



QualityRights

Realising supported decision making and advance planning

WHO QualityRights training to act, unite and empower for mental health

(PILOT VERSION)

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What is the WHO QualityRights initiative?



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

1 Build capacity to understand and promote human rights, recovery and independent living in the community.

2 Create community based and recovery oriented services that respect and promote human rights.

3 Improve the quality of care and human rights conditions in inpatient, outpatient and community based mental health and related services.

4 Develop a civil society movement to conduct advocacy and influence policy-making to promote human rights.

5 Reform national policies and legislation in line with best practice, the CRPD and other international human rights standards.

For more information: http://www.who.int/mental_health/policy/quality_rights/en/

WHO QualityRights - Guidance and training tools

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

Service assessment and improvement tools

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

Training tools

Core modules

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

Advanced modules

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

Guidance tools

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

About this training and guidance

This training and guidance has been developed to provide an in-depth understanding on what it means to respect legal capacity in mental health and related areas as well as concrete strategies to ensure that people are able to exercise their right to legal capacity in all areas of their life. In this context a wide range of scenarios are used to describe how different models of supported decision making can be applied in practice.

Who is this training workshop for?

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

Who should deliver the training?

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

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

Guidance for facilitators

Principles for running the training programme

Participation and interaction

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

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

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

Cultural sensitivity

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

Open, non-judgmental environment

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

Use of language

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

Operating in the current legislature and policy context

During the training, some participants may express concerns about the legislative or policy context in their countries. Indeed, some of the content may contradict national legislation or policy. For example, the topic on supported decision making may appear to conflict with existing national guardianship laws. Similarly, laws that provide for involuntary detention and treatment contradict the overall approach of these modules. This can raise issues and concerns, particularly around professional liability.

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

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

Being positive and inspiring

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

Group work

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

Facilitator notes

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

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

Preliminary note on language

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

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

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

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

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

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

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

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

Learning objectives, topics and resources

Learning objectives

Participants will:

- Be able to appreciate how stigma and negative assumptions about people with psychosocial, intellectual and cognitive disabilities impact their right to make decisions.
- 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.
- Understand the importance of supporting people to exercise their fundamental human right to make their own choices and have control over their lives.
- Be able to identify personal actions that can be taken to adopt a supported decision making approach in everyday practice.
- Understand the importance of advance planning as a way of ensuring that the decision making power of people is respected.

Topics

Topic 1: Challenging denial of legal capacity in mental health

Topic 2: Substitute vs supported decision making

Topic 3: Supported decision making in practice

Topic 4: Preventing exploitation from people acting as supporters

Topic 5: Nominating a person to communicate one's will and preferences

Topic 6: Positive steps to adopt a supported decision making approach

Topic 7: What is advance planning?

Topic 8: Making advance planning documents

Resources required

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

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

Additional resources needed include:

- Internet access in the room, in order to show videos
- Loud speakers for the video audio
- Projector screen and projector equipment
- 1 or more microphones for facilitator(s) and at least 3 additional wireless microphones for participants
- At least 2 flip charts or similar and paper and pens
- Copies of Appendix 1 for **Exercise 1.1** for all participants

- Copies of Annex 2 and Annex 3 for **Presentation: Challenging misconceptions and negative stereotypes in mental health** for all participants
- Copies of Annex 4 for **Exercise 1.3** for all participants
- Copies of Annex 5 for **Exercise 1.4** for all participants
- Copies of Annex 6 for **Presentation: Supported decision making, a new approach to decision making** for all participants
- Copies of Annex 7 for **Exercise 3.2** for all participants
- Copies of Annex 8 for **Exercise 4.1** for all participants
- Copies of Annex 9 for **Exercise 8.1** for all participants
- Copies of Annex 10 for **Exercise 8.2** for all participants

Time

14 hours 25 min

Number of participants

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

Welcome and introduction

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



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

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

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



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

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

In this training we will be exploring how to promote the right to legal capacity and make decisions and choices for themselves. It is important to acknowledge that upholding people's right to legal capacity can seem challenging in certain scenarios.

For example, what about people who want to commit suicide, or people with severe dementia? What if someone is experiencing an acute crisis and is doing things that seem dangerous? What if refusing treatment means the person is going to get worse? What if someone is unconscious? Is it really feasible to promote the 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.



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

Distribute to participants copies of Appendix 1 ("Confessions of a non-compliant patient" by Judi Chamberlin).

Give the group approximately 15 min 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 and other people using mental health and related services are often deprived of the possibility to make decisions?

In answering this question, participants are likely to bring up a number of common misconceptions and negative stereotypes. The facilitator need to be aware of these misconceptions and negative stereotypes and 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 of the self-stigma that they experience. The purpose of this part of the exercise is to challenge these.

Make a list of the misconceptions and negative stereotypes brought up by participants on the flip chart.

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 are chronically ill and not much can be done to support them.
- They would always refuse treatment if they had a choice, and that would be bad for them.
- They do not have the right to decide on financial matters.
- They do not have the ability to start a family and care for their children.
- They are unaware of or lack insight concerning their condition, and therefore 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 finance.
- 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.

For those of you that think people with psychosocial, intellectual or cognitive disabilities shouldn't make decisions, in what respect do you think they lack this ability? How do you really know that?

Possible responses from participants may include:

- Some people with psychosocial, intellectual or cognitive disabilities have confused ideas about reality, which will lead to wrong and bad decisions.
- Some people with psychosocial disabilities hear voices that can influence their actions with harmful consequences.

After listening to participants, it is important to give room to people who disagree with these misconceptions and negative stereotypes in order to allow the facilitator and others to challenge these.

Pre-empt the following presentation by saying that people know what is happening around them, even when they need high level of support, and can make decisions even if they hear voices, or have beliefs that seem strange to others. In addition, many people make 'bad' decisions and what is seen as 'good' or 'bad' may differ across people.



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 thing. The CRPD has helped to clarify and elaborate the differences (1):

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

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

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

Functional tests:

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

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

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

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

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 was not capable of making the decision to begin with 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 related 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.

Status approach:

The status approach is when people with psychosocial, intellectual or cognitive disabilities are automatically assumed to lack mental capacity (i.e. ability to make decision) 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 don’t have. These are misconceptions and negative stereotypes which are important to challenges.

The ability to make decisions is never “all or nothing”. The types of decisions that we make and how well we make them may vary at different times in our lives. For example, making decisions may be more difficult because of stress, tiredness, because of a health condition, etc. Additionally, the more decisions we make, the more skilled we become at making them over time.

Both the misconceptions and lack of understanding of about the term ‘mental capacity’ have led to the denial of the right to legal capacity. Because of this confusion we will now use the terms ‘decision making skills’ or ‘ability to make decisions’ instead of mental capacity.



Presentation: Challenging misconceptions and negative stereotypes in mental health (30 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 brought up during Exercise 1.1.

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

Misconceptions and negative stereotypes often include:

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

Challenging the misconceptions and negative stereotypes:

After each concrete example below, invite the group 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.

Encourage discussion by asking participants:

- Do you find any aspect of this story disturbing?
- What could you have done in this situation?

1. **Misconception: People with psychosocial, intellectual and 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.
- Sometimes decisions that seemed bad at first are merely challenging but actually turn out to be good.
- In addition, the opposite assumption - that people without psychosocial, intellectual and cognitive disabilities make good decisions - is not true either.
- But even when people make a decision that has negative consequences it is still their right to do so.

Example: *Elena has been diagnosed with an intellectual impairment. She used to find it difficult to manage her budget because she was often forgetting how much money she had already spent. As a consequence, she always lacked money and didn't have a sufficient budget for food. One of her friends informed her about an app she could download on her phone to keep track of her expenditures. Elena's parents thought that the app 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, anytime she is not sure, she consults her phone to see how much 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’s decision to use the app was very good and there was no need to put her under guardianship to manage her finances (i.e. a form of substitute decision making). It also shows how people’s ability to make decisions can be maximised through a variety of supports, methods and tools.

2. Misconception: People with psychosocial, intellectual, and cognitive disabilities sometimes have wrong ideas about reality, which leads to bad decisions.

- Just because a person has unusual or different beliefs about life and reality, or hears voices for example, 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 life.
- Different people in the general population have what may be considered by others very ‘unusual’ beliefs (“new age” ideas, for instance), but this doesn’t mean that they lack the ability to make decisions.

Example: Maria is a woman who has heard voices since she was a child. Most of the time, these voices describe her actions. However, when Maria is particularly stressed, the voices can become threatening and order her to act in certain ways. Maria’s family thought that because of this she could not have a normal life and that she would need a guardian. However, after years of experiencing voices, Maria has managed to live with them. She knows that sometimes they are just communicating something about her emotions and whenever they require her to take action, she talks about this with her partner before making any decisions or taking action. She currently leads a full life and this year she has graduated with honours from her university.

In this case we can see that Maria’s ability to make decisions is not affected by the fact that she is hearing voices. Whenever a stressful situation occurs and she needs help to make decisions, she openly discuss about it with her partner, whom she trusts and who supports her.

Show at this point 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 20/06/2016 in which a person who hears voices talks about her experience and the things she has achieved in her life.

For more examples of people with psychosocial, intellectual and cognitive disabilities who have achieved successes in their lives, see the module *Promoting human rights in mental health*.

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

- When people refuse a specific type of treatment or prefer different care or support options, they have generally very good reasons for making this decision. It should be acknowledged that people with psychosocial, intellectual and cognitive disabilities are, as other people, experts about their own body.

- What is acceptable, preferred and effective differs from person to person and the decisions of people with psychosocial, intellectual and cognitive disabilities are as valid as the decisions of others.

***Example:** Joshua has received a diagnosis of bipolar disorder and has been taking medication for several months. After a long time reflecting he decides to stop his medication. Everyone thinks it is a terrible idea because the previous times he stopped taking his medication he was admitted to the hospital. However, Joshua has stability in his life now and is confident that he can manage his life without this type of treatment. His doctor advises him against stopping the medication and explains to him what the risks of doing so are. However he also provides Joshua with resources concerning withdrawing from medication. After listening to the doctor, Joshua still maintains his decision, and the doctor respects this. They decide together that if Joshua is feeling unwell, he can call the doctor to discuss the situation further.*

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

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

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

***Example:** Anna admits herself to a psychiatric ward because she is experiencing a deep period of sadness that has left her unable to get out of bed and go to work most days. She has been experiencing such phases for quite a while now and has tried several treatments. She knows from past experience that most antidepressants make her feel irritated and lead to insomnia. She has had good results with interpersonal group therapy before, so she says she would be willing to receive this type of support and explains her reasons to the psychiatric ward staff.*

Here we can see that, although Anna faces a really difficult period in her life, she is fully aware of the consequences that different treatments and support options have on her and knows better than anybody else, including the staff of the service, what works best for her. Her personal experience and expertise should not be undervalued or disregarded.

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

- Although families and care partners can provide invaluable support, they may sometimes act in what they think is in the best interest of the person concerned, and exclude the person in the decisions that 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.

Example: Luca has been diagnosed with schizophrenia. He enjoys cooking very much and would like to take formal studies in this area. His parents disagree and tell him that the classes are too expensive. The real reason is that they are afraid that people will make fun of Luca and that he would become isolated during his studies.

Here is an example where the family is trying to protect their son from potential harm because they think Luca won't be accepted by others.

The cooking course may be very beneficial for Luca as they are likely to teach him new skills and allow him to meet different people as well as increasing opportunities for employment in an area that he values. Often when the family overprotect their relative, they prevent them from gaining skill 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, and 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 and cognitive disabilities, as other people, have the right to make decisions about their own body and are able to do so, even during difficult circumstances.

Example: Eunice is a woman diagnosed with major depression. When she was pregnant, she experienced a crisis and decided to go to a mental health service. She went to the 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 get worse with the added pressure of looking after a child. However, even though she was feeling unwell, Eunice didn't 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.

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

- The ability to make decisions about all areas in 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.
- 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.

***Example:** Gavin has been going back and forth between periods of highs where he does not sleep for days and can be reckless with money, and lows where he feels hopeless and considers suicide. During a crisis, he spent all of the family’s money to buy a luxury car. Now, he is recovering, but as a consequence of his actions, he has incurred a lot of debt which he needs to clear soon. So he decides to sell his car and work overtime in order to make extra money. He has calculated that in two years he should be able to clear all his debts.*

In addition, Gavin went to the bank and set up a joint account requiring two signatures – that of himself and his wife Michelle- for banking decisions including major withdrawals or expenditures. In this way, financial decisions will always be made jointly involving both Gavin and Michelle, which will help him to avoid a similar situation arising in the future. He also arranged for a percentage of his salary to be transferred automatically to the joint account to make sure that the needs of his children will be covered if a similar issue arises again.

This example shows that although there had been a time when Gavin’s needed support to make decisions, this was only a temporary situation. Psychosocial, intellectual or cognitive disabilities should not be a reason for assuming that people are unable to make decisions and depriving them of their right to legal capacity.

This scenario also shows that solutions can be found to protect the rights of family members and others who can suffer adverse consequences when their relative goes through difficult times.

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

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

Example: Gavin and his wife Michelle (see above) are now working diligently together to make decisions related to finances and avoid the kind of problems they experienced earlier when Gavin would make impulse purchases. One thing Michelle quickly learned with Gavin was to ask him what he wanted, related to purchases, rather than tell him what he could do or not do. When she learned to ask questions and listen to his reasons for wanting things, they would have more productive conversations about what he wanted to spend money on and why, and she could understand the emotional needs he was trying to fill so that they could explore other ways for him to get those needs met.

The right to legal capacity in the CRPD

The UN Convention on the Rights of Persons with Disabilities 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 others in all aspects of life**. It was drafted in 2006 with the substantial involvement of people with disabilities, including people with psychosocial, intellectual and cognitive disabilities.

The Convention aims to protect the human rights of people with disabilities, fight discrimination, stigma and stereotypes, promote inclusion and participation and 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 the General Comment on this article (Appendix 2 and 3).

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

According to article 12 of the CRPD, the right to legal capacity never can 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 **also** guaranteed for people who have significant support needs (e.g. those who do not communicate in traditional ways, or who may be perceived by others to not communicate at all, those who are extremely isolated, those who have no existing support network, those who are at risk of abuse and exploitation) (2). These people are **also** protected by the provisions of article 12.

Formal and informal decision-making

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

Article 12 clearly states that all people, including people with disabilities, must have the right to make decisions for themselves and to have those decisions respected by others, and that their

decisions are to be recognised as valid decision under the law. Article 12 provides protection for both formal decision making and informal day-to-day decision making.

In the case of formal decisions, for example, around marriage, buying property and signing contracts, decisions for people with psychosocial, intellectual and cognitive disabilities are often made by court appointed guardians, mental health and other practitioners and families. This process has different names in different countries, for example, guardianship, conservatorship, etc.

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



Exercise 1.2: Examples of denial of the right to legal capacity (15 min)

Read with participants the two examples below:

Bob:

Bob was diagnosed with schizoaffective disorder and 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.

Paul:

Paul has been diagnosed as having an intellectual impairment and works at a grocery shop three days a week. Thanks to this job, he is able to save some money in a bank account. He would like to go on holiday to visit his cousin in the south and use his money to buy a train ticket. However, his father is his legal guardian, and does not allow him to access his bank account on his own. His father thinks that it is safer for Paul to stay at home, so does not allow Paul to buy the 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?

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

At home, people are in some cases denied the right to make decisions about their own lives and daily activities. Family members may make all these decisions for them; this is sometimes as a consequence of 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 very often occurs **in mental health and related services**. In some services, the right to legal capacity is almost systematically violated.

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

In addition, staff often make decisions because they think it is quicker, more convenient and less time consuming.

The result is that decision making power is taken away from people without talking with or listening to them (e.g. decisions 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.).



Exercise 1.3: Everyday examples of decision making (20 min)

Provide the group with copies of the table below (Appendix 4), please note the examples in italics are just some ideas – the group should try and come up with their own examples.

You can also draw the table on the flip chart.

Invite the group to provide concrete examples of decisions made for people with psychosocial, intellectual and cognitive disabilities in mental health and related services or at home.

Then ask them who decides and why.

How are decisions made?			
	Issues	Who decides?	Why?
<i>In the service</i>	<i>e.g. TV programs</i>	<i>e.g. the staff</i>	<i>e.g. to avoid any conflict between people using the service</i>
<i>At home</i>	<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</i>
	<i>e.g. going out</i>	<i>e.g. the family</i>	<i>e.g. because they think need to be protected from possible harm in the community</i>

After filling the table, ask participants the following questions:

- Do you think that people are encouraged or discouraged to make their own choices?
- In what ways do these arrangements help/hinder recovery?
- How can the arrangements be changed /improved?



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 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 does it make you feel when you were deprived of your right to legal capacity?

Potential answers for participants may include:

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

After the discussion, show the following:

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

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

The negative effects of not allowing people to make major life decisions are very important 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, small decisions people make in life – such as what drink to buy, what shirt to wear or what to eat – put together, make up an individual's personality and contribute to their role and identity in society.

Consistently taking away people's right to make decisions, big and small ones, can be profoundly disempowering and foster helplessness, dependence and non-participation.

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. It 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 (2):

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



Exercise 1.4: Decision-making as a means for empowerment (30 min)

Ask the group to read Rory Doody's personal account of his experience of decision making (3). Provide the group with copies of Appendix 5 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, nursing and I did it willingly, and 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 say it was the beginning of a journey, a very slow and painful journey that brought me to the realisation that there were things that I could do in my life and that there were choices that I could make that would impact 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 of 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.

Provide the group with the opportunity to comment on the text above. 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 tablet
- I’m going to go to the outpatients’ department
- I really and truly had handed over my life and my will
- There were many times that I begged to be put into hospital
- 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, his treatment, and feels empowered and more confident
- He develops and maintains relationships (he makes a great friend)

- Positive changes happens 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
- He can also help others as he is now a mental health advocate

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, https://www.youtube.com/watch?v=GGlig8w_oZQ (35:36) Date accessed 10/08/2016



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

The presentation will briefly outline the benefits of supported decision-making. These include:

- Improvement of decision making skills
- Increased, self-esteem, self-confidence and autonomy
- Realisation of important areas of life
- Personal empowerment
- Personal development as human beings and citizens
- Widening of people's networks
- Feeling supported
- 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 in this topic.

Ask the participants to think about the following questions:

Has your opinion about people with psychosocial, intellectual and cognitive disabilities' ability to make decisions changed?

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

Are you aware of some practical ways of respecting people's right to legal capacity (i.e. 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 related services. However, it is important to emphasize that even when people's personal opinion has not changed they still have a responsibility to respect human rights and this should take precedence over their personal opinion and their cultural and academic background.

Topic 2: Substitute vs supported decision making



Exercise 2.1: Meaningful support (15 min.)

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

You may want to start the exercise by discussing a simple, everyday example that has no major impact on people's life:

E.g.: 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 good action.

So generally, it is better to make sure that the person likes coffee beforehand, for example you may have observed what they usually drink or you may directly ask them.

After this initial discussion you should shift the conversation towards more important decisions. Pick a specific area to discuss with the group.

For example:

- Decisions around someone's healthcare, including mental well being
- Decisions around someone's financial affairs
- Decisions around where someone should live
- Decisions around someone's employment or training
- Decisions around who a person should have contact or a relationship with

Then, ask the participants the following questions:

What do you understand by the following statement?

"Nothing about us without us"

To what extent do you agree with it?

Why / why not?

Invite participants to share their thoughts and write the main ideas on the flip chart.

It is important to make clear to participants that helping people is good, but sometimes good intentions do not actually help people. The fact that you think you are doing the right thing for a person 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 in 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.

You may also 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 in the previous topic, people with psychosocial, intellectual and cognitive disabilities are often deprived of the right to legal capacity and 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 of the person concerned.

In yet other circumstances, laws allow others (for instance the Court, the director or manager of a mental health or related 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 who makes the decisions.
- People may think decisions actually get made for people who are assumed to be incapable of making 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.

Problems with substitute decision making

Substitute decision making is often used 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 that people's right to legal capacity.

In addition, it does not respect the person concerned as a decision-maker. It excludes the people from the decisions concerning them, despite the fact that these decisions are likely to have a significant impact and repercussions on their lives.

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

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

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

Substitute decision making results in a vicious circle: if people never have the opportunity to make a decision, then they can never learn to make them – this is true for all of us: decision making is like a muscle that you need to exercise in order to strengthen it!

The more people exercise decision making skills, the more confident they become. Conversely the more other people make decisions for them the less confident they will become when confronted with a situation where they have to make a decision. That is why; some people who have never had a right to make decisions may prefer to defer this responsibility to others.

For example, if you always let others make decision concerning finances (e.g. your husband or wife, your parents) you will never become experienced in making these sorts of decisions.

As explained previously, people with psychosocial disabilities, intellectual and 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 (4),(5),(6).

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/> date accessed 11/07/2016



Presentation: Supported decision making, a new approach to decision making (45 min.)

At times, all people may need support to make decisions in different areas of life. In other words, there may be times in life when a person, including a person with a psychosocial, intellectual or cognitive disability, may find it more difficult and challenging to make decisions on their own.

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

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

A person may need support to understand the information, weigh up different options, understand the possible consequences of different options and communicate their decisions to others (e.g. banks, utility companies, restaurants, health workers).

- For example, in the context of a mental health or related service, a trained advocate can support a person to understand the benefits and/or negative effects of a particular course of treatment, discuss the pros and cons of the treatment, and communicate the preferences of the person concerned, if the person is unable to do so.

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 live on the streets. Therefore, supported decision making might also involve providing the opportunity for people to form relationships of trust, where these are absent in their lives. In all these cases, 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.

'Supporters' may help others to realize that the person with the disability is also a person with a history, interests and aims in life, and is someone who has the right to exercise their legal capacity (7).

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

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

The unequal power between mental health and other practitioners and people using services acts as an important barrier to supported decision making in these settings. Often people using services hold the belief that practitioners are able to do what they want because of their position and the level of authority that they hold; while people using services themselves have little influence in their care (8). It is important to address and change power dynamics in order to achieve supported decision making as much as possible in that setting.

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

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

[Distribute to participants copies of Annex 6 \(reproduced below\).](#)

The following box (9) is a useful checklist tool to initiate a supported decision making approach. However, additional steps will need to be included on a person-by-person basis.

Do you?
<ul style="list-style-type: none">● Provide relevant information<ul style="list-style-type: none">➤ Does the person have all the relevant information they need to make a particular decision?➤ If they have a choice, have they been given information on all the alternatives?● Communicate in an appropriate way:<ul style="list-style-type: none">➤ Explain or present the information in a way that is easier for the person to understand (for example, by using simple language or visual aids)?➤ Explore different methods of communication if required, including non-verbal communication?➤ Ascertain if anyone else can help with communication (for example, a family member, support worker, interpreter, speech and language therapist or advocate)?● Make the person feel at ease:<ul style="list-style-type: none">➤ Identify if there are particular times of day when the person's understanding is better?➤ Identify if there are particular locations where the person may feel more at ease?➤ Ascertain whether the decision could be put off to see whether the person can make the decision at a later time when circumstances are right for them?● Support the person:<ul style="list-style-type: none">➤ 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/independent of a person with a psychosocial, intellectual and cognitive disability.

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 it that way.

Unwanted and inadequate support may be felt by people as an unacceptable intrusion in 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. Even in extreme circumstances, when the person is unable to communicate their wishes and preferences directly, decisions must be made based on the **best interpretation of the will and preferences of the person**. These can be determined, for example, by:
 - referring to what is already known about the person (their views on different matters, beliefs, values in life, etc. - if these are not known by supporters they can ask the person's close friends and/or relatives.
 - referring to advance planning documents which should 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 or word for describing these pre-existing models. It is about implementing a completely different approach in which the person always remains at the centre of and drives the decisions.

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.

In the health care context, the role of mental health and other practitioners in this process is fundamental. Sometimes practitioners have a strong commitment to the idea that they are already doing supported decision making. 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 supported decision making.

In addition, mental health and other practitioners often fail to account for the power differential 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 issues are counteracted by practitioners by paying attention to the values, expectations, will and preferences of the people they are working with, understanding their interpretative system and acting in line with these.

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 to make any particular decision. For example, asking a person if they prefer to take their medication or to be detained in a mental health or related service is not respectful of their right to make decisions.

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

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

However it is important to note that: Imposing or forcing treatment itself can cause harm either immediately or further down the track. The harm caused to the person can take many forms including, trauma, humiliation, physical injuries, negative effects of medication, etc.



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

The following table (10) summarises the shift from substitute decision making towards supported decision making. To make this shift is necessary to move from the left-side of the table to the right hand one.

From	To
A presumption that people with psychosocial disabilities and people with intellectual disabilities don't have the mental capacity/ability to make their own decisions	A presumption that people with psychosocial disabilities and people with intellectual disabilities can make decisions by themselves and for themselves, with the assistance of their supporters if needed.
Assessing deficits in mental capacity (ability to make decision)	Exploring the type and level of support that may be required to make decisions
Detention in mental health and related services	Exploration of support alternatives in the community
Best interests (where others determine what is the best decision or course of action for a person)	Will and preference (Where all decisions are based on the will and preferences of the person or in some cases on the best interpretation of their wishes and preferences in situations when the person is unable to communicate)
Substitute decision making and appointment of substitute decision makers (where other people make decisions for you according to their own standards and not your will preferences)	Supported decision making (where people make decisions for themselves and by themselves with the support of others)



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 concerning different areas of life. People do not always have sufficient knowledge, experience or time to make every kind of decisions on their own.

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

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

For example, about whether to enter a new relationship, what purchase to make (e.g. which brand of bicycle, car or bed to buy), where to go on holiday, where to live, what university to go to, 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 you to find the relevant information.
- You trusted the person whose opinion you sought.
- The support person connected you 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 you had not thought about.
- The support person helped you to weigh the pros and cons.
- The support person helped you to identify the real problem.
- The support person reminded you of your previous experience(s) which were relevant to the decision at stake.
- The support person helped you to make a decision in line with your personal objectives and values.
- The support person made you feel that it was going to be ok, no matter what decision you 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 give you the appropriate information.
- Even if the information was accurate you were not able to understand it.
- The support person already had a strong position on the question.
- The support person told you what they would do in this situation (rather than focusing on what you would like to do).
- The support person encouraged you to make a decision to please them, not to please you.
- The support person finally made the decision on your behalf.



Presentation: different forms of support (50 min.)

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

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 and 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 about the area or issue they are considering.

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 to ensure that persons with disabilities 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, provide support as is reasonable, and recognize the person's requirement for supports in the decision-making process.

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

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

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

As mentioned earlier, 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 allow people with psychosocial, intellectual and cognitive disabilities to make decisions in a way which is similar to people without disabilities.
- However, formal support may sometimes be necessary for complex or important decisions, when informal support is not sufficient and/or when the person has important support needs.

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

Sometimes people with more significant support needs may need the ongoing assistance of a support network of family and friends to assist and ensure the best interpretation of their will and preferences to third parties. In these situations, one of the main challenges will be to get legal recognition of this as supported decision making rather than substitute decision making.

Formal support

- **The Swedish Personal Ombudsman (PO) (11):**
 - The Personal Ombudsman (PO) system is a model of supported decision making. The service is generally offered by NGOs.
 - POs are skilled persons who work on the request of the person needing services. They help clients with a range of issues: family-matters, health care, housing, 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.
 - There is no written agreement between the PO and the client to avoid burdensome administrative processes and paperwork.
 - 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 telephone and internet, and 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 economic matters. The POs are not seen as an alternative to guardianship by the Swedish government. The two systems are not connected and developed separately. Therefore a person might have a PO and a guardian at the same time. But 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 (12):

- In 2014, 6000 persons were supported by a PO in Sweden.
- 84 percent of Swedish municipalities included POs in their social service system.
- Individuals with disabilities who are supported by a PO require less care and their psychosocial situation improves.
- In the long-term it reduces costs for the social system.
-

Ask the group to listen to Maths Jespersen speaking about the Swedish psychiatric reform and present the Innovative Policy “**Personal Ombudsmen System**” in the following video: <https://youtu.be/xqma4wK8sC0> (13:50) Date accessed 13/06/2016

- **Independent Advocacy (Scotland, United Kingdom) (13)**
 - Independent Advocacy is a way to help people, including people with psychosocial, intellectual and cognitive disabilities to have a stronger voice and to have as much control as possible over their own lives.
 - Independent Advocacy organisations are separate from organisations 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 get 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) (14),(15),(16)**

Open Dialogue is a Finnish alternative to the traditional mental health system for people diagnosed with "psychoses" such as "schizophrenia". This approach aims to respect the decision-making of the person concerned, and at the same time, also support 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 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 for the meeting is jointly decided. In order to counter stigma and provide safety, the meetings can take place at the home of the person seeking support.

In Open dialogue, the person seeking support, family and care partners are all invited to participate alongside the open dialogue team member in daily meetings that are open, non-secretive and non-

hierarchical. Everyone openly voices and reflects on their thoughts and feelings, and everyone's voice is heard, particularly the voice of the person seeking support.

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 make decisions about treatment on behalf of the person concerned. On the contrary, the team members follow the themes and issues brought up by the person and their family members or supporters. Dialogue explores how they understand the situation and how, in their own language, they 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. As a consequence, 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 five year follow-up study (17) on people experiencing a first psychotic episode treated in Stockholm from 1991 to 1992 (before the development of a psychosocial program 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 5 years.

For more information on Open Dialogue, participants can watch the following videos:

➤ Short option: Daniel Mackler, **Jaakko Seikkula Speaks on Finnish Open Dialogue, Social Networks, and Recovery from Psychosis** (8:24)
<https://www.youtube.com/watch?v=ywtPedxhC3U&feature=related&app=desktop> Date accessed 04/07/2016

➤ Long option: Daniel Mackler, **OPEN DIALOGUE: an alternative Finnish approach to healing psychosis** (COMPLETE FILM) (1:13:59) <https://www.youtube.com/watch?v=HDVhZHJagfQ> date accessed 06/07/2016

Informal support:

- **Support network**

- E.g. Circle of support (UK) (18):

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

The focus person is in charge, both in deciding who to invite to be into 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.

For more information, show participants the following video: [Circle networks, Circle of Support](https://youtu.be/w6RX_WQmSf4?t=54) (4:58, starting at 0:54) https://youtu.be/w6RX_WQmSf4?t=54 Date accessed 04/07/2016

- **Peer support**

Peer support refers to the idea that people with psychosocial, intellectual, and cognitive disabilities can help others in similar situations. 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. 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 or outside mental health and related services, peer workers should always be independent.

- **Support from family and friends**

For many people the support and understanding of their families 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, they are more likely to be on hand to encourage and support the person to exercise their right to legal capacity, e.g. offering people to engage in activities of their liking or providing support on how to manage a budget.

They can also be a great source of information to enable others to understand the background of the person, their values and objectives in life, their previous experience(s) of mental health and related 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 of challenging situations involving the person;
- Being overprotective of the person
- Feeling entitled to share part of their family member’s story with others in ways the person would not want the information to be shared.

Reemphasize the idea that:

Supported decision making cannot happen if there are significant conflicts with the family/friends. However, in these cases, all the stakeholders should work together to mediate conflicts and improve the family situation.



Exercise 2.3: Scenario – Understanding support in supported decision making (20 min.)

Explain to participants that this is a simple scenario, as opposed to a challenging one, in order to explain the concepts in 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 scenario will be addressed in a subsequent exercise.

Judith

Read to participants the paragraph below.

One morning, a young woman named Judith arrives at the mental health service. As she seems very depressed and agitated. She is diagnosed with depression and immediately put on anti-depressants although she says she does not want to take medication. She becomes increasingly nervous, irritable and agitated. The staff of the service give her benzodiazepines to manage the agitation. The sedating effect of the medication makes it difficult for her to interact with other people and as a result, she becomes isolated, loses confidence in herself and feels even worse. 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:

- Judith was deprived of her right to make decisions about what treatment she should receive.
- 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 for 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, and support her to communicate her preferences and ensure that these were respected.
- Treatment or support could have been offered on an ambulatory basis, it was not necessary to leave her at the service.
- They could have accepted her decision and respected her choice of care options other than medication.

Now read a different version of Judith's story, in which staff adopted a supportive approach:

One morning, a young woman named Judith arrives at the mental health service. As she seems depressed and agitated, a nurse suggests to Judith that they go to a quiet room in order to discuss what is troubling her. The nurse asks Judith if she would like to share her feelings with her and tell her a bit more about her situation.

Judith explains that she has been feeling very depressed 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. She says she would like care and support but does not want antidepressants. She adds that she took antidepressants in the past which made her feel very tense, irritable and also agitated.

The nurse says there are various types of medication which she could try (different from those that she had used in the past). She explains that there are also alternatives to drug treatments such as individual psychotherapy, group therapy or counselling sessions. She also explains that Judith could explore and engage in activities that make her feel good (e.g. massages, meditation). She offers to schedule an appointment with the psychiatrist, the peer support worker, the psychologist and/or the occupational therapist to discuss the different options. She also asks Judith if she prefers to be supported at home or at the mental health service and if there are people in particular that she trusts and whom that she would like to contact to support her.

Judith knows and values someone who has had similar experiences with depression with whom she has been spending time recently. Judith feels that her friend can help her weigh up the pros and cons of different treatment, care and support options, and help her to make a decision. The nurse says that if her friend agrees, Judith will be able to nominate her as a supported decision maker, and involve her in the formulation of her treatment plan.

Give participants an opportunity to comment on this alternative scenario.

Topic 3: Supported decision making in practice



Exercise 3.1: Scenarios – Deciding on supporters and support options (25 min.)

Explain to participants that this is a simple scenario, as opposed to a challenging one, in order to explain the concepts in 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 scenario will be addressed in a subsequent exercise.

Example: Jack

Read the paragraph below to the participants.

Jack is 42 years old and due to a serious gambling problem has accumulated a lot of debt. He has been homeless for some time but now lives with Mike, a friend of his late father whom he has known for many years. He is not close to his family, who live on the other side of the country. He has not heard from them for a long time. Recently, he has found a job as a waiter. Now, he would like to have support in helping to manage his gambling problem and also his finances, but he is not close to anyone.

Then ask the group:

1) Who could act as a supported decision maker in Jack's case?

A possible answer may be that the friend of his father seems willing to help Jack but maybe he knows and trusts other people in the community. He doesn't seem to be close to his family so they might not be the most appropriate people in this case. It should be clear that, in the end, Jack is the person who knows what is best for him and he should be asked the question about who could provide support.

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

2) What can be done for Jack's gambling problem and financial situation?

An easy solution would be to put a guardianship order in place in order to control Jack's finances. However this is not respectful of Jack's autonomy, self-determination and human rights.

Possible alternative solutions are:

- **Peer support groups for gambling addiction and problem gambling.** These groups often ask the person concerned to choose a sponsor. A sponsor is a person with a previous gambling problem who has time and experience remaining free from addiction, and can often provide invaluable guidance and support.
- **Jack could introduce mechanisms to help him better control his finances.** He might decide for himself that he wants to get rid of his credit cards, let someone else be in charge of his money and keep a limited amount of cash on him at all times (Keep in mind that this is not

substitute decision making as it is Jack who is choosing to restrict his right to make decisions on financial matters for a certain period of time).

- **Learning techniques to manage negative and overwhelming feelings without gambling**
Unpleasant feelings such as sadness, loneliness and fear can trigger compulsive gambling or make it worse. There are other ways to keep these overwhelming feelings in check. These may include exercising, meditating, spending time with friends, taking up new hobbies, or exploring relaxation techniques.
- **Cognitive-behavioural therapy for problem gambling.** This focuses on changing unhealthy gambling behaviours and thoughts. It also teaches people with gambling problems how to fight gambling urges, deal with uncomfortable emotions rather than to escape through gambling, and solve financial, work, and relationship problems that might have been caused by his gambling problems.
- Participants may come up with additional ideas for how to support Jack.

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

Jack (continued)

Jack acknowledges that he has a gambling problem. At the present moment, he recognizes that he is not able to control the impulse to gamble, even though he knows his gambling problem is hurting himself. For this reason, he decides to ask Mike to be his supporter and to be in charge of his money for some time. In addition, he decides to take part in a peer support group for gambling problems where he is learning strategies to fight gambling urges. He also makes some new friends. Subsequently, Jack is recovering from his gambling problem and little by little is repaying his debts.

Example: Mary

Read the story below to the participants:

Mary is a young woman with two children, whose experience of depressive episodes sometimes makes it challenging and overwhelming for her to raise her children on her own. She would like support in this area. She gets on very well with her sister (Sophie) as well as her best friend Jane.

Ask the group the following question:

How could Sophie and Jane help Mary with parenting issues?

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

The participants may come up with other, original ideas for how to help Mary.

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

Mary (continued)

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

- Her friend will check in on her on a regular basis in person or by phone.
- Jane says she will look into family supports that may be available for Mary and help her fill in any forms that may be required or accompany her if any visits to social services are required.
- The sister and friend will sometimes take the children for the weekend if Mary 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 organised for the children to help them understand the situation, support their relationship with their mother and make sure that they don't feel abandoned or neglected when their mother 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.

Distribute to each group one of the examples below (see Appendix 7 below).

Example 1

One morning, a young woman named Rose arrives at the mental health service, accompanied by police officers. She had tried to kill herself by jumping off a bridge, but police officers were present at the scene and they were able to save her life. A few minutes after her arrival, Rose claims that she is ok now. She doesn't want any treatment and asks to be allowed to go back home, where she lives alone. Rose seems not to have a family and does not have an advance directive.

Example 2

Roger is a young man diagnosed with schizophrenia. He was admitted to the hospital because he has cancer and needs to begin treatment for it right away. During the first day at the hospital, he became convinced that doctors and nurses wanted to poison him. Now Roger is refusing the treatment for his cancer. He has no family and does not have an advance directive.

Example 3

Michael is a young man who is experiencing a crisis and has decided to spend all of his money to create a breeding farm for chinchillas. He has decided that the garden of the mental health service is the place most suitable for the farm; so he comes to visit the service in order to ask staff their

permission to create it. He tells them that he wants to sell his house 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 bearing in mind that no advance directives have been developed by the people concerned?

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

What do you think could happen if the right of each person to make decisions is not respected?

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 has presented their ideas, allow for structured discussion in plenary among the three groups.

A response to this issue should include 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 for alternatives in order to respect people's right to make decisions include:

Example 1 (Rose)

- Trying to understand why she wants to kill herself and also why she does not want treatment – i.e. is it one particular type of treatment all or treatments.
- Asking what she thinks would help her to feel better.
- Trying to explore with her different possible solutions to her problems.
- Asking if there is a person she trusts that can help in this situation.
- Exploring with her what other options she has instead of staying alone (which might mean staying in the mental health service or some other place that is safe on a voluntary basis, where she would not be alone).
- Linking her to a peer worker and other support networks in the community.
- In order to avoid this situation again staff could encourage her at an appropriate moment when she feels better to prepare an advance directive that she and others could follow should she find herself in a similar situation in the future.
- Providing Rose with access to support earlier, before reaching a point where she wanted to end her life.

Example 2 (Roger)

- Talking with Roger to gain his trust and give him time and space before starting the cancer treatment.
- Involving non-medical professionals (advocates, etc.) who can try to understand and discuss with him the advantages and risks of beginning the cancer treatment.
- Asking Roger if there is a person he trusts who could support him.
- Asking Roger if there is someone he trusts among the doctors and the nurses.
- Linking him to a peer who is a cancer survivor or cancer support network in the community.
- In order to avoid this situation again staff could encourage Roger at an appropriate moment after the crisis to prepare an advance directive that he and others could follow should he find himself in a similar situation in the future.

Example3 (Michael)

- Talking with Michael to encourage him to think longer before spending all of his money on his project, and to think carefully of other projects or opportunities for a business.
- Explaining him that he is not allowed to create a farm in the service but maybe he could start by creating a smaller farm elsewhere in order to better understand whether or not it is a lucrative business.
- Asking Michael if there is a person he trusts who can give advice on his project.
- Encouraging and support Michael 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.
- Linking him to peer workers or peer support networks in the community.
- Encourage him to identify what his financial needs are for living and put that money aside so that if the farm does not work out he still has sufficient money to live on.
- In order to avoid this situation again staff could encourage Michael at an appropriate moment to prepare an advance directive relating to his finances that he and others could follow should he find himself in a similar situation in the future



Presentation: System Failures in Supported Decision Making (10 min.)

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

It should be clear to the group that making decisions on behalf of other people is never acceptable. We should always consider this as a violation of people's right to exercise legal capacity as a "system failure" and a bad out-come, even when it seems that all the alternatives have been tried.

Most of the time, such a failure would not have occurred if support had been provided earlier, before the situation has escalated.

This includes support to the person and support to their relatives who may also suffer adverse consequences during difficult situations. These support mechanisms should be discussed and agreed upon between all the people concerned.

Each system failure should be a trigger to do better next time. It should also push mental health and other practitioner and families to review all the strategies put in place to avoid the violation of the person's right to legal capacity, in order to understand what went wrong.

In mental health and related services, a report should be written to summarize the findings of the review process.

If the person agrees, the data collected should be made accessible to staff in order to continually learn and improve ways of managing challenging situations.

The report should also be shared with all staff, families and people using the service as well as external, fully independent, advocates.

A meeting can be organized with all the stakeholders to discuss ways to avoid the same situation in the future.



Exercise 3.3: Scenario - System failures (19) (20 min.)

Peter

Read the paragraph below to participants.

Peter is a young man who lives with his parents. He becomes more and more isolated, displays behaviours his parents do not understand, and starts to become aggressive and even threatening to his parents. The parents find themselves unable to cope. Peter refuses to see a doctor and the parents worry for his and their safety. Nonetheless, Peter is clear about what he will and will not do. Eventually, after some weeks have passed he doesn't want to see anyone, barricades himself in his room and refuses to exit.

Then ask the group:

1) What can be done to support Peter in this case?

A possible answer may be that a friend or someone that Peter knows and trusts in the community can try to approach him and talk with him. This person could try to enter into a real, sincere, and open dialogue with Peter, in order to understand his feelings and reasons for his behaviour. It is nearly always necessary to be creative in finding solutions which are acceptable to the person and very often requires a very good understanding of their will and preferences.

Once the participants have had the opportunity to discuss this first question ask:

2) What can be done to support Peter's parents?

Keep in mind that both Peter and his parents are experiencing serious adverse effects. While Peter may refuse support, the parents may themselves benefit from intensive emotional support and planning to understand what their options are. This kind of support should always be offered and arranged for care partners who are experiencing serious adverse effects.

Possible alternative solutions are:

- **Arranging for a temporary “safe home” in the community where Peter’s parents can stay until the situation has resolved.**
- **Peer support groups for family members who are experiencing adverse effects.**
- **Relieving difficult and overwhelming feelings linked to the challenging situation.** These could include difficult feelings such as sadness, loneliness and fear all of which could make the situation worse. There are ways to help manage these feelings. These may include exercising, meditating, spending time with friends, taking up new hobbies, or exploring relaxation techniques.
- Counselling may help the parents to realise that they need to take care of themselves, even during this period of crisis with Peter.
- **Individual therapy for coping with stressful situations.**
- The participants may come up with other ideas for how to help Peter’s parents

Peter (continued)

Once the second question has been discussed read the outcome of the case study. Mention to participants that in this scenario, the country’s judicial system, including the tribunal referred to in the text, has replaced guardianship measures with a supported decision making approach.

Peter continues to refuse to see anyone or to exit from his room. Now, he is also refusing to eat and drink. Some friends try to talk with him but without any success. Peter’s parents have the perception that their son’s condition has deteriorated to the extent that he is no longer expressing his will and preferences. They believe that their son would not want others to let him remain in this situation.

As a consequence, they apply to the Tribunal for a determination about whether they can act on behalf of Peter. After hearing evidence from Peter’s closest friends and family members, the Tribunal determine that it would be consistent with Peter’s will and preferences to authorise his parents to admit him on his behalf to a mental health service for assessment and treatment.

A few weeks after, Peter is still in the mental health service and is able to communicate again. He explains to his parents that he did not want to be admitted to the mental health service and still does not want to be there. He says that he would prefer to go to a respite house run by peers that he heard about. He also says that he did not want to hurt anybody and that his parents were right to take action when he became threatening and aggressive.

His parents offer to take the necessary steps in order to facilitate his transfer to the respite house as soon as possible. They agree that if the same situation arises in the future, Peter’s parent would do their best to ensure that Peter will go to the respite house and not to a mental health service. Peter also explain that he has learned from this experience and understood that others would not necessarily guess exactly what he wants when he is in that state. Therefore, he would write an advance directive to make sure that others are aware of his choices for similar situations in the future.

In this case, a system failure occurred because Peter's will and preferences and therefore his right to legal capacity was not respected when he was admitted to a mental health service against his will. It is a system failure because even though different alternatives were explored, Peter's right to legal capacity was ultimately violated.

The following needs to be learned from system failures:

- The outcome might have been different if an acceptable intervention had been provided before the situation developed into a crisis.
- After a system failure has occurred, discussion must take place to review how the situation has been managed (what went wrong, but also what went well) and ensure that the same mistakes are not made again in the future.

Topic 4: Preventing exploitation from people acting as supporters



Exercise 4.1: How to prevent exploitation from people acting as supporters (30 min)

This exercise is meant to help the group come up with a list of steps that can be taken to prevent exploitation from supporters.

The participants can be split into three groups, each of which will receive a different case study (see Appendix 8).

Exemple 1

Paul is a young man who regularly attends a day care center. He withdraws money to buy a motorbike and since he is not used to shopping, he asks for the help of a staff member, Kevin. Kevin, instead of helping him to shop around, sells Paul an old motorbike for the price of a new one. Paul agrees with the deal as he does not want to create problems between him and Kevin.

Example 2

David lives in a supported house. He loves to try new foods and wines and, for this reason, he withdraws money on his own and then spends it on eating in restaurants. Each time he goes to the restaurant, a person from his community that he has chosen as a supporter accompanies him and David always pays for him.

Example 3

Mirela has an intellectual disability and lives with her family. She has inherited a big apartment in the centre of the city from an old uncle who was particularly attached to her. Her family convinces her to sell the apartment to her brother at a bargain price. Mirela agrees with the deal as she is not really informed about the prices in the real estate sector.

Ask the following questions and record participants' ideas on the flip chart:

- What went wrong in these cases?
- Could things have been done differently?
- Could you suggest positive steps to take in order to avoid exploitation from supporters?

Underline to participants the fact that it is important that mental health and other practitioners should not be the nominated supporters of people using the service in which they work because of

the huge risk of conflict of interest. Although they should not be formal ‘supporters’, they still have an important role in promoting supported decision making.



Presentation: How can we avoid exploitation from supporters? (15 min.)

How can we avoid exploitation from supporters?

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

- People with psychosocial, intellectual and cognitive disabilities
- Families
- Mental health and other practitioners
- Advocates and peer workers
- People working in organisations of persons with disabilities
- Monitors
- Other relevant people from the community

A clear policy on this issue should exist at each mental health and related service.

It is important that the policy highlights that:

- Mental health and other practitioners should not take on the role of formal supporters.
- Supporters’ role should be for the shortest time possible and tailored to the person’s circumstances.
- Supporters must not profit from the funds of the people they are working for, caring for or otherwise supporting.
- Independent support from outside the mental health or related service should be offered and made available whenever a person asks for it.
- External groups including advocacy and peer support workers should be able to freely access and talk to people within mental health and related services.

Safeguards, such as monitors, should exist to ensure no exploitation occurs.

What is a monitor? (19)

A monitor is a person whose role would be to protect the decision-making rights, will and preferences of the person concerned, including the right to take risks and to make mistakes. They should be independent and appointed by the state.

More specifically, the monitor would need to ensure that supporters comply with all the duties expected of them. They must be able to challenge the actions of supporters if they are not acting in accordance with the will and preferences of the person.

Monitor should not be staff of the service. They should be fully independent.

In addition, there should be mechanisms (such as complaints and monitoring mechanisms) to hold people who abuse of their supportive role accountable.

Topic 5: Nominating a person to communicate one's will and preferences



Presentation: Nominated persons to communicate wishes and preferences (20 min.)

People must be given the power to nominate others of their choosing, in advance, to act for them and communicate their will and preferences, for situations in which they cannot communicate their wishes or in which they would prefer someone else to communicate on their behalf. For example, if they become unconscious, catatonic, have very severe and profound communication impairment or other situations which prevent them from expressing their wishes and preferences directly.

In these situations, it can be useful for mental health and other practitioners to find out whether assistive technology or other forms of accommodation could help.

If not, they should consult with the nominated person(s) of the individual who have previous knowledge of and can communicate the person's will and preferences.

A person may nominate one specific person or a group of people who would collectively determine and communicate decisions based on the wishes and preferences of the person. They can also nominate different representatives for different issues (e.g. health, finances).

Nominated persons, in this sense, are **not** 'substitute decision makers'. They should not make decisions 'instead' of the person. Nor should a nominated representative make decisions in terms of what they *think* is in the 'best interest' of the person concerned.

In some jurisdictions, the law requires a substituted decision maker to *take into account* the wishes and preferences of the person when making a decision. However, these wishes or preferences are *only one* of the criteria that substitute decision makers must take into account. Ultimately, in these jurisdictions, they can still make the decision based on other criteria (e.g. the potential benefits for the person). This model is not supported decision making.

In the supported decision making model however, **the nominated person's role is to communicate the person's wishes and preferences based on what the person would have wanted or on what the person has said they want in these particular circumstances** (i.e. best interpretation of the will and preferences of the person).

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, for example in the person's care and treatment plan and medical records.

The nominated person should:

- **Be a trusted person:** someone who knows the person well and is able to respect their rights and make the person's values, will and preferences prevail when a decision is being made.
- **Be available:** It is important to choose someone who can make themselves available when necessary. For example, someone who is travelling around the world or someone who has too many family or other obligations may not be the best person to consider.
- **NOT be a service staff member of a mental health or related service:** This is to avoid any conflict of interest as staff may sometimes favour practices that are not necessarily what the person would have wanted (e.g. keeping the person at the hospital for a long period, increasing medication due to insufficient staff at the hospital etc.).
- **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 monitored and subject to accountability mechanisms:** Safeguards should be in place to make sure that nominated persons do not abuse their role.

Sometimes, a decision has to be made and nothing is known about the person's wishes and preferences (e.g. a person arrives at a service, does not communicate and it's not possible to identify any supporter in that person's life)

In this case, an independent person (e.g. advocate) should be appointed. The appointed person will have a duty to make every effort possible to identify the person's beliefs and values and make decisions that are the best interpretation of the will and preferences of the person concerned. However because little is yet know about the person, it may not be completely correct. This situation must only be temporary. The nominated person has the duty to take steps to get to know the person better and to help them to build a social network, so that they can personally choose a supporter.

Topic 6: Positive steps to adopt a supported decision making approach



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 should be able to receive support from someone they choose and trust and who can understand their values, wishes and background and respect their will and preferences.
4. The level of support required depends on the complexity of the decision and situation of the person who is making the decision.
5. People have a right to learn from experience and to make bad decisions.
6. People have a right to disagree with others.
7. People have a right to change their minds including the right to refuse support if no longer desirable.
8. Decisions should always be based on the will and preferences of the person.



Exercise 6.1: 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 group to commit to respect and strengthen people's autonomy through personal action.

Start by brainstorming with the group a list of possible personal actions. Write ideas on the flip charts. Ask the group:

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 (i.e. not merely as one of a group of 'patients'). Get to know their opinions, their background and their relatives.
- Take the time to ask people their opinions, preferences, likes, dislikes and don't assume you know what they want.
- Acknowledge the fact that you may not always agree with a decision, but you still want to support the person and the decisions that they make.
- Acknowledge the fact that people can change their minds.
- Provide people with clear information.
- Help people 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 any treatment or program in settings different from the mental health or related service (at home, in the community, at a friend’s place, etc.) so that involuntary admission is avoided.



Presentation: Tips for supporters (5 min.)

- Take the time to listen to the person and understand what they want.
- Get to know the person that you support (what they like or dislike, what are their goals in life, etc...).
- 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 as their will and preferences may change.
- Find information about individuals, networks or services that can provide 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 6.2: Mental health and related service level action to promote legal capacity and supported decision making (20 min.)

Next invite participants to brainstorm as a group a list of changes that need to be implemented in mental health and related services in order to adopt a supported decision making 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 for your service to facilitate legal capacity and supported decision making?

Then show possible responses to this question and ask the participants to comment and discuss the different propositions:

- Provide the staff with information to understand issues around the right to legal capacity and around supported decision making;
- Encourage staff to develop their communication skills, including systematically asking their opinions and preferences to people using the service;
- Promote training sessions and discussions around 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 decisions, if necessary in an appropriate format;
- Involve people using the service in the organisation of the service and the planning of activities;
- 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, outside groups etc.);
- Facilitate interaction between people using the service and their family and friends, dedicate time and space in the service so that they can meet and discuss;
- Facilitate the creation of peer-support groups so that people using the service can access these.

Topic 7: What is advance planning?



Presentation: What is advance planning? (50 min.)

As we have seen in the previous session, supported decision making can ensure people remain at the centre of decisions. Advance planning is another mechanism designed to ensure that the will and preferences of the person are respected.

Advance planning refers to the process of making known one's choices and preferences about future care or treatment, and ensuring that other people are aware of these choices. Advance plans are sometimes called living wills or advance directives. They apply during times when people may be having important difficulties in making or communicating decisions.

In some countries and cultures, people may not have a tradition of writing documents (such as wills, contracts, etc.). However, this does not prevent people from orally making their choices about care, treatment and support known to their support network.

People should always have a choice to write advance plans or not. It should not be a requirement imposed by a mental health or related service or by a service staff.

If the person concerned becomes unable to express their wishes, others can refer to that person's advance plan to make sure they follow the treatment, care and support options the person wants or does not want.

In this section we will focus on advance planning for treatment, care and support. However, people may also want to specify their wishes about other aspect of their lives (e.g. who is taking care of the children, home, bills, taxes, pets, etc. when the person is unable to). To do so, people can write advance statements of their wishes and feelings. Advance statements are not limited in scope and generally not binding so people can use them to indicate their preferences about a wide range of issues. The development of an advance plan for treatment, care and support, as well as advance statements can be 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 to help people to live the life they want and 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 (health workers, families, friends, etc.). (For more information see the QualityRights module *Promoting recovery in mental health and related services*).

Content of advance plans:

For many different reasons, some people may not want to plan in advance for their care and treatment. For example, they may be confident that if they cannot 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. The person can nominate one person or a group of people who would discuss together to find out what is the best interpretation of the will and preferences of the person concerned and make the decision collectively. The person who is making the advance plan 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.

Example: *In Yasmin's family, when a decision needs to be made, 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 the future. She also thinks that science and medicine are continuously 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.*

Other people, on the contrary may find very useful to anticipate and specify in advance, in a written document, all future choices about care, treatment and support.

- They can specify which treatment, care and support options they want.
- They can also specify which treatment, care and support options they do not want and as such ensure that they do not receive any intervention against their wishes.
- In addition, they can also nominate a person whose role is to communicate their wishes and preferences to others based on the directives stated in the plan (this has already been discussed above).

Generally, advance plans should not prevent people from changing their minds. For example, if a person specifies in their advance plan that they refuse to have a specific type of treatment, and then, at the time of a crisis, they change their mind and decide that they want to have this treatment, their decisions should be respected.

However, some people may want to anticipate the situation where during a time when they feel unwell, they may make a decision which is not in line with their wishes and preferences. In this case, they can **explicitly** specify what they stated in their advance plan or directive should take precedence over their stated wishes and preferences during specific event. This mechanism is called "Ulysses clauses" in some jurisdictions.

Here are some Examples:

1. *Tom has been diagnosed with bipolar disorder. He knows that a particular type of medication causes him extremely negative effects. 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 would 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. *Noa knows that an important problem when she experiences a crisis is that she does not sleep during several days. In the past she has found that taking sedative medication during a very short period of time was very helpful. However, when she is experiencing a crisis, she sometimes starts to believe that people around want to poison her and refuses all forms of food or medication. To avoid that situation, she writes in her advance directive that during a crisis, she consents to receive sedative medication by injection during the first three days, and that her advance directive overrides her possible objections on the matter.*
- The more details people provide in their advance plan or directive, the more likely it will be implemented in the way that they would want. In addition, by thinking about and elaborating scenarios that people are likely to encounter, it can bring clarity to the decision making.

When should advance plans come into effect (20)?

In most countries, advance plan come into effect when people are assessed as not having mental capacity (i.e. the ability to make decisions).

In addition, in these countries, the law requires that people have “capacity” to make a valid advance plan. This means, for example, that if people under guardianship make an advance plan, it would not have any legal value. It also means that advance plans will not have legal validity if made during crisis or other situations in which the person is not seen as having the ability to make decisions.

The UN CRPD requires a completely different approach. As we have seen, according to article 12 of the CRPD, people have their right to legal capacity **at all times**. The purpose of advance plans is therefore to communicate wishes and preferences when the person is unwell, while ensuring that the person still **retains their right to legal capacity**. The fact that the advance plans comes into effect does not categorise a person as ‘legally incapable’, nor does it represent a judgment about their cognitive abilities.

The person can set out the circumstances in which they want the plan or directive to be activated or deactivated e.g. when the person goes into crisis or is hospitalised. The directive then acts as a communication tool, which ensures the person’s preferences are respected without any impact on the right to legal capacity.

Therefore it is important to specify in the plan, how and when supporters can tell that the person is unwell and would like a particular intervention or support as well as when the person no longer would like a particular intervention or support.

The benefits of advance planning

A study in Ireland has shown that the majority of people using services perceived advance directives as useful for future times of crisis and would be willing to use them if available (20).

Studies have also shown that advance plans or directives give people more control over their treatment and reduce the use of coercive interventions (21). In particular, a recent comprehensive review and meta-analysis has found that advance statements reduced by 23% the use of compulsory admissions. In comparison, Community Treatments Orders or other coercive community measures were not successful in reducing rates of involuntary admissions (22).

Advance planning also has some benefits for service providers. 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 would be held responsible or liable for any bad outcomes that may occur. Legislations in countries should make sure that practitioners are not be held responsible if they follow the instructions stated in the person's advance plan or directive. This would help to remove barriers that may prevent practitioners from using advance plans or directives and respecting people's choices.

However, it is also really important that practitioners see the development of an advance plan as an important part of the recovery process not only as a legal document or a 'task' they need to 'tick off their checklists'.

Advance planning in countries

Different models of advance planning exist among countries. Some countries have adopted laws around advance planning.

For example, In England and Wales, provisions for advance directives allow people to refuse, specific types of treatment in advance.

British Columbia also has advance directives in which people can specify the treatment they refuse to receive. In addition, in the British Columbia model people may specify which treatments they would be prepared to accept.

It's important to note that advance refusal of treatment is different from advance consent to treatment people would be prepared to accept.

- Advance refusal may guarantee that a person will not be given that specific form of treatment, care or support.

- However, advance consent to treatment does *not* guarantee that the person will be given that form of treatment, care or support (for example if the mental health or related service does not offer this treatment or if resources in the service do not allow for this treatment).

Although some of these documents are legally binding (i.e. people are required by law to respect them), to date, they have been limited in scope. The law in England and Wales and in British Columbia envisages situations when binding advance plans can be overridden (e.g. lifesaving emergencies, incompatibility with the known wishes and preference of the person, etc.).

Sometimes many good things that some countries have put in place are undone by the fact that advance plans can be overridden when, for example, a person is, involuntarily admitted (this is the case, for example, under the Mental Health Act in England and Wales in the UK). Therefore, a person who is detained involuntarily can also be given treatment against their will despite the existence of an advance directive. This is not in line with the CRPD.

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

Make clear to participants that mental health and others practitioners should only help people using services to consider who and what they would choose to include in an advance plan, not fill it in for them. The plan needs to reflect what care, treatment and support the person wants or does not want, not what the practitioner think they should have or not have. This will be developed later in this module.

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

ADVANCE DIRECTIVE FORM

What is important to me - my wishes and preferences:

When others are communicating my wishes and preferences for me, I would like them to take note of the following:

- *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 do not want my father involved as I did not grow up with him and he does not know me well enough*
- *I will need assistance with looking after, feeding and walking my dog*

2) The following are extracts of blank advance directive forms (23).

As you can see on this page, there is a blank space where people can insert information about what care and treatment option they found helpful. Below they can also write about what care and treatment options did not help them in the past.

MENTAL HEALTH

For my treatment, care and support (including any medication), I have found the following helpful:

These things have not helped in the past:

Initials _____ witness _____

3) On this page, you can see that people may indicate further information regarding health issues, such as allergies, medication, etc.

REST OF LIFE

Other health issues (physical issues, allergies, medications, strategies)

Initials _____ witness _____

- 4) On these two pages there are blank spaces to enable people to write directives regarding non health related issues.

For example, they can write directives about who is going to take care of their children or pets if they are temporarily unable to do so (on the left page) and about things that they like to do (on the right page).

This information enables supporters to get to know and understand the person's wishes and preferences and helps to ensure that these are respected.

REST OF LIFE

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

Initials _____ witness _____

REST OF LIFE

These are other things that I would like people supporting me to know about (for example, interests, daily routines, life history, etc.) Use the notes section at the end if you need more room:



Initials _____ witness _____

5) In this box, you can find an example of advance statements (24)

“I am Hindu and a strict vegetarian. This means I do not eat any meat or fish. I do eat eggs or dairy products so I am very happy to be given these.”

“When I am having low periods, I talk a lot about death and I think out loud about the best ways to end my life. If I start talking like this, do not encourage it, but please do not shout at me either. It means that I am in crisis and need somebody just to be with me and support me.”

“I do not want to be given electroconvulsive therapy in any circumstance, even if it is an emergency and my life is at risk.”

“Please do not call me ‘mate’. I particularly hate it when people I don’t know call me this.”

People can also write advance statements of their wishes, preferences and values on in their recovery plan or in a stand-alone document.



Exercise 7.1: planning ahead (15 min)

The aim of this exercise is to encourage participants to think about the prerequisite for advance planning to be successful.

Ask the participants the following question:

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

Possible responses could include but are not limited to:

- What is likely to happen to me in the case of a crisis?
- What are the possible triggers and early warning signs for a crisis or a relapse?
- What is best to help me resolve a crisis?
- What are the different treatment, care and support options that can help in my recovery?
- How willing is the staff in the service to engage in advance planning process?
- What are the pros and cons of the different treatment, care and support options, and of having none of these?
- Where I can be supported in the case of a crisis or on an ongoing basis?
- Who can support me in the case of a crisis or on an ongoing basis?
- What are my rights concerning treatment and care (e.g. right to refuse treatment, right to choose one practitioner or health care provider)?

Topic 8: Making advance planning documents

Now that the purpose and prerequisites of advance planning are understood, it is important to consider the process of making advance planning documents. The following presentation will describe different steps that may be helpful to do 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 to make 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 preference of the person, not those of other people.

Mental health and other practitioners, family members and care partners are highly 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

A good start is simply to start thinking about it. The person who wants to make an advance plan may start by considering the following:

- What type of treatment, care or support do I want or do I not want?
- What type of treatment generally makes me feel better or worse?
- Last time I had a crisis, what happened?
- From that experience, what did I like? What didn't I like?
- What went right or wrong in the past concerning my care or treatment?
- Who helped and who did not help and why?

The person may also start to identify people who can be helpful to consult when making or implementing an advance plan. Questions to think about may be:

- 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 as me?

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

Step 2: Discuss

Once the person has identified people that they want to be involved in the advance planning, they can (but do not have to) discuss the possible options with these identified persons. For example, a practitioner or a peer can advise about what treatments, care and support options are available, the implications and possible side effects of accepting or refusing certain kind of medical treatments, etc. People who provide advice should be aware of various alternatives available to the person. They should be open to different options and not be fixed to one particular view or option.

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

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. Often this involves completing a specific form and having it witnessed by another person. It is also very important to know in advance whether there are any specific circumstances in which other people will be exceptionally authorised to override a binding advance planning document.

A lawyer can be consulted for advice but sometimes social services, mental health or other practitioners, peer supporters or organisations of persons with disabilities may be able to provide the information needed.

Step 4: Formalise the advance plan

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

It is important that the document is dated and signed by the person concerned. If relevant, the person can ask witnesses to sign it, if necessary before an official authority. The person who filled in the form should retain a copy, and other copies should be kept in the person's medical records and by any support people specified in the advance document. In some place, online registry (i.e. registry where all advance plan can be centralised and saved) or crisis card systems (i.e. cards that can be kept in a wallet in which people state their wishes and preferences) may also be available.

Some people may require assistance in formulating the advance plan, to make sure that their wishes and preferences are clearly stated and understandable to everyone without possible confusion or ambiguity. Some services or organisations may provide the support of independent trained facilitators in 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 it comes into effect. It is advisable for the person concerned to provide copies of the

advance plan to family members, friends, supporters as well as mental health and other practitioners.

Step 6: Review the advance plan periodically

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

It is also very important for supporters to remain engaged with the person on an ongoing basis, as their will and preference may change over time. This is to ensure that they and others do not carry out interventions on the basis of actions specified in outdated documents which no longer reflect the current wishes and preferences of the person.



Exercise 8.1: What others must know... (40 min)

This exercise is intended to encourage participants to think about possible information that could be included in advance planning documents. For each of the categories below, ask the participants to provide examples from their personal experience or the experience of someone they know.

You can also divide the participants into groups and ask each group to provide examples for one of the tables below. The examples mentioned in the boxes below are for illustrative purpose only; participants should be encouraged to provide their own examples.

As discussed, an advance plan can be integrated into a recovery plan. The tables below are extracted from several information sources of a Recovery Plan template relevant to advance care, treatment and support planning (25),(26),(27),(28) (Provide the group with copies of the Appendix 9). A Complete Recovery Plan template is also available in the module on *Promoting recovery in mental health and related services*.

What I am like when I am feeling well:

E.g.:

Naturally introverted and relatively quiet

Relaxed and good-natured

Get along well with others but do not often seek them out

I enjoy going out with my friends

Like to read and make art

Signs that show I am in crisis and would like others to support me in my care, keep me safe and help me make decisions.

E.g. :

I get irritable with people

I stay indoors more and stay by myself

I talk to myself in an irritable way

I start to say and act differently from how I would usually act

Make it clear that information in the previous table is included to give a general picture of what a person is like when they are well and not well. The purpose is not to use this information as a means for imposing a treatment on a person. It is instead an opportunity for someone to check with the person directly if they would like support.

Giving reasons why a specific choice is made makes it easier for supporters and mental health and other practitioners to understand the decision and therefore to respect it.

People I want to be involved if I am in crisis:

Name	Their Connection to Me (e.g. friend, relative, social worker)	Telephone and/or Email
E.g. :John	Brother	
E.g. :Mark	Social worker	
E.g. :Ismael	Peer Supporter	
E.g. :Susan	Friend	

People I do <u>not</u> want to be involved if I am experiencing a crisis:	
Name (relation)	Reason why I do not want them involved (optional):
E.g. : Ivan (Friend)	I feel judged by Ivan
E.g. :Ben (Older Brother)	He blames me for everything that has happened to me, and does not have the patience to help me when I am feeling sad or down
E.g. :Cynthia (My old Doctor)	She always wants to take me to the hospital and I do not like it. They don't treat me right and it makes me feel even worse
E.g. : Emily (My neighbour)	I do not trust her as she always talks about everyone in the neighbourhood

I PREFER to go to	
Place: E.g.:	Reason:
<ul style="list-style-type: none"> <input type="radio"/> Home <input type="radio"/> My parent's house <input type="radio"/> A specified service <input type="radio"/> The day care centre 	<ul style="list-style-type: none"> <input type="radio"/> because it is where I am most comfortable <input type="radio"/> because I feel safe <input type="radio"/> because they were kind and supportive to me there <input type="radio"/> because the structure helps and the staff are friendly
I prefer <u>NOI</u> to go to	
E.g.:	
<ul style="list-style-type: none"> <input type="radio"/> a specified service <input type="radio"/> home 	<ul style="list-style-type: none"> <input type="radio"/> because I am afraid of the people there and they never listen to me <input type="radio"/> because I am ashamed to have people come to support me when my house is untidy, which is the normal state when I am unwell

Services or supports that I am currently receiving
E.g.: <ul style="list-style-type: none"> • Weekly individual psychotherapy
Services or supports that have helped when I have been in crisis in the past
E.g.: <ul style="list-style-type: none"> • Exercising everyday • More frequent individual psychotherapy sessions • Having my brother stay with me at home for a week
Services or supports that I do <u>NOT</u> want and why I would prefer to avoid them
E.g.: <ul style="list-style-type: none"> • Group therapy because it makes me anxious to talk about my thoughts or feelings in front of others • ECT because it badly affected my memory
Services or supports to deal with family issues or other critical situations
E.g.: <ul style="list-style-type: none"> • Having frequent contact with my peer supporter

What people can do that IS HELPFUL for me when I am in crisis (please list):
E.g.: <ul style="list-style-type: none"> ○ Listen to me talk about why I am upset ○ Avoid telling me to calm down or give me advice ○ Keep me safe from doing dangerous things (such as hurting myself) ○ Not to tell me what I am seeing or hearing is wrong because for me in these moments, everything that I see or hear is real ○ Do not over-protect me because it doesn't help. When you over-protect me, this often hinders my recovery because then I am not living in the 'real' world ○ Not to treat me like a child because I am not. I am an adult who can make mistakes like anybody else

What I do NOT find helpful	WHY it is not helpful
E.g.: Shouting	E.g.: Makes me more anxious and scared
E.g.: Telling me to calm down	E.g.: Does not help me feel calm, makes it worse
E.g.: People deciding how to handle the situation without asking me	E.g.: I know myself best and want to feel respected and listened to
E.g.: People telling me I am wrong or telling me that what I am saying or seeing isn't real	E.g.: For me everything I see or hear is real and telling me it is wrong makes me upset
E.g.: Making important decisions without asking me or considering my opinion first	E.g.: It is very frustrating when people don't let me make my own decisions



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 an advance plan all in one go. They can take one or more breaks if necessary or do 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. peer support worker, 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 what they did to come up with their own ideas about what to put in their advance plan.



Exercise 8.2: Discussion: Real life examples of advance planning 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 all kind of treatment and support. This exercise is intended to overcome that concern.

Here is a list of real statements (29),(30), expressed in advance planning documents in the UK and in India.

Provide participants with Appendix 10 and give them time to read the statements. Emphasise the fact that they are real life examples:

“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.”

Encourage the group to express their views on the 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?

After the general discussion you may want to emphasise the fact that the studies in both high, medium and low income countries reach the same conclusion on the content of advance planning documents: when people are given the possibility to make advance statements concerning their care and treatment, these statements are not unreasonable and do not place unrealistic demands but, on the contrary, make very good sense in relation to the person's life in an overwhelming majority of cases. In addition, people in general do not refuse all kind of care, treatment or support but simply want to have control over what they receive.



Exercise 8.3: 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 the group the following questions:

What could be done in mental health and related 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 first complete their own advance plan to better understand the process.
- Provide information to people about advance planning.
- Regularly provide the opportunity to formalise or modify advance planning documents.
- Provide people with private space and time to think about their plan, consult others and write their advance plan, possibly with the assistance of people who have their own plans.
- Link people using the service with trained persons to facilitate the development of advance planning documents.
- Organise a workshop for people to learn about the process and to start drafting their advance plans.
- Allow people who are unable to write to have their wishes and preferences recorded.
- Ensure that advance planning documents are not lost or forgotten, e.g. make a clear mention of the existence of an advance plan in the patient record, have the advance plans written in a bright colour sheet or in an online location accessible to supporters and service providers.
- Plan regular meetings to discuss with staff about the existence of advance planning documents as well as treatment and care options chosen by people using the service.
- Set up an online registry, crisis card system or input to an electronic medical record.

What do you think the role of practitioners and supporters should be in helping a person develop their advance plan?

- Explaining to people the existence and purpose of advance planning documents, in a form or language that they can understand.
- Helping people to obtain information about care, treatment and recovery options which they may want to specify in their plan.
- Helping people services to identify appropriate times to make advance plans.
- Supporting people in formalising advance plans.
- Referring to the advance plan document if the person is no longer able to communicate
- Making sure that others refer to the advance planning document when necessary.
- Support people to identify potential supporters among family members and friends, where this is wanted by the person.
- Making sure that the person concerned talks with and receives the agreement from whoever they want (inside and outside the mental health or related service) to support them in developing advance planning documents.
- Maintain ongoing engagement with the person in order to keep up to date with their current the wishes and preference and encourage the person to update the plan when new information becomes available or circumstances change.



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 peoples' 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?

Annexes

Annex 1: Confessions of a non-compliant patient

By Judy Chamberlin (31)

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 labeled 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?

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 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 favor. 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 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 places 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 '70's, 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 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 survivor. 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 2: Article 12 of CRPD with associated simplified version

(32),(33)

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.

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 rights of people with disabilities:

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

Article 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 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 4: How are decisions made?

	How are decisions made?		
	Issues	Who decides?	Why?
<i>In the service</i>			
<i>At home</i>			

Annex 5: Decision-making as a means for empowerment (3)

“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, nursing and I did it willingly, and 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 say it was the beginning of a journey, a very slow and painful journey that brought me to the realisation that there were things that I could do in my life and that there were choices that I could make that would impact 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 of 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.

Annex 6: Supported Decision Making Checklist (9)

Do you?

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

Annex 7: Challenging situations

Example 1

One morning, a young woman named Rose arrives at the mental health service, accompanied by police officers. She had tried to kill herself by jumping off a bridge, but police officers were present at the scene and they were able to save her life. A few minutes after her arrival, Rose claims that she is ok now. She doesn't want any treatment and asks to be allowed to go back home, where she lives alone. Rose seems not to have a family and does not have an advance directive.

Example 2

Roger is a young man diagnosed with schizophrenia. He was admitted to the hospital because he has cancer and needs to begin treatment for it right away. During the first day at the hospital, he became convinced that doctors and nurses wanted to poison him. Now Roger is refusing the treatment for his cancer. He has no family and does not have an advance directive.

Example 3

Michael is a young man who is experiencing a crisis and has decided to spend all of his money to create a breeding farm for chinchillas. He has decided that the garden of the mental health service is the place most suitable for the farm; so he comes to visit the service in order to ask staff their permission to create it. He tells them that he wants to sell his house to invest more money in his project.

Annex 8: How to prevent exploitation from people acting as supporters

Example 1

Paul is a young man who regularly attends a day care center. He withdraws money to buy a motorbike and since he is not used to shopping, he asks for the help of a staff member, Kevin. Kevin, instead of helping him to shop around, sells Paul an old motorbike for the price of a new one. Paul agrees with the deal as he does not want to create problems between him and Kevin.

Example 2

David lives in a supported house. He loves to try new foods and wines and, for this reason, he withdraws money on his own and then spends it on eating in restaurants. Each time he goes to the restaurant, a person from his community that he has chosen as a supporter accompanies him and David always pays for him.

Example 3

Mirela has an intellectual disability and lives with her family. She has inherited a big apartment in the centre of the city from an old uncle who was particularly attached to her. Her family convinces her to sell the apartment to her brother at a bargain price. Mirela agrees with the deal as she is not really informed about the prices in the real estate sector.

Annex 9: Extract of a Recovery Plan template

What I am like when I am feeling well:

Signs that show I am in crisis and would like others to support me in my care, keep me safe and help me make decisions.

How you can tell my supporters can stop using this plan:

People I want to be involved if I am in crisis:		
Name	Their Connection to Me (e.g. friend, relative, social worker)	Telephone and/or Email

People I do not want to be involved if I am in crisis:	
Name	Reason why I do not want them involved (optional):

I PREFER to go to

Place:

Reason why:

I prefer NOT to go to

Service, treatment or supports that you are **currently receiving**

Service, treatment or supports that have **helped to reduce your symptoms** when you have been in crisis in the past

Service, treatment or supports that you do **NOT** want and why you would prefer to avoid them

Service, treatment or supports to deal with family issues or other critical situations

What people can do that IS HELPFUL for me when I am in crisis (please list):

--

What I do NOT find helpful

Why it is not helpful

What I do NOT find helpful	Why it is not helpful

Annex 10: Real life examples of advance planning statements

(29),(30)

“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.”

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