support (e.g. my right to refuse treatment and my right to choose one practitioner or health-care provider over another)?

It is useful to identify people who can be consulted for help when making or implementing an advance plan. Questions to think about include:

- Are there specific people who I would like to support me to make decisions in different areas of my life? Who are they?
- Who can I trust to support me and communicate my will and preferences?

- Who would be a good contact person if I experience a crisis?
- Who knows me well?
- Who shares the same beliefs/values/vision of life?

The people to consult might include, for example:

- Partner/husband/wife
- Friends
- Family members
- Care partners
- Mental health and other practitioners
- Trained facilitators
- Someone in a peer role
- Religious or community leaders.

Step 2: Discuss

Once persons have identified the people who they want to be involved in the advance planning process, they can discuss the possible options with them if they wish. Alternatively they may wish to research the different options first and then discuss them with potential experts or supporters.

For instance, practitioners or a peer can advise about what treatments, care and support options are available for different health conditions, and the implications and possible negative effects of accepting or refusing certain kinds of medical treatments, etc. People who provide advice should be aware of the various alternatives available to the person concerned. They should be open to different options and not be fixed in their view as to the most appropriate option.

The person may also want to discuss with family and friends the implications of certain options for them.

Discussion should identify who would be ready to offer practical help to the person concerned (e.g. with daily obligations and routines).

Step 3: Be aware of the legal framework

In some countries, certain advance planning documents are legally binding. In some cases, this means that a specific procedure needs to be followed if the directive is to be considered enforceable. It may be necessary to ensure that the document is dated and signed by the person concerned. The law may also require witnesses to sign the plan, sometimes in front of an official authority.

It is also very important to know in advance whether there are any specific circumstances in which other people will be exceptionally authorized to override a binding advance planning document.

Lawyers, independent advocates, peer supporters or organizations of persons with disabilities may be able to provide the information needed.

Step 4: Formalize the advance plan

Now that the person has an idea about what he or she wants in terms of future care, support and treatment and who they want to be involved, they can document their choices in writing. If an advance planning form already exists in that country, then that form should be completed. If no such form currently exists, it is possible to record choices on a recovery plan or a separate document.

Some people may require assistance in formulating the advance plan in order to ensure that their will and preferences are clearly stated and are understandable to everyone, without possibility of confusion or ambiguity. Some services or organizations may provide the support of independent trained facilitators or advocates for this process.

Step 5: Make others aware that the advance plan exists

It is important to make sure that others are aware of the existence of the advance plan so they can refer to it when necessary.

The person who filled in the form should retain a copy and other copies should be given to all relevant persons, including family members, friends and supporters as well as mental health and other practitioners. Copies of the advance plan should be kept in the person's medical records. In some countries, online registry (i.e. a registry where copies of all advance plans are kept) or crisis card systems (i.e. cards on which people state their will and preferences and that can be kept in a wallet) may also be available. With new technologies it is easier to make advance plans accessible (e.g. a copy can be kept on one's telephone at all times).

Step 6: Review the advance plan periodically

People's choices and preferences concerning care, support and treatment may change and evolve over time. Similarly, advance plans may need to be changed and updated in order to reflect new will and preferences, especially when people experience significant changes in their lives. In such situations it is essential to ensure that copies of the new plans replace the old ones, and that everyone concerned is provided with the changed/updated advance plan.

As a person's will and preferences are continually evolving, including during crisis situations, it is very important for supporters to remain engaged with the person on an ongoing basis. This is to ensure that they are considering not only what is stated in the document but also the current wishes of the person, and that they are not referring to outdated documents that no longer reflect the current will and preferences of the person.



Exercise 7.1: What others must know... (40 min.)

This exercise is intended to encourage participants to think about possible information that could be included in an advance planning document that they would develop for themselves.

Provide participants with a copy of Annex 8 and ask them to complete at least three sections of the advance plan template. Once the exercise has been completed, the facilitator can discuss responses to the different sections in plenary.



Presentation: Tips when making an advance plan: (5 min.)

When people make an advance plan, they may need to think about difficult past experiences which can be distressing. Here is some advice that may help:

- People do not need to make a complete advance plan all in one go. They can take breaks if necessary or draft it over the course of several days or weeks.
- People should develop their advance plans when they are feeling good, not when they are feeling bad.
- It can be useful for the person to ask someone they trust to support them in the process of developing their advance plan (e.g. a peer support worker or a close, trusted friend). The supporter(s) may find it useful to create their own advance plan in the meantime.
- It can also help to have support from someone who has already created their own advance plan and who can therefore offer suggestions or share how they created their plan.



Exercise 7.2: Discussion: Real-life examples of advance statements (20 min.)

In this exercise it should be made very clear to participants that people are free to include whatever they want in their advance planning documents. However, one concern expressed by some mental health and other practitioners is that people will include unrealistic and unreasonable requests or refuse every kind of treatment and support. This exercise is intended to overcome that concern.

Here is a list of real statements (27),(28) expressed in advance planning documents in India and the United Kingdom.

Provide participants with Annex 9 and give them time to read the statements. Emphasize that they are real-life examples:

“I would like people to tell me about, or give me feedback on, the symptoms they observe and tell me what’s wrong.”

“I don’t want threats of injection; I would like people to talk to me and explain the need to take medication.”

“If I am in hospital for a long period, I would like nurses to arrange for me to have a haircut.”

“I have been in and out of hospital because the assessment was done by people who do not know me and didn’t pick up that I was becoming unwell therefore kept discharging me. I would like the triage ward not to discharge me before speaking to my consultant”.

“[I would like] clarity in my medication – a proper plan of who is giving me my medication and when.”

“I would prefer to be in hospital on an informal basis so I can be involved in decision-making concerning my care.”

“Medication A I do not want; it makes me experience bad dreams. B makes me feel worse and I would prefer medication C to medication D.”

“It is also very important for me to look after my appearance as this makes me feel better.”

“I prefer not to talk to someone who takes things personally (e.g. family)”

“I prefer to be treated at home because when I am in hospital I worry about my children.”

“[During a crisis] the Home Treatment team can give me extra help. If the Respite home is available, I could stay there. If [my husband] is struggling I could come into hospital informally.”

“I don’t like medicine that makes me very sleepy.”

“[Please don’t prescribe] medicines which cause drowsiness.”

Encourage the group to express their views on these statements. You can ask the following questions:

- Do you think that these statements make good sense?
- Can you understand why people have included these statements in their advance planning documents?



Exercise 7.3: Supporting people in making advance planning documents (30 min.)

This exercise is aimed at encouraging participants to think about different ways to enable people to make advance planning documents. Ask participants the following question:

What could be done in mental health and social services to facilitate the drafting of advance planning documents?

Possible answers may include:

Provide information and training to the staff about advance planning.

Encourage staff to complete their own advance plan to better understand the process.

Provide information to people about advance planning.

Hold a regularly check with the person who has made an advance plan to see if they need to modify it.

Check with people who have not made a formal advance plan to see whether they wish to do so. If so, refer them to an independent advocate to assist in developing the advance plan.

Don’t pressure people to fill in their plan. Allow them to have time and space to think about their plan, consult others and write their advance plan at their own pace.

Link people using the service with trained persons who can facilitate the development of advance planning documents.

Organize a workshop to enable people to learn about the process and to start drafting their advance plans.

Provide accommodations for those who will need assistance in drafting advance planning documents – e.g. by allowing people who are unable to write to have their wishes and preferences recorded.

Ensure that advance planning documents are not lost or forgotten. For instance, make a clear mention of the existence of an advance plan in the person’s medical record, have the advance plans written or printed in a bright colour, and keep the plan in an online location that is accessible to supporters and service providers.

Plan regular meetings to discuss with staff the existence of advance planning documents and treatment and care options chosen by people using the service.

Develop a service policy that highlights the requirement of service staff to respect people’s will and preference at all times, and by instituting the voluntary use of advance plans.



Reflective exercise: Concluding the training (5 min.)

Facilitator note: to conclude this module, ask the participants the following questions:

What are the key points you will retain from this module?

Has the way in which you think about people's ability to make decisions changed?

Has your understanding of how people can be supported in making decisions changed?

If yes, how has it changed? If not, why do you think it has not changed?

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Annexes

Annex 1: Scenarios

Topic 1: Presentation - Challenging misconceptions and negative stereotypes in mental health, Elena

Elena has been diagnosed with an intellectual impairment. She used to find it difficult to manage her budget because she often forgot how much money she had already spent. Consequently, she always lacked money and did not have a sufficient budget for food. One of her friends informed her about an application she could download to her telephone to keep track of her expenditures. Elena's parents thought that the application was not going to work and that she needed a guardian to control her money. However, Elena searched for the app, and then decided to use it. Now, whenever she is not sure, she consults her telephone to see how much money she has left in her bank account and what she has already bought. She is even able to save some money every month.

Topic 1: Presentation - Challenging misconceptions and negative stereotypes in mental health, Feng

Feng is a man who has heard voices since he was an adolescent. Most of the time, these voices describe his actions. However, when Feng is particularly stressed the voices can become threatening and order him to act in certain ways (e.g. saying that other people want to attack him and that he should attack them first to protect himself). Feng's family thought that because of this he could not have a normal life and that he would need a guardian. However, after years of experiencing voices, Feng has managed to live with them. He knows that sometimes they are communicating something very important about his emotions (e.g. that he is stressed, worried or tired) and whenever they suggest he must take action, he talks about this with key people in his life before making any decisions or taking action that causes him distress or which he believes is potentially harmful. He currently leads a full life and this year he has graduated from his university.

Topic 1: Presentation - Challenging misconceptions and negative stereotypes in mental health, Amara

Amara has received a diagnosis of bipolar disorder and has been taking medication for several months. After reflecting for a long time, she decides to stop taking her medication. Everyone around her thinks it is a terrible idea because the previous times she stopped taking her medication she was admitted to hospital. However, Amara has stability in her life now and is confident that she can manage her life without this type of treatment. Her doctor advises her against stopping the medication and explains to her what the risks of doing so are. However, the doctor also provides Amara with resources concerning withdrawing from the medication. After listening to the doctor, Amara still maintains her decision, and the doctor respects this. They decide together that if Amara experiences difficulties with the withdrawal, she can contact the doctor to discuss the situation further. The doctor promises Amara that she will not treat her against her will or pressure her to take medication at any time. Both Amara and her doctor will investigate approaches that do not involve medication and where they are available in the local area (such as crisis respite), so that Amara has meaningful options from which to choose if she experiences difficulty with the withdrawal or at any other time.

Topic 1: Presentation - Challenging misconceptions and negative stereotypes in mental health, Lucas

Anna, Lucas' sister, goes with Lucas to a community-based mental health centre because he is experiencing a period of deep sadness that has left him unable to get out of bed and go to work most days. He has been experiencing such phases for quite a while now and has tried several treatments.

He knows from past experience that most antidepressants make him feel irritated and lead to insomnia. He has had good results with interpersonal group therapy before, so he says he would be willing to receive this type of support and explains his reasons to the workers at the community-based mental health centre.

Topic 1: Presentation - Challenging misconceptions and negative stereotypes in mental health, Anna

Anna hears voices and sometimes responds to them out loud. She enjoys technology very much and would like to take formal studies in engineering. Her parents disagree and tell her that the classes are too expensive. The real reason is that they are afraid that people will make fun of Anna and that she will become isolated during her studies, especially as there are so few women in this field.

Topic 1: Presentation - Challenging misconceptions and negative stereotypes in mental health, Eunice

Eunice is a woman diagnosed with major depression. During her pregnancy, for a time she experienced the inability to get up and go to work. She would also cry for most of the day. She therefore decided to go to a mental health service with her partner. During the consultation, the doctor ignored her and spoke directly to her partner, telling him that he would recommend an abortion since Eunice would be likely to become worse with the added pressure of looking after a child.

However, even though she was feeling unwell, Eunice did not allow the doctors to perform the abortion.

Now, Eunice and her partner have a 5-year-old lively daughter and are happy. The fact that Eunice was able to decide for herself about her own body, even when experiencing a crisis, was fundamental in her recovery.

Topic 1: Presentation - Challenging misconceptions and negative stereotypes in mental health, Tareq

Tareq is a young man with an intellectual disability. Three days a week he works in a grocery store. This means that for the remaining days of the week he does not have any structure for his day which makes him feel frustrated and insecure. Fortunately, Tareq was able to get the support of a personal assistant who can help him to structure his free days on weekly basis. Most days Tareq has several ideas about what he would like to do and makes plans himself – such as visiting a neighbour, making lunch, and riding his bicycle to the city centre to meet a friend. On other days he has more difficulty deciding what he wants to do and on these days his personal assistant is really helpful in proposing options for things Tareq can do during the day. Sometimes, Tareq will call his personal assistant several times during the day to ask questions when things do not go to plan. The assistant listens to him and suggests options when he asks.

Topic 1: Presentation - Challenging misconceptions and negative stereotypes in mental health, Gavin and Michael

Gavin and his partner Michael are working together to make decisions related to finances and avoid the kind of problems they experienced earlier when Gavin would make impulse purchases. One thing Michael learned quickly was to ask Gavin what he wanted to purchase and why, rather than telling him what he should or should not do. When Michael was able to engage with him in this way, they would have more productive conversations about what he wanted to spend money on and why, and

Michael could understand the emotional needs he was trying to fill with purchases at certain times in his life. These conversations also allowed Gavin to understand and consider other possible ways for his needs to be met.

Topic 1: Exercise 1.2 Examples of denials of the right to legal capacity, João

João was diagnosed with schizoaffective disorder and was told that he has anosognosia which, the staff of the service explained, means “lack of insight” or “lack of awareness”. He is told the reason he thinks he does not need medication is because he does not know how truly ill he is and the belief that he does not need medication is just a symptom of the illness. He is told that if he refuses to take the medication they will need to re-evaluate his ability to make other important decisions in life, like returning to work.

Topic 1: Exercise 1.2 - Examples of denials of the right to legal capacity, Rania

Rania has an intellectual disability. She works at the local library four days a week. Thanks to this job, she is able to save some money. She would like to go on holiday to visit her cousin in the south and use this money to buy a train ticket. However, her father is her legal guardian, and he thinks that it is unsafe for Rania to travel, so he does not allow her to go out to buy a train ticket.

Topic 2: Exercise 2.3 – Understanding Support in Supported Decision-Making, Sunita (1)

One morning Sunita has her first consultation at the mental health unit of a teaching hospital. She appears to be very agitated and explains that she is feeling very down. She subsequently receives a diagnosis of depression.

The medical officer insists that she immediately starts to take antidepressants although she says she does not want to take medication. She reluctantly starts the treatment, but she becomes increasingly nervous, irritable and agitated on the medication. She returns to the service and the medical officer in charge at her first appointment prescribes her benzodiazepines to manage her agitation.

The sedating effect of the medication makes it difficult for her to interact with other people and after several weeks she becomes isolated, loses confidence in herself and feels even worse. She also decides to take herself off the medication but she experiences withdrawal symptoms, including severe headaches, nausea and insomnia. She never had an opportunity to talk about what was troubling her.

Topic 2: Exercise 2.3 – Understanding Support in Supported Decision-Making, Sunita (2)

One morning Sunita has her first consultation at the mental health unit of a teaching hospital. As she seems distressed and agitated, the medical officer in charge suggests to Sunita that they go to a quiet room in order to discuss what is troubling her. The medical officer asks Sunita if she would like to share her feelings with her and tell her a little more about her situation.

Sunita explains that she has been feeling very down during the past months to the point that she was neglecting herself: she has not been washing regularly, and her eating and sleeping have become irregular. Sunita is reluctant to go into the details of why she is feeling distressed and agitated.

She says she would like care and support but does not want antidepressants as her experience with these in the past was not positive. The medical officer says there are different types of medication which she could try. She also explains that there are alternatives to drug treatments such as individual psychotherapy, group therapy or counselling sessions which might be helpful to Sunita. She also

suggests that Sunita could explore and engage in activities available in the community that might make her feel better, such as relaxation yoga classes.

She offers to schedule an appointment with the psychiatrist, the peer support worker, the psychologist and the occupational therapist to discuss the different options. She asks Sunita if she would prefer to have a brief stay at the mental health unit or to go home and receive support there. She also asks if there are people who Sunita trusts and whom she would like to contact to support her.

Sunita knows and values a good friend of hers who has had similar experiences with depression with whom she has been spending time recently. She feels that her friend can help her weigh up the pros and cons of different treatments, care and support options, and help her to make a decision. The medical officer says that Sunita could nominate her as a supporter and involve her in the formulation of her recovery plan.

Sunita now feels more comfortable with the medical officer and about the support she will receive. She opens up to the medical officer that things are really difficult for her at home and that her husband is abusive. The medical officer says that there is a very good NGO which supports women in her situation and shelters women who are in danger. She offers to give her the contact of the organization.

Topic 3: Exercise 3.1 Scenarios -Deciding on supporters and support options, Ximena (1)

Ximena is a 79-year-old woman who lives on her own in a small apartment. She is separated from her husband of 30 years with whom she has very little contact. They have two children, both of whom live in different parts of the country. She has a few close friends who live near to her.

Ximena has noticed that she has been forgetting important appointments, forgetting to make payments, getting confused about where she is and how she got there, and not being able to distinguish between dreams and real activities. She thinks this might be because she is withdrawing from some medication that she has been taking for years. She sees her doctor who refers her to specialized testing, after which she receives a diagnosis of vascular dementia. She is devastated to hear about the diagnosis, fears for her future and what will happen to her and that she will end up in a nursing home isolated and neglected and not able to do the things she enjoys with her friends who live nearby in the local neighbourhood.

Topic 3: Exercise 3.1 Scenarios -Deciding on supporters and support options, Ximena (2)

Ximena acknowledges that she does need some support but at this stage preferred to limit this to a small range of informal supports. She has automated all regular payments that need to be made, and she has automated reminder messages for routine tasks and appointments that need to be carried out. She has discussed her situation with her friends and they are more than happy to provide additional support to accompany her to appointments and to help her keep track of them. After several discussions with a social worker, she has planned an advance directive that specifies her wishes for the long term. She has discussed this with her family and friends, which has brought a great deal of relief and reduced her anxiety about some aspects of the future. Ximena maintains a good relationship with the social worker who helped her to initiate an advance directive and who visits her once a month to see if everything is going well. Ximena knows that she (and her family and friends) can call the social worker at any moment.

Topic 3: Exercise 3.1 Scenarios -Deciding on supporters and support options, Jack (1)

Jack is a young man with two children whose experience of low moods sometimes makes it challenging, and even overwhelming, for him to raise his children on his own.

At times, Jack finds it extremely difficult to manage the emotional and financial needs of the family as well as the logistics of the home. He really wants his children to have a good life because his own parents were unable to take care of him properly when he was a child, and he does not want his children to experience the same hardships.

Jack would like support in managing certain aspects of his home and family life. He gets on very well with his brother (Marlo) as well as his best friend Jane and approaches them to explore the possibility of supporting him.

Topic 3: Exercise 3.1 Scenarios -Deciding on supporters and support options, Jack (2)

Jack contacts Jane and Marlo and tells them he would like them to attend a couple of his counselling sessions during which they could discuss parenting issues. Once they have met with the counsellor, they agree on a plan:

- His friend Jane will check in on him on a regular basis in person or by phone.
- Marlo says he will look into family supports that may be available for Jack and will help him fill in any forms that may be required or accompany him if any visits to social services are necessary.
- The brother and friend will sometimes take the children for the weekend if Jack is feeling overwhelmed.
- They also agree to be available to discuss any big decisions concerning the children (e.g. schooling, holidays, etc.).

Counselling sessions will also be organized for the children to help them understand the situation, to support their relationship with their father, and to make sure that they don't feel abandoned or neglected when their father feels unwell.

Topic 3: Exercise 3.2 – Scenarios- challenging situations, Claudia

Claudia is a young woman and has always wanted to have a child. She has a boyfriend with whom she plans to marry. Claudia lives with her parents and they support her in her daily life. Her parents have told her that they do not give permission for her to marry or have a child and have placed limitations on Claudia seeing her boyfriend. They believe there are too many risks involved and that she would not be able to care for a child on her own due to her having an intellectual disability. Her general practitioner has also told her that it would be irresponsible for a person with an intellectual disability to have a child.

Topic 3: Exercise 3.2 – Scenarios- challenging situations, Nasima

Nasima is a woman who has been bullied and teased by others since she was a child. Even as an adult, her parents decided it is better to keep her at home where they believed she will be more secure and less likely to be harmed by the bullying. They also stop her from going to the market and participating in community festivals – activities which she loves. Since Nasima completed school, she has not been eligible for entitlements and community supports. She desperately wants to find a way to have her own money. However, she has great difficulty finding a position that accommodates her needs and requirements.

Topic 3: Exercise 3.2 – Scenarios- challenging situations, Christopher

Christopher is a young man who has suddenly and drastically changed the direction of his life. Recently, he started to have many different ideas about a career for himself but has been moving quickly from one idea to another. Most recently, he has decided to pick up dogs and cats from streets in order to save them. He has decided that the garden of the mental health service is the place most suitable for them, so he comes to visit the service in order to ask staff their permission to create an animal shelter there. He tells them that he wants to sell his personal belongings in order to invest more money in his project.

Topic 6: Presentation – What is advanced planning? Yasmin

When a decision needs to be made In Yasmin’s family, people generally come together to discuss and find a solution which everybody agrees on. Yasmin does not think that she can anticipate all the decisions to be made if she becomes unable to communicate her choices in future. In the area of health, she also thinks that science and medicine are constantly evolving and new treatments may become available. Therefore, she writes an advance directive stating that if one day she becomes unable to communicate her health decisions, she wants her husband, parents, brothers and sisters to gather and reach a decision based on what they think she would have wanted in these circumstances.

Annex 2: Confessions of a non-compliant patient

By Judi Chamberlin¹

A famous comedian once said, "I've been rich, and I've been poor, and believe me, rich is better." Well, I've been a good patient, and I've been a bad patient, and believe me, being a good patient helps to get you out of the hospital, but being a bad patient helps to get you back to real life.

Being a patient was the most devastating experience of my life. At a time when I was already fragile, already vulnerable, being labelled and treated only confirmed to me that I was worthless. It was clear that my thoughts, feelings, and opinions counted for little. I was presumed not to be able to take care of myself, not to be able to make decisions in my own best interest, and to need mental health professionals to run my life for me. For this total disregard of my wishes and feelings, I was expected to be appreciative and grateful. In fact, anything less was tacked as a further symptom of my illness, as one more indication that I truly needed more of the same.

I tried hard to be a good patient. I saw what happened to bad patients: they were the ones in the seclusion rooms, the ones who got sent to the worst wards, the ones who had been in the hospital for years, or who had come back again and again. I was determined not to be like them. So I gritted my teeth and told the staff what they wanted to hear. I told them I appreciated their help. I told them I was glad to be in the safe environment of the hospital. I said that I knew I was sick, and that I wanted to get better. In short, I lied. I didn't cry and scream and tell them that I hated them and their hospital and their drugs and their diagnoses, even though that was what I was really feeling. I'd learned where that kind of thing got me – that's how I ended up in the state hospital in the first place. I'd been a bad patient, and this was where it had gotten me. My diagnosis was chronic schizophrenia, my prognosis was that I'd spend my life going in and out of hospitals.

I'd been so outraged during my first few hospitalizations, in the psychiatric ward of a large general hospital, and in a couple of supposedly prestigious private psychiatric hospitals. I hated the regimentation, the requirement that I take drugs that slowed my body and my mind, the lack of fresh air and exercise, the way we were followed everywhere. So I complained, I protested, I even tried running away. And where had it gotten me? Behind the thick walls and barred windows and locked doors of a "hospital" that was far more of a prison than the ones I'd been trying to escape from. The implicit message was clear: this was what happened to bad patients.

I learned to hide my feelings, especially negative ones. The very first day in the state hospital, I received a valuable piece of advice. Feeling frightened, abandoned, and alone, I started to cry in the day room. Another patient came and sat beside me, leaned over and whispered, "Don't do that. They'll think you're depressed". So I learned to cry only at night, in my bed, under the covers without making a sound.

My only aim during my two-month stay in the state hospital (probably the longest two months of my life) was to get out. If that meant being a good patient, if that meant playing the game, telling them what they wanted to hear, then so be it. At the same time, I was consumed with the clear conviction that there was something fundamentally wrong here. Who were these people that had taken such total control of our lives? Why were they the experts on what we should do, how we should live? Why was the ugliness, and even the brutality, of what was happening to us overlooked and ignored? Why had the world turned its back on us?

¹ Chamberlin J. Confessions of a non-compliant patient. *J Psychosoc Nurs Ment Health Serv.* 1998;36(4):49–52.

So I became a good patient outwardly, while inside I nurtured a secret rebellion that was no less real for being hidden. I used to imagine a future in which an army of former patients marched on the hospital, emptied it of patients and staff, and then burned all the buildings to the ground. In my fantasy, we joined hands and danced around this bonfire of oppression. You see, in my heart I was already a very, very bad patient!

One of the things I had already discovered in my journey through various hospitals, which culminated in my involuntary commitment to the state hospital, is that psychiatric drugs didn't help me. Every drug I was given made me feel worse, not better. They made me fat, lethargic, unable to think or to remember. When I could, I refused drugs. Before I got committed, I used to hide the pills in my cheek, and spit them out when I was alone. In the state hospital, I didn't dare to try this trick. I dutifully swallowed the pills, hating the way they made me feel, knowing that, once I was free, I would stop taking them. Once again, I was non-compliant in thought before I could be non-compliant in deed.

Now I want to make one thing very clear here. I am not advocating that no one should take psychiatric drugs. What I am saying, and I want to make sure this point is understood, is that each individual needs to discover for himself or herself whether or not the drugs are part of the solution, or part of the problem. Many people I know and respect tell me that they would not be where they are in their recovery were it not for the particular drugs that they have found work for them. On the other hand, many others, of which I am one, have found that only when we clear ourselves of all psychiatric drugs do we begin to find the road to recovery. We need to respect these choices, and to understand that there is no one single path for all of us.

Psychiatric drugs, like all drugs, have side-effects. If the positive effects outweigh the negative effects, then people will generally choose to take the drugs. When the negative effects, however, outweigh the positive ones, then the choice not to take the drugs is a good and reasonable one. Side-effects can be more easily tolerated when one is gaining something positive in return. Let me give an example from my own experience. Every day, I take anti-inflammatory drugs to control the symptoms of arthritis. Without these drugs, I would be in pain much of the time, and would find it difficult to move easily. I'm willing to put up with the danger of developing ulcers (and I take another drug to help protect my stomach), because the cost-benefit ratio works out in my favour. If, on the other hand, the anti-inflammatory drug didn't relieve the arthritis pain, then the cost-benefit ratio would go the other way, and I would stop taking the drug and discuss with my rheumatologist what other approach to try.

Here is the key difference between what happens to psychiatric patients and what happens to people with physical illnesses. With my rheumatologist, and with my lung doctor (I also have a chronic lung disease). I am a full partner in my own treatment and recovery. I am consulted, listened to, and given the information I need to make informed choices. I acknowledge that the doctors have expertise that I lack, and they, in turn, acknowledge that I have information about the workings of my own body that they need to guide them in their recommendations. Sometimes, we disagree. Then we talk about it. Sometimes I take their advice, while other times I don't.

Psychiatric patients, on the other hand, are usually assumed not to know what is best for us, and to need supervision and control. We are often assumed to be talking in code; only so-called "experts" can figure out what we really mean. A patient who refuses psychiatric drugs may have very good reasons – the risk of tardive dyskinesia, for example, or the experience of too many undesirable negative effects. But professionals often assume that we are expressing a symbolic rebellion of some sort when we try to give a straightforward explanation of what we want, and what we don't want. I'm sure you've all heard the many psychiatrist jokes that feature the punch line, "Hmm, I wonder what

he means by that?" Well, doctor, I want to tell you, we usually mean just what we are saying. In the slogan of the women's movement: "What part of no don't you understand?"

I consider myself a very lucky person. I don't think that I have some special talent or ability that has enabled me to recover when so many others seem stuck in eternal patienthood. I believe that recovery is for everyone. In the words of the mission statement of the National Empowerment Center, we carry a message of recovery, empowerment, hope and healing to people who have been diagnosed with mental illness. We carry that message with authority because we are a consumer-run organization and each of us is living a personal journey of recovery and empowerment. We are convinced that recovery and empowerment are not the privilege of a few exceptional leaders, but rather are possible for each person who has been diagnosed with a mental illness. Whether on the back ward of a state mental institution or working as an executive in corporation, we want people who are mental health consumers to regain control over their lives and the resources that affect their lives.

One of the elements that makes recovery possible is the regaining of one's belief in oneself. Patients are constantly indoctrinated with the message, explicit or implicit, that we are defective human beings who shouldn't aim too high. In fact, there are diagnostic labels, including "grandiosity" and "lack of insight," to remind us that our dreams and hopes are often seen as barriers to recovery instead of one of its vital components.

Professionals and patients often have very different ideas of what the word "recovery" means. Recovery, to me, doesn't mean denying my problems or pretending that they don't exist. I have learned a lot from people with physical disabilities, who think of recovery not in terms, necessarily, of restoring lost function, but of finding ways to compensate or substitute for what one may be unable to do. Some of the most able people I know, in the true sense of the word, are activists in the physical disability movement – they may not be able to see, or hear, or move their limbs, but they have found ways to do the things they want to do despite these difficulties, and despite those professionals who advised them not even to try. Without our dreams, without our hopes for the future, without our aspirations to move ahead, we become truly "hopeless cases".

I often hear professionals say that, while they support the ideas of recovery and empowerment in principle, it just won't work for their clients, who are too sick, too disabled, too unmotivated. Whenever I hear these objections, I want to know more about what kinds of programs these professionals work in, and what goes on there. I know that the professionals who knew me as their patient thought the same things about me. That's the dilemma of the "good patient". A good patient is one who is compliant, who does what he or she is told, who doesn't make trouble, but who also doesn't ever really get better. A "good patient" is often someone who has given up hope and who has internalized the staff's very limited vision of his or her potential.

Now, again, I want to make myself clear. I'm not saying that mental health professionals are evil people who want to hold us all in the grip of permanent patienthood, and who don't want us to get well. What I'm saying is that there's something about being a "good patient" that is, unintentionally perhaps, incompatible with recovery and empowerment. When many of us who have become leaders in the consumer/survivor movement compare notes, we find that one of the factors we usually have in common is that we were labeled "bad patients". We were "uncooperative," we were "non-compliant," we were "manipulative," we "lacked insight". Often, we were the ones who were told we would never get better. I know I was! But twenty-five years of activism in the consumer/survivor movement has been the key element in my own process of recovery.

Let's look at this word "compliance". My dictionary tells me it means "acquiescent," "submissive," "yielding". Emotionally healthy people are supposed to be strong and assertive. It's slaves and subjects who must be compliant. Yet compliance is often a high value in professionals' assessments of how well we are doing. Being a good patient becomes more important than getting well. It's like the healthy

woman/healthy person dilemma. Psychological researchers have found that while emotionally healthy adults, gender unspecified, are supposed to be assertive and ambitious, emotionally healthy women are supposed to put others' needs before their own. If you're a woman and fulfill the stereotyped "woman's role," then you're not an emotionally healthy person. If, on the other hand, you are strong and assertive, then you can be labeled as not being an emotionally healthy woman.

Getting better, we were informed by staff, meant following their visions of our lives, not our own. Let me give you an example, from a book called Reality Police by Anthony Brandt:

[Brandt says] I was thought to be a hopeful case, for example, so the doctor assigned to it worked up a life plan for me...I was to stay in the hospital three months or so to stabilize my life, she said. When I seemed up to it, I would go to work in the hospital's "sheltered workshop" where I would make boxes for IBM and be paid on a piecework basis. When I had made enough boxes I would then be moved to the halfway house in Kingston, across the Hudson, where they would arrange a job for me in a special place called Gateway Industries established for the rehabilitation of mental patients. There I would presumably make more boxes. Eventually I might move out of the halfway house into my own apartment.

What Anthony Brandt's doctor didn't know was that Brandt was not a "mental patient" at all. He was a writer who had feigned the symptoms of mental illness in order to find out first-hand what the life of a mental patient was like. He had a successful career and a real life that he could return to. He didn't have to accept limited view of his abilities as potential. Most real mental patients are not so lucky.

Anthony Brandt wrote his book in the mid-1970s, but what happened to him unfortunately continues to happen today. All those "unmotivated clients" I keep hearing about are the ones who are on a silent sit-down strike about others' visions of what their lives should be like. When I ask professionals what it is that their clients are "unmotivated" about, it usually turns out to be washing floors or dishes on the one hand or going to meaningless meetings on the other. Would you be "motivated" to reveal your deepest secrets to a stranger, for example, someone you have no reason to believe you can trust with this sensitive information? And, more important, should you be "motivated" to do so? People, in general, are motivated to do things that they want to do, or which will get them things which they want. Just because someone has a diagnosis of "mental illness" doesn't change that fundamental fact of human nature. All the time and energy that mental health professionals seem to put into "motivating" their clients to do things they don't want to do would, I think, be better spent helping clients to figure out what things they want for themselves, and the strategies to achieve them.

We need to start encouraging people to dream, and to articulate their own visions of their own futures. We may not achieve all our dreams but hoping and wishing are food for the human spirit. We, all of us, need real goals to aspire to, goals that we determine, aims that are individual and personal. I feel crushed when I visit programs that are training their clients for futures as residents of halfway houses and part-time workers in menial jobs. And if I, a visitor, feel my spirit being crushed, how do the people trapped in those programs feel?

Researchers have asked clinicians what kinds of housing, for example, their clients need, and been told that congregate, segregating housing was the best setting. At the same time, the researchers have asked the clients directly what kind of housing they want and have been told that people would choose (if they were given the choice) to live in their own homes or apartments, alone, or with one other person they had chosen to live with. At the end of the year, the researchers found, the clients who got the kind of housing they wanted were doing better than the clients that got the housing that was thought to be clinically appropriate. Helping people to reach their goals is, among other things, therapeutic.

One of the reasons I believe I was able to escape the role of chronic patient that had been predicted for me was that I was able to leave the surveillance and control of the mental health system when I left the state hospital. Today, that's called "falling through the cracks". While I agree that it's important to help people avoid hunger and homelessness, such help must not come at too high a price. Help that comes with unwanted strings – "We'll give you housing if you take medication," "We'll sign your SSI papers if you go to the day program" – is help that is paid for in imprisoned spirits and stifled dreams. We should not be surprised that some people won't sell their souls so cheaply.

Let us celebrate the spirit of non-compliance that is the self struggling to survive. Let us celebrate the unbowed head, the heart that still dreams, the voice that refuses to be silent. I wish I could show you the picture that hangs on my office wall, which inspires me every day – a drawing by Tanya Temkin, a wonderful artist and psychiatric survivor activist. In a gloomy and barred room a group of women sit slumped in defeat, dresses in rags, while on the opposite wall their shadows, upright, with raised arms and wild hair and clenched fists, dance the triumphant dance of the spirit that will not die.

Annex 3: Article 12 of CRPD with associated simplified version

(2,3)

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 05 March 2018)

Equal recognition before the law

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 to 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.

² Convention on the Rights of Persons with Disabilities (CRPD). United Nations General Assembly Resolution A/RES/61/106: Article 12 – Equal recognition before the law. New York (NY): United Nations; January 2007. (<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html>, accessed 8 February 2017).

³ 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).

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
- Not to have their homes or money taken away from them.

Annex 4: General comment No. 1 (2014)

(4)

Article 12: Equal recognition before the law

I. Introduction

1. Equality before the law is a basic general principle of human rights protection and is indispensable for the exercise of other human rights. The Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights specifically guarantee the right to equality before the law. Article 12 of the Convention on the Rights of Persons with Disabilities further describes the content of this civil right and focuses on the areas in which people with disabilities have traditionally been denied the right. Article 12 does not set out additional rights for people with disabilities; it simply describes the specific elements that States parties are required to take into account to ensure the right to equality before the law for people with disabilities, on an equal basis with others.
2. Given the importance of this article, the Committee facilitated interactive forums for discussions on legal capacity. From the very useful exchange on the provisions of article 12 by experts, States parties, disabled persons' organizations, non-governmental organizations, treaty monitoring bodies, national human rights institutions and United Nations agencies, the Committee found it imperative to provide further guidance in a general comment.
3. On the basis of the initial reports of various States parties that it has reviewed so far, the Committee observes that there is a general misunderstanding of the exact scope of the obligations of States parties under article 12 of the Convention. Indeed, there has been a general failure to understand that the human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making. The aim of the present general comment is to explore the general obligations deriving from the various components of article 12.
4. The present general comment reflects an interpretation of article 12 which is premised on the general principles of the Convention, as outlined in article 3, namely, respect for the inherent dignity, individual autonomy — including the freedom to make one's own choices —, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women; and respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.
5. The Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of Persons with Disabilities each specify that the right to equal recognition before the law is operative "everywhere". In other words, there are no permissible circumstances under international human rights law in which a person may be deprived of the right to recognition as a person before the law, or in which this right may be

⁴ Committee on the Rights of Persons with Disabilities. General Comment n°1 (2014), CRPD/C/GC/1, Article 12 (Equal recognition before the law) at the Eleventh session of the Committee on the Rights of Persons with Disabilities, 31 March–11 April 2014. Geneva: Convention on the Rights of Persons with Disabilities; 2014. (<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf>, accessed 18 November 2018).

limited. This is reinforced by article 4, paragraph 2, of the International Covenant on Civil and Political Rights, which allows no derogation from this right, even in times of public emergency. Although an equivalent prohibition on derogation from the right to equal recognition before the law is not specified in the Convention on the Rights of Persons with Disabilities, the provision in the International Covenant covers such protection by virtue of article 4, paragraph 4, of the Convention, which establishes that the provisions of the Convention on the Rights of Persons with Disabilities do not derogate from existing international law.

6. The right to equality before the law is also reflected in other core international and regional human rights treaties. Article 15 of the Convention on the Elimination of All Forms of Discrimination against Women guarantees women's equality before the law and requires the recognition of women's legal capacity on an equal basis with men, including with regard to concluding contracts, administering property and exercising their rights in the justice system. Article 3 of the African Charter on Human and Peoples' Rights provides for the right of every person to be equal before the law and to enjoy equal protection of the law. Article 3 of the American Convention on Human Rights enshrines the right to juridical personality and the right of every person to recognition as a person before the law.
7. States parties must holistically examine all areas of law to ensure that the right of persons with disabilities to legal capacity is not restricted on an unequal basis with others. Historically, persons with disabilities have been denied their right to legal capacity in many areas in a discriminatory manner under substitute decision-making regimes such as guardianship, conservatorship and mental health laws that permit forced treatment. These practices must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others.
8. Article 12 of the Convention affirms that all persons with disabilities have full legal capacity. Legal capacity has been prejudicially denied to many groups throughout history, including women (particularly upon marriage) and ethnic minorities. However, persons with disabilities remain the group whose legal capacity is most commonly denied in legal systems worldwide. The right to equal recognition before the law implies that legal capacity is a universal attribute inherent in all persons by virtue of their humanity and must be upheld for persons with disabilities on an equal basis with others. Legal capacity is indispensable for the exercise of civil, political, economic, social and cultural rights. It acquires a special significance for persons with disabilities when they have to make fundamental decisions regarding their health, education and work. The denial of legal capacity to persons with disabilities has, in many cases, led to their being deprived of many fundamental rights, including the right to vote, the right to marry and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty.
9. All persons with disabilities, including those with physical, mental, intellectual or sensory impairments, can be affected by denial of legal capacity and substitute decision-making. However, persons with cognitive or psychosocial disabilities have been, and still are, disproportionately affected by substitute decision-making regimes and denial of legal capacity. The Committee reaffirms that a person's status as a person with a disability or the existence of an impairment (including a physical or sensory impairment) must never be grounds for denying legal capacity or any of the rights provided for in article 12. All practices that in purpose or effect violate article 12 must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others.

10. This general comment focuses primarily on the normative content of article 12 and the State obligations that emerge therefrom. The Committee will continue to carry out work in this area so as to provide further in-depth guidance on the rights and obligations deriving from article 12 in future concluding observations, general comments and other documents.

II. Normative content of article 12

Article 12, paragraph 1

11. Article 12, paragraph 1, reaffirms the right of persons with disabilities to be recognized as persons before the law. This guarantees that every human being is respected as a person possessing legal personality, which is a prerequisite for the recognition of a person's legal capacity.

Article 12, paragraph 2

12. Article 12, paragraph 2, recognizes that persons with disabilities enjoy legal capacity on an equal basis with others in all areas of life. Legal capacity includes the capacity to be both a holder of rights and an actor under the law. Legal capacity to be a holder of rights entitles a person to full protection of his or her rights by the legal system. Legal capacity to act under the law recognizes that person as an agent with the power to engage in transactions and create, modify or end legal relationships. The right to recognition as a legal agent is provided for in article 12, paragraph 5, of the Convention, which outlines the duty of States parties to "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 ... ensure that persons with disabilities are not arbitrarily deprived of their property".
13. Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors. Legal instruments such as the Universal Declaration of Human Rights (art. 6), the International Covenant on Civil and Political Rights (art. 16) and the Convention on the Elimination of All Forms of Discrimination Against Women (art. 15) do not specify the distinction between mental and legal capacity. Article 12 of the Convention on the Rights of Persons with Disabilities, however, makes it clear that "unsoundness of mind" and other discriminatory labels are not legitimate reasons for the denial of legal capacity (both legal standing and legal agency). Under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.
14. Legal capacity is an inherent right accorded to all people, including persons with disabilities. As noted above, it consists of two strands. The first is legal standing to hold rights and to be recognized as a legal person before the law. This may include, for example, having a birth certificate, seeking medical assistance, registering to be on the electoral role or applying for a passport. The second is legal agency to act on those rights and to have those actions recognized by the law. It is this component that is frequently denied or diminished for persons with disabilities. For example, laws may allow persons with disabilities to own property, but may not always respect the actions taken by them in terms of buying and selling property. Legal capacity means that all people, including persons with disabilities, have legal standing

and legal agency simply by virtue of being human. Therefore, both strands of legal capacity must be recognized for the right to legal capacity to be fulfilled; they cannot be separated. The concept of mental capacity is highly controversial in and of itself. Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity.

15. In most of the State party reports that the Committee has examined so far, the concepts of mental and legal capacity have been conflated so that where a person is considered to have impaired decision-making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently removed. This is decided simply on the basis of the diagnosis of an impairment (status approach), or where a person makes a decision that is considered to have negative consequences (outcome approach), or where a person's decision-making skills are considered to be deficient (functional approach). The functional approach attempts to assess mental capacity and deny legal capacity accordingly. It is often based on whether a person can understand the nature and consequences of a decision and/or whether he or she can use or weigh the relevant information. This approach is flawed for two key reasons: (a) it is discriminatorily applied to people with disabilities; and (b) it presumes to be able to accurately assess the inner-workings of the human mind and, when the person does not pass the assessment, it then denies him or her a core human right — the right to equal recognition before the law. In all of those approaches, a person's disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but, rather, requires that support be provided in the exercise of legal capacity.

Article 12, paragraph 3

16. Article 12, paragraph 3, recognizes that States parties have an obligation to provide persons with disabilities with access to support in the exercise of their legal capacity. States parties must refrain from denying persons with disabilities their legal capacity and must, rather, provide persons with disabilities access to the support necessary to enable them to make decisions that have legal effect.
17. Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making. Article 12, paragraph 3, does not specify what form the support should take. "Support" is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication. Support to persons with disabilities in the exercise of their legal capacity might include measures relating to universal design and accessibility — for example, requiring private and public actors, such as banks and financial institutions, to provide information in an understandable format or to provide professional sign language interpretation — in order to enable persons with disabilities to perform the legal acts required to open a bank account, conclude contracts or conduct other social transactions. Support can also constitute the development and recognition of diverse, non-conventional methods of communication, especially for those who use non-verbal forms of communication to express their will and preferences. For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their

will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others. All persons with disabilities have the right to engage in advance planning and should be given the opportunity to do so on an equal basis with others. States parties can provide various forms of advance planning mechanisms to accommodate various preferences, but all the options should be non-discriminatory. Support should be provided to a person, where desired, to complete an advance planning process. The point at which an advance directive enters into force (and ceases to have effect) should be decided by the person and included in the text of the directive; it should not be based on an assessment that the person lacks mental capacity.

18. The type and intensity of support to be provided will vary significantly from one person to another owing to the diversity of persons with disabilities. This is in accordance with article 3 (d), which sets out “respect for difference and acceptance of persons with disabilities as part of human diversity and humanity” as a general principle of the Convention. At all times, including in crisis situations, the individual autonomy and capacity of persons with disabilities to make decisions must be respected.
19. Some persons with disabilities only seek recognition of their right to legal capacity on an equal basis with others, as provided for in article 12, paragraph 2, of the Convention, and may not wish to exercise their right to support, as provided for in article 12, paragraph 3.

Article 12, paragraph 4

20. Article 12, paragraph 4, outlines the safeguards that must be present in a system of support in the exercise of legal capacity. Article 12, paragraph 4, must be read in conjunction with the rest of article 12 and the whole Convention. It requires States parties to create appropriate and effective safeguards for the exercise of legal capacity. The primary purpose of these safeguards must be to ensure the respect of the person’s rights, will and preferences. In order to accomplish this, the safeguards must provide protection from abuse on an equal basis with others.
21. Where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the “best interpretation of will and preferences” must replace the “best interests” determinations. This respects the rights, will and preferences of the individual, in accordance with article 12, paragraph 4. The “best interests” principle is not a safeguard which complies with article 12 in relation to adults. The “will and preferences” paradigm must replace the “best interests” paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others.
22. All people risk being subject to “undue influence”, yet this may be exacerbated for those who rely on the support of others to make decisions. Undue influence is characterized as occurring, where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation. Safeguards for the exercise of legal capacity must include protection against undue influence; however, the protection must respect the rights, will and preferences of the person, including the right to take risks and make mistakes.

Article 12, paragraph 5

23. Article 12, paragraph 5, requires States parties to take measures, including legislative, administrative, judicial and other practical measures, to ensure the rights of persons with disabilities with respect to financial and economic affairs, on an equal basis with others. Access to finance and property has traditionally been denied to persons with disabilities based on the medical model of disability. That approach of denying persons with disabilities legal capacity for financial matters must be replaced with support to exercise legal capacity, in accordance with article 12, paragraph 3. In the same way as gender may not be used as the basis for discrimination in the areas of finance and property,¹ neither may disability.

III. Obligations of States parties

24. States parties have an obligation to respect, protect and fulfil the right of all persons with disabilities to equal recognition before the law. In this regard, States parties should refrain from any action that deprives persons with disabilities of the right to equal recognition before the law. States parties should take action to prevent non-State actors and private persons from interfering with the ability of persons with disabilities to realize and enjoy their human rights, including the right to legal capacity. One of the aims of support in the exercise of legal capacity is to build the confidence and skills of persons with disabilities so that they can exercise their legal capacity with less support in the future, if they so wish. States parties have an obligation to provide training for persons receiving support so that they can decide when less support is needed or when they no longer require support in the exercise of their legal capacity.
25. In order to fully recognize “universal legal capacity”, whereby all persons, regardless of disability or decision-making skills, inherently possess legal capacity, States parties must abolish denials of legal capacity that are discriminatory on the basis of disability in purpose or effect.²
26. In its concluding observations on States parties’ initial reports, in relation to article 12, the Committee on the Rights of Persons with Disabilities has repeatedly stated that States parties must “review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person’s autonomy, will and preferences”.
27. Substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where (i) legal capacity is removed from a person, even if this is in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will; and (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective “best interests” of the person concerned, as opposed to being based on the person’s own will and preferences.
28. States parties’ obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention.

29. A supported decision-making regime comprises various support options which give primacy to a person's will and preferences and respect human rights norms. It should provide protection for all rights, including those related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live, etc.) and rights related to freedom from abuse and ill-treatment (right to life, right to physical integrity, etc.). Furthermore, systems of supported decision-making should not over-regulate the lives of persons with disabilities. While supported decision-making regimes can take many forms, they should all incorporate certain key provisions to ensure compliance with article 12 of the Convention, including the following:
- (a) Supported decision-making must be available to all. A person's level of support needs, especially where these are high, should not be a barrier to obtaining support in decision-making;
 - (b) All forms of support in the exercise of legal capacity, including more intensive forms of support, must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests;
 - (c) A person's mode of communication must not be a barrier to obtaining support in decision-making, even where this communication is non-conventional, or understood by very few people;
 - (d) Legal recognition of the support person(s) formally chosen by a person must be available and accessible, and States have an obligation to facilitate the creation of support, particularly for people who are isolated and may not have access to naturally occurring support in the community. This must include a mechanism for third parties to verify the identity of a support person as well as a mechanism for third parties to challenge the action of a support person if they believe that the support person is not acting in accordance with the will and preferences of the person concerned;
 - (e) In order to comply with the requirement, set out in article 12, paragraph 3, of the Convention, for States parties to take measures to "provide access" to the support required, States parties must ensure that support is available at nominal or no cost to persons with disabilities and that lack of financial resources is not a barrier to accessing support in the exercise of legal capacity;
 - (f) Support in decision-making must not be used as justification for limiting other fundamental rights of persons with disabilities, especially the right to vote, the right to marry, or establish a civil partnership, and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty;
 - (g) The person must have the right to refuse support and terminate or change the support relationship at any time;
 - (h) Safeguards must be set up for all processes relating to legal capacity and support in exercising legal capacity. The goal of safeguards is to ensure that the person's will and preferences are respected.
 - (i) The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity.
30. The right to equality before the law has long been recognized as a civil and political right, with roots in the International Covenant on Civil and Political Rights. Civil and political rights attach at the moment of ratification and States parties are required to take steps to immediately realize those rights. As such, the rights provided for in article 12 apply at the moment of ratification and are subject to immediate realization. The State obligation,

provided for in article 12, paragraph 3, to provide access to support in the exercise of legal capacity is an obligation for the fulfilment of the civil and political right to equal recognition before the law. “Progressive realization” (art. 4, para. 2) does not apply to the provisions of article 12. Upon ratifying the Convention, States parties must immediately begin taking steps towards the realization of the rights provided for in article 12. Those steps must be deliberate, well-planned and include consultation with and meaningful participation of people with disabilities and their organizations.

IV. Relationship with other provisions of the Convention

31. Recognition of legal capacity is inextricably linked to the enjoyment of many other human rights provided for in the Convention on the Rights of Persons with Disabilities, including, but not limited to, the right to access justice (art. 13); the right to be free from involuntary detention in a mental health facility and not to be forced to undergo mental health treatment (art. 14); the right to respect for one’s physical and mental integrity (art. 17); the right to liberty of movement and nationality (art. 18); the right to choose where and with whom to live (art. 19); the right to freedom of expression (art. 21); the right to marry and found a family (art. 23); the right to consent to medical treatment (art. 25); and the right to vote and stand for election (art. 29). Without recognition of the person as a person before the law, the ability to assert, exercise and enforce those rights, and many other rights provided for in the Convention, is significantly compromised.

Article 5: Equality and non-discrimination

32. To achieve equal recognition before the law, legal capacity must not be denied discriminatorily. Article 5 of the Convention guarantees equality for all persons under and before the law and the right to equal protection of the law. It expressly prohibits all discrimination on the basis of disability. Discrimination on the basis of disability is defined in article 2 of the Convention as “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”. Denial of legal capacity having the purpose or effect of interfering with the right of persons with disabilities to equal recognition before the law is a violation of articles 5 and 12 of the Convention. States have the ability to restrict the legal capacity of a person based on certain circumstances, such as bankruptcy or criminal conviction. However, the right to equal recognition before the law and freedom from discrimination requires that when the State denies legal capacity, it must be on the same basis for all persons. Denial of legal capacity must not be based on a personal trait such as gender, race, or disability, or have the purpose or effect of treating the person differently.
33. Freedom from discrimination in the recognition of legal capacity restores autonomy and respects the human dignity of the person in accordance with the principles enshrined in article 3 (a) of the Convention. Freedom to make one’s own choices most often requires legal capacity. Independence and autonomy include the power to have one’s decisions legally respected. The need for support and reasonable accommodation in making decisions shall not be used to question a person’s legal capacity. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity (art. 3 (d)) is incompatible with granting legal capacity on an assimilationist basis.
34. Non-discrimination includes the right to reasonable accommodation in the exercise of legal capacity (art. 5, para. 3). Reasonable accommodation is defined in article 2 of the Convention

as “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”. The right to reasonable accommodation in the exercise of legal capacity is separate from, and complementary to, the right to support in the exercise of legal capacity. States parties are required to make any necessary modifications or adjustments to allow persons with disabilities to exercise their legal capacity, unless it is a disproportionate or undue burden. Such modifications or adjustments may include, but are not limited to, access to essential buildings such as courts, banks, social benefit offices and voting venues; accessible information regarding decisions which have legal effect; and personal assistance. The right to support in the exercise of legal capacity shall not be limited by the claim of disproportionate or undue burden. The State has an absolute obligation to provide access to support in the exercise of legal capacity.

Article 6: Women with disabilities

35. Article 15 of the Convention on the Elimination of All Forms of Discrimination against Women provides for women’s legal capacity on an equal basis with men, thereby acknowledging that recognition of legal capacity is integral to equal recognition before the law: “States parties shall accord to women, in civil matters, a legal capacity identical to that of men and the same opportunities to exercise that capacity. In particular, they shall give women equal rights to conclude contracts and to administer property and shall treat them equally in all stages of procedure in courts and tribunals” (para. 2). This provision applies to all women, including women with disabilities. The Convention on the Rights of Persons with Disabilities recognizes that women with disabilities may be subject to multiple and intersectional forms of discrimination based on gender and disability. For example, women with disabilities are subjected to high rates of forced sterilization, and are often denied control of their reproductive health and decision-making, the assumption being that they are not capable of consenting to sex. Certain jurisdictions also have higher rates of imposing substitute decision-makers on women than on men. Therefore, it is particularly important to reaffirm that the legal capacity of women with disabilities should be recognized on an equal basis with others.

Article 7: Children with disabilities

36. While article 12 of the Convention protects equality before the law for all persons, regardless of age, article 7 of the Convention recognizes the developing capacities of children and requires that “in all actions concerning children with disabilities, the best interests of the child ... be a primary consideration” (para. 2) and that “their views [be] given due weight in accordance with their age and maturity” (para. 3). To comply with article 12, States parties must examine their laws to ensure that the will and preferences of children with disabilities are respected on an equal basis with other children.

Article 9: Accessibility

37. The rights provided for in article 12 are closely tied to State obligations relating to accessibility (art. 9) because the right to equal recognition before the law is necessary to enable persons with disabilities to live independently and participate fully in all aspects of life.

Article 9 requires the identification and elimination of barriers to facilities or services open or provided to the public. Lack of accessibility to information and communication and inaccessible services may constitute barriers to the realization of legal capacity for some persons with disabilities, in practice. Therefore, States parties must make all procedures for the exercise of legal capacity, and all information and communication pertaining to it, fully accessible. States parties must review their laws and practices to ensure that the right to legal capacity and accessibility are being realized.

Article 13: Access to justice

38. States parties have an obligation to ensure that persons with disabilities have access to justice on an equal basis with others. The recognition of the right to legal capacity is essential for access to justice in many respects. In order to seek enforcement of their rights and obligations on an equal basis with others, persons with disabilities must be recognized as persons before the law with equal standing in courts and tribunals. States parties must also ensure that persons with disabilities have access to legal representation on an equal basis with others. This has been identified as a problem in many jurisdictions and must be remedied, including by ensuring that persons who experience interference with their right to legal capacity have the opportunity to challenge such interference — on their own behalf or with legal representation — and to defend their rights in court. Persons with disabilities have often been excluded from key roles in the justice system as lawyers, judges, witnesses or members of a jury.
39. Police officers, social workers and other first responders must be trained to recognize persons with disabilities as full persons before the law and to give the same weight to complaints and statements from persons with disabilities as they would to non-disabled persons. This entails training and awareness-raising in these important professions. Persons with disabilities must also be granted legal capacity to testify on an equal basis with others. Article 12 of the Convention guarantees support in the exercise of legal capacity, including the capacity to testify in judicial, administrative and other legal proceedings. Such support could take various forms, including recognition of diverse communication methods, allowing video testimony in certain situations, procedural accommodation, the provision of professional sign language interpretation and other assistive methods. The judiciary must also be trained and made aware of their obligation to respect the legal capacity of persons with disabilities, including legal agency and standing.

Articles 14 and 25: Liberty, security and consent

40. Respecting the right to legal capacity of persons with disabilities on an equal basis with others includes respecting the right of persons with disabilities to liberty and security of the person. The denial of the legal capacity of persons with disabilities and their detention in institutions against their will, either without their consent or with the consent of a substitute decision-maker, is an ongoing problem. This practice constitutes arbitrary deprivation of liberty and violates articles 12 and 14 of the Convention. States parties must refrain from such practices and establish a mechanism to review cases whereby persons with disabilities have been placed in a residential setting without their specific consent.
41. The right to enjoyment of the highest attainable standard of health (art. 25) includes the right to health care on the basis of free and informed consent. States parties have an obligation to require all health and medical professionals (including psychiatric professionals) to obtain the free and informed consent of persons with disabilities prior to any treatment. In conjunction with the right to legal capacity on an equal basis with others, States parties have

an obligation not to permit substitute decision-makers to provide consent on behalf of persons with disabilities. All health and medical personnel should ensure appropriate consultation that directly engages the person with disabilities. They should also ensure, to the best of their ability, that assistants or support persons do not substitute or have undue influence over the decisions of persons with disabilities.

Articles 15, 16 and 17: Respect for personal integrity and freedom from torture, violence, exploitation and abuse

42. As has been stated by the Committee in several concluding observations, forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement of the rights to personal integrity (art. 17); freedom from torture (art. 15); and freedom from violence, exploitation and abuse (art. 16). This practice denies the legal capacity of a person to choose medical treatment and is therefore a violation of article 12 of the Convention. States parties must, instead, respect the legal capacity of persons with disabilities to make decisions at all times, including in crisis situations; must ensure that accurate and accessible information is provided about service options and that non-medical approaches are made available; and must provide access to independent support. States parties have an obligation to provide access to support for decisions regarding psychiatric and other medical treatment. Forced treatment is a particular problem for persons with psychosocial, intellectual and other cognitive disabilities. States parties must abolish policies and legislative provisions that allow or perpetrate forced treatment, as it is an ongoing violation found in mental health laws across the globe, despite empirical evidence indicating its lack of effectiveness and the views of people using mental health systems who have experienced deep pain and trauma as a result of forced treatment. The Committee recommends that States parties ensure that decisions relating to a person's physical or mental integrity can only be taken with the free and informed consent of the person concerned.

Article 18: Nationality

43. Persons with disabilities have the right to a name and registration of their birth as part of the right to recognition everywhere as a person before the law (art. 18, para. 2). States parties must take the necessary measures to ensure that children with disabilities are registered at birth. This right is provided for in the Convention on the Rights of the Child (art. 7); however, children with disabilities are disproportionately likely not to be registered as compared with other children. This not only denies them citizenship, but often also denies them access to health care and education, and can even lead to their death. Since there is no official record of their existence, their death may occur with relative impunity.

Article 19: Living independently and being included in the community

44. To fully realize the rights provided for in article 12, it is imperative that persons with disabilities have opportunities to develop and express their will and preferences, in order to exercise their legal capacity on an equal basis with others. This means that persons with disabilities must have the opportunity to live independently in the community and to make choices and to have control over their everyday lives, on an equal basis with others, as provided for in article 19.

45. Interpreting article 12, paragraph 3, in the light of the right to live in the community (art. 19) means that support in the exercise of legal capacity should be provided through a community-based approach. States parties must recognize that communities are assets and partners in the process of learning what types of support are needed in the exercise of legal capacity, including raising awareness about different support options. States parties must recognize the social networks and naturally occurring community support (including friends, family and schools) of persons with disabilities as key to supported decision-making. This is consistent with the Convention's emphasis on the full inclusion and participation of persons with disabilities in the community
46. The segregation of persons with disabilities in institutions continues to be a pervasive and insidious problem that violates a number of the rights guaranteed under the Convention. The problem is exacerbated by the widespread denial of legal capacity to persons with disabilities, which allows others to consent to their placement in institutional settings. The directors of institutions are also commonly vested with the legal capacity of the persons residing therein. This places all power and control over the person in the hands of the institution. In order to comply with the Convention and respect the human rights of persons with disabilities, deinstitutionalization must be achieved and legal capacity must be restored to all persons with disabilities, who must be able to choose where and with whom to live (art. 19). A person's choice of where and with whom to live should not affect his or her right to access support in the exercise of his or her legal capacity.

Article 22: Privacy

47. Substitute decision-making regimes, in addition to being incompatible with article 12 of the Convention, also potentially violate the right to privacy of persons with disabilities, as substitute decision-makers usually gain access to a wide range of personal and other information regarding the person. In establishing supported decision-making systems, States parties must ensure that those providing support in the exercise of legal capacity fully respect the right to privacy of persons with disabilities.

Article 29: Political participation

48. Denial or restriction of legal capacity has been used to deny political participation, especially the right to vote, to certain persons with disabilities. In order to fully realize the equal recognition of legal capacity in all aspects of life, it is important to recognize the legal capacity of persons with disabilities in public and political life (art. 29). This means that a person's decision-making ability cannot be a justification for any exclusion of persons with disabilities from exercising their political rights, including the right to vote, the right to stand for election and the right to serve as a member of a jury.
49. States parties have an obligation to protect and promote the right of persons with disabilities to access the support of their choice in voting by secret ballot, and to participate in all elections and referendums without discrimination. The Committee further recommends that States parties guarantee the right of persons with disabilities to stand for election, to hold office effectively and to perform all public functions at all levels of government, with reasonable accommodation and support, where desired, in the exercise of their legal capacity.

V. Implementation at the national level

50. In the light of the normative content and obligations outlined above, States parties should take the following steps to ensure the full implementation of article 12 of the Convention on the Rights of Persons with Disabilities:
- (a) Recognize persons with disabilities as persons before the law, having legal personality and legal capacity in all aspects of life, on an equal basis with others. This requires the abolition of substitute decision-making regimes and mechanisms that deny legal capacity and which discriminate in purpose or effect against persons with disabilities. It is recommended that States parties create statutory language protecting the right to legal capacity on an equal basis for all;
 - (b) Establish, recognize and provide persons with disabilities with access to a broad range of support in the exercise of their legal capacity. Safeguards for such support must be premised on respect for the rights, will and preferences of persons with disabilities. The support should meet the criteria set out in paragraph 29 above on the obligations of States parties to comply with article 12, paragraph 3, of the Convention;
 - (c) Closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations, in the development and implementation of legislation, policies and other decision-making processes that give effect to article 12.
51. The Committee encourages States parties to undertake or devote resources to the research and development of best practices respecting the right to equal recognition of the legal capacity of persons with disabilities and support in the exercise of legal capacity.
52. States parties are encouraged to develop effective mechanisms to combat both formal and informal substitute decision-making. To this end, the Committee urges States parties to ensure that persons with disabilities have the opportunity to make meaningful choices in their lives and develop their personalities, to support the exercise of their legal capacity. This includes, but is not limited to, opportunities to build social networks; opportunities to work and earn a living on an equal basis with others; multiple choices for place of residence in the community; and inclusion in education at all levels.

Annex 5: How are decisions made?

	How are decisions made?		
	Issues	Who decides?	Why?
In the service			
At home			

Annex 6: Decision-making as a means for empowerment

(5)

“Eventually, I met a peer. I met somebody after coming out of the hospital, I met somebody in the community and we became great friends and eventually this man asked me “What are you going to do?” and it totally took me aback. I said “What do you mean? I’m going to take my tablets, I’m going to go to the outpatients’ department and ... I’m better” and he said “No, no, no, what are you going to do?”

What that did for me was, although I did not know this at the time, that was the start of a journey of empowerment, and it was the start for me of taking responsibility for my own life. I really and truly had handed over my life and my will to the institution of doctors, psychiatrists, psychologists, occupational therapists and nurses and I did it willingly. There were many times that I begged to be put into hospital. I was so afraid of where I was in my life.

When I was asked that question – “What are you going to do?” – it took me aback in a big way. As I said, it was the beginning of a journey, a very slow and painful journey that brought me to the realization that there were things that I could do in my life and that there were choices that I could make that would have an impact on my life, that I didn’t have to leave it up to others.

One of those choices – one of the consequences of those choices – I presented to my doctor one day. At this stage I had gotten married and I didn’t exactly get the reception where people threw their arms around me and congratulated me for getting married but I do remember the day that I told my doctor that my wife was pregnant and the poor man his eyes fell to the floor. They fell to the floor and he just couldn’t work with it like, he just couldn’t accept it. I know he is a nice man and he is caring but all those good things, he didn’t want it for me; he didn’t think it was right, that I would be able to handle it and do well with it. He is not my doctor anymore and I have four kids now. Maybe I should have come back to him!”

Rory is today a recovery development advocate.

⁵ Amnesty International Ireland. Rory Doody on his experience of Ireland's capacity legislation and mental health services [video]. Dublin: Amnesty International Ireland; 2013.

Annex 7: Supported decision-making checklist

(6)

Supported decision-making checklist

Do you do the following?

- Provide relevant information:
 - Give the person all the relevant information they need to make a particular decision.
 - Give the person all the information they asked for.
 - Give the person information on all the 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 whether the person accepts this help.
- Make the person feel at ease:
 - Identify if there are particular times of the 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 delayed 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.

⁶ Department of Constitutional Affairs. Mental Capacity Act, 2005, Code of Practice. London: The Stationery Office on behalf of the Department for Constitutional Affairs; 2005.

Annex 8: Extract of a Recovery Plan template

Examples of advance plan templates

1. In this box, you can find an example of what a completed advance planning document might look like.

Advance PLAN Example Template

What are important to me in my life – my will and preferences:

- I value my independence above everything, and this should be the primary consideration in all issues affecting me and decisions communicated for me.
- I would like to receive my usual support and care at home but not at the mental health service.
- I am happy for my mother and best friend to be kept involved in supporting me but I do not want my father involved as I did not grow up with him and he does not know me well enough.

2. Current health issues should be included with directions about your preferences for how these should be managed and why.

HEALTH ISSUES including mental health issues, indicating what has helped and what has not helped

Health issue 1:

Management preference

Helpful:

Not helpful:

Health issue 2:

Management preference

Helpful:

Not helpful:

Health issue 3:

Management preference

Helpful:

Not helpful:

Health issue 4:

Management preference

Helpful:

Not helpful:

3. Consent or refusal for medical treatment, including “do not resuscitate” clauses.

I consent to the following medical treatment in (specify treatment and the specific circumstances for that treatment and reasons why)

I refuse the following medical treatment (specify treatment that you refuse, the specific circumstances and reasons why)

4. Unacceptable health outcomes after medical intervention, including high levels of dependency and care, not being able to communicate my wishes and preferences.

Health outcomes resulting from medical intervention that are unacceptable to me

5. Preferences and directives regarding related non-health issues.

This information enables supporters to get to know and understand a person's will and preferences and helps to ensure that these are respected. It provides important information about who the person would like to take care of children and pets if the person is temporarily unable to do so, and also information about the activities that the person likes to do.

Children, Accommodation, Keys, Pets, Garden, Relationships, Social ties, Work

Important aspects about me that I would like people supporting me to know about (e.g. interests, daily routines, life history, etc.)

6. People to consult on different areas of my life (e.g, finances, relationships, daily tasks, health matters).

About me

Finances

Relationships

Daily routine tasks

Health matters

7. If I am dying the following things are important to me.

If I am dying, the following things are important to me

Annex 9: Real life examples of advance planning statements

(7,8)

“I would like people to voice or feedback to me symptoms they observe and tell me what’s wrong.”

“I don’t want threats of injection; I would like people to talk to me explaining the need to take medication”

“If I am in hospital for a long period I would like nurses to arrange for me to have a haircut.”

“I have been in and out of hospital because the assessment was done by people who do not know me and didn’t pick up I was becoming unwell so kept discharging me. I would like the triage ward not to discharge me before speaking to my Consultant”.

“[I would like] clarity in my medication – a proper plan of who is giving me my medication and when.”

“I would prefer to be in hospital on an informal basis so I can be involved in decision making around my care.”

“Medication A I do not want, it makes me experience bad dreams. B makes me feel worse and I would prefer medication C to D.”

“It is also very important for me to look after my appearance this makes me feel better.”

“I prefer not talking to someone who takes things personally (e.g. family)”

“I prefer to be treated at home because when I am in hospital I worry about my children.”

“[During a crisis] the Home Treatment team can give me extra-help. If the Respite home is available I could stay there. If [my husband] is struggling I could come into hospital informally.”

“I don’t like medicine that makes me very sleepy.”

“[Please don’t prescribe] medicines which cause drowsiness.”

⁷ Farrelly S, Brown G, Rose D, Doherty E, Henderson RC, Birchwood M, et al. What service users with psychotic disorders want in a mental health crisis or relapse: thematic analysis of joint crisis plans. *Soc Psychiatry Psychiatr Epidemiol.* 2014;49(10):1609–17. doi: <https://doi.org/10.1007/s00127-014-0869-1>.

⁸ Pathare S. Discrimination against persons with mental disorders: the importance of legal capacity, studies from India [online publication]. Pune: Soumitra Pathare; 2014. (http://dare.uvu.vu.nl/bitstream/handle/1871/54424/complete_dissertation.pdf?sequence=1&isAllowed=y, accessed 13 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.



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