Course Slides

Supported decision-making and advance planning

WHO QualityRights specialized training

World Health Organization

Act, Unite & Empower for Mental Health

QualityRights

WHO/MSD/QR/19.8

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Accompanying course guide is available here https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools

WHO QualityRights: Goals and objectives

GOAL: Improve access to good quality mental health and social services and to promote the human rights of people with mental health conditions, psychosocial, intellectual or cognitive disabilities

- Build capacity to combat stigma and discrimination and promote human rights and recovery
- Improve the quality and human rights conditions in mental health and social services
- Create community-based services and recovery-oriented services that respect and promote human rights
- Support the development of a civil society movement to conduct advocacy and influence policy-making
- Reform national policies and legislation in line with the CRPD and other international human rights standards

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A few words about terminology in this training – 1

- Language and terminology are used differently by different people in different contexts.
- "Psychosocial disability" includes people who have received a mental health-related diagnosis or who self-identify with this term.
- "Cognitive disability" and "intellectual disability" refer to people who have received a diagnosis related to their cognitive or intellectual function, including dementia and autism.
- The term "disability" highlights the barriers that hinder the full participation in society of people with actual or perceived impairments and the fact that they are protected under the CRPD.
    - The use of "disability" in this context does not imply that people have an impairment or a disorder.

A few words about terminology in this training – 2

- “People who are using” or “who have previously used” mental health and social services refer to people who do not necessarily identify as having a disability but who have a variety of experiences applicable to this training.
- The term “mental health and social services” refers to a wide range of services provided by countries within the public, private and nongovernmental sectors.
- Terminology has been chosen for inclusiveness.
    - It is a personal choice to self-identify with certain expressions or concepts, but human rights apply to everyone everywhere.
    - A diagnosis or disability should never define a person.
    - We are all individuals, with a unique social context, personality, goals, aspirations and relationships with others.

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What we aim to achieve during this module

- As a result of the training, participants will:
  - appreciate how negative assumptions about people with psychosocial, intellectual or cognitive disabilities affect their right to make decisions;
  - understand the importance of supporting people in exercising their human rights to make their own choices;
  - understand the difference between substitute decision-making and supported decision-making;
  - understand the human rights principles underlying supported decision-making;
  - be able to take personal actions to adopt a supported decision-making approach;
  - be able to use advance planning as a tool to ensure that people’s will and preferences are respected.

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Topics covered in this module

- **Topic 1**: Challenging denial of legal capacity in mental health
- **Topic 2**: Substitute versus supported decision-making
- **Topic 3**: Supported decision-making in practice
- **Topic 4**: Nominating a person to communicate best interpretation of will and preferences
- **Topic 5**: Positive steps to adopt a supported decision-making approach
- **Topic 6**: What is advance planning?
- **Topic 7**: Making advance planning documents

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

Presentation : Brief introduction to this module

- This training explores how to promote a person’s right to legal capacity.
- This can seem challenging in certain situations – for e.g. what if someone:
    - Wants to end their life?
    - Has severe dementia?
    - Experiences acute crisis?
    - Is doing something dangerous?
    - Without treatment will get worse?
    - Is unconscious?
    - Unable to communicate?
- Even in challenging situations, we must always strive to find ways to ensure that people are the focus for all decisions concerning their lives.
- There are always ways to promote the right to exercise legal capacity.

Exercise 1.1: Confessions of a non-compliant patient - 1

- Read **'Confessions of a non-compliant patient'** (Annex 2)
- 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?

Exercise 1.1: Confessions of a non-compliant patient - 2

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

Presentation: Understanding the right to legal capacity – 1

- Legal capacity and mental capacity are two separate concepts but are often mistakenly seen as the same.
- The CRPD has helped to clarify and elaborate the differences
- Legal capacity is an inherent and inalienable right with two dimensions:
  - the right to hold rights, and
  - the right to exercise these rights.
- The right to legal capacity is necessary for the enjoyment of all other rights.

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Presentation: Understanding the right to legal capacity – 2

- Mental capacity refers to a person’s decision-making skills (or decision-making abilities).
- Misconceptions and lack of understanding about the term “mental capacity” have led to the frequent denial of the right to legal capacity for people with disabilities.
- Because of this confusion the terms “decision-making skills” or “ability to make decisions” will often be used in this training instead of mental capacity.

Presentation: Understanding the right to legal capacity – 3

Status approach

- The status approach is taken when people with psychosocial, intellectual or cognitive disabilities are automatically assumed to lack mental capacity by virtue of having a disability or diagnosis.
- With this approach, “mental capacity” is often considered to be a stable and permanent status that people either have or do not have.
- These misconceptions and negative stereotypes are important to challenge.

Presentation: Understanding the right to legal capacity – 4

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 they are not capable of making the decision “due to their condition”.
- This is known as the “outcome approach”
- This approach is often used by practitioners and by family members.
- BUT - everyone at times makes decisions and choices that others don’t agree with - this should not be a reason to deny people the right to make decisions.

Presentation: Understanding the right to legal capacity – 5

Functional tests

- In the mental health field, functional tests for “mental capacity” are often to determine whether a person can:
  - understand information about a specific decision
  - understand the potential consequences of the decision
  - communicate the decision.
- “Functional” or “capacity” tests are generally carried out by mental health and other practitioners or capacity assessors.
- These tests are flawed because the way we make decisions cannot be measured scientifically.
- There is no universal process of decision-making - no right or wrong way to make decisions.
- Everyone has a right to make decisions at all times, including in crisis situations or extreme states, regardless of their assessed ability to make or to communicate decisions.

Presentation: Challenging misconceptions and negative stereotypes in mental health – 1

- Misconceptions and negative stereotypes often include:
  - People with psychosocial, intellectual or cognitive disabilities make bad decisions.
  - They sometimes have wrong ideas about reality.
  - They should not decide about their treatment.
  - They do not know what is best for them.
  - Families and care partners know best what is good for them.
  - Practitioners know best what is good for them.
  - They lack the ability to make decisions.
  - They like to be told what to do and are afraid to make decisions for themselves.

Presentation: Challenging misconceptions and negative stereotypes in mental health – 2

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

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

Presentation: Challenging misconceptions and negative stereotypes in mental health – 3

Example: Elena has been diagnosed with an intellectual impairment. She used to find it difficult to manage her budget because she often forgot how much money she had already spent. Consequently, she always lacked money and did not have a sufficient budget for food. One of her friends informed her about an application she could download to her telephone to keep track of her expenditures.

Elena's parents thought that the application was not going to work and that she needed a guardian to control her money. However, Elena searched for the app, and then decided to use it. Now, whenever she is not sure, she consults her telephone to see how much money she has left in her bank account and what she has already bought. She is even able to save some money every month.

- Elena was able to find a solution to her problem with the support of her friend, despite the disagreement of her parents.
- People's ability to make decisions can be maximized through a variety of supports, methods and tools.

Presentation: Challenging misconceptions and negative stereotypes in mental health – 4

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

- Just because a person has unique, unusual, different beliefs about life and reality, or hears voices, this does not mean that they should be prevented from making decisions.
- Even in these situations, many people still know what is going on in their everyday lives.
- People may have what others consider to be unusual beliefs, but this does not mean that they lack the ability to make decisions.
- It is normal for family and friends to feel concern about how a loved one’s life is going, but they need to respect their independence and responsibility for their own decisions & actions.

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Presentation: Challenging misconceptions and negative stereotypes in mental health – 5

Example: Feng is a man who has heard voices since he was an adolescent. Most of the time, these voices describe his actions. However, when Feng is particularly stressed the voices can become threatening and order him to act in certain ways (e.g. saying that other people want to attack him and that he should attack them first to protect himself). Feng's family thought that because of this he could not have a normal life and that he would need a guardian.

However, after years of experiencing voices, Feng has managed to live with them. He knows that sometimes they are communicating something very important about his emotions (e.g. that he is stressed, worried or tired) and whenever they suggest he must take action, he talks about this with key people in his life before making any decisions or taking action that causes him distress or which he believes is potentially harmful. He currently leads a full life and this year he has graduated from his university.

- Feng's ability to make decisions is not affected by the fact that he is hearing voices.
- Whenever a stressful situation occurs and he needs help to make decisions, he openly discusses his situation and thoughts with trusted people.

Presentation: Challenging misconceptions and negative stereotypes in mental health – 6

Video

- Eleanor Longden, TED Talks https://www.youtube.com/watch?v=syjEN3peCJw .

Presentation: Challenging misconceptions and negative stereotypes in mental health – 7

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

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

Presentation: Challenging misconceptions and negative stereotypes in mental health – 8

Example: Amara has received a diagnosis of bipolar disorder and has been taking medication for several months. After reflecting for a long time, she decides to stop taking her medication. Everyone around her thinks it is a terrible idea because the previous times she stopped taking her medication she was admitted to hospital.

However, Amara has stability in her life now and is confident that she can manage her life without this type of treatment. Her doctor advises her against stopping the medication and explains to her what the risks of doing so are. However, the doctor also provides Amara with resources concerning withdrawing from the medication.

After listening to the doctor, Amara still maintains her decision, and the doctor respects this. They decide together that if Amara experiences difficulties with the withdrawal, she can contact the doctor to discuss the situation further. The doctor promises Amara that she will not treat her against her will or pressure her to take medication at any time.

Both Amara and her doctor will investigate approaches that do not involve medication and where they are available in the local area (such as crisis respite), so that Amara has meaningful options from which to choose if she experiences difficulty with the withdrawal or at any other time.

- The doctor respects Amara’s right to make decisions about her treatment.
- The decision may turn out to be good or not, but Amara’s will and preferences are respected, and she is empowered to have control over her life.
- Her doctor continues to support Amara irrespective of disagreeing with her decision.

Presentation: Challenging misconceptions and negative stereotypes in mental health – 9

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

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

Presentation: Challenging misconceptions and negative stereotypes in mental health – 10

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

Although Lucas faces a really difficult period in his life, he is fully aware of the consequences of different treatments and support options on him.

- He knows better than anybody what works best for him.
- His personal experience and expertise should be valued and respected and his support requests should be facilitated.
- He should not be forced or pressured to take medication.

Presentation: Challenging misconceptions and negative stereotypes in mental health – 11

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

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

Presentation: Challenging misconceptions and negative stereotypes in mental health – 12

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

- Anna's parents are trying to protect her from potential harm because they think Anna will not be accepted by others.
- The engineering course may benefit Anna, teach her new skills, allow her to meet different people, and increase opportunities for employment in an area that she values.
- A family that overprotects a relative often prevents them from gaining skills that may benefit and empower them and make them more assertive and less vulnerable.

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Presentation: Challenging misconceptions and negative stereotypes in mental health – 13

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

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

Presentation: Challenging misconceptions and negative stereotypes in mental health – 14

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

However, even though she was feeling unwell, Eunice did not allow the doctors to perform the abortion. Now, Eunice and her partner have a 5-year-old lively daughter and are happy. The fact that Eunice was able to decide for herself about her own body, even when experiencing a crisis, was fundamental in her recovery.

- Eunice is able to make an important decision even during a crisis.
- Her life would have been negatively affected if others had made the decision for her.
- Many women with disabilities are subjected to forced abortion with no respect for their decisions and choices.

Presentation: Challenging misconceptions and negative stereotypes in mental health – 15

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

- Our ability to make decisions varies at different times in life, throughout our lives, and depends on the decision to be made and the context.
- Sometimes people find it easy to make decisions, and at other times they find it challenging.
- The fact that people may need support to make decisions on some occasions or about some issues, does not mean they are unable to make decisions in general.

Presentation: Challenging misconceptions and negative stereotypes in mental health – 16

Example: Tareq is a young man with an intellectual disability. Three days a week he works in a grocery store. This means that for the remaining days of the week he does not have any structure for his day which makes him feel frustrated and insecure.

Fortunately, Tareq was able to get the support of a personal assistant who can help him to structure his free days on weekly basis. Most days Tareq has several ideas about what he would like to do and makes plans himself – such as visiting a neighbour, making lunch, and riding his bicycle to the city centre to meet a friend. On other days he has more difficulty deciding what he wants to do and on these days his personal assistant is really helpful in proposing options for things Tareq can do during the day.

Sometimes, Tareq will call his personal assistant several times during the day to ask questions when things do not go to plan. The assistant listens to him and suggests options when he asks.

Presentation: Challenging misconceptions and negative stereotypes in mental health – 17

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

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

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Presentation: Challenging misconceptions and negative stereotypes in mental health – 18

Example: Gavin and his partner Michael are working together to make decisions related to finances and avoid the kind of problems they experienced earlier when Gavin would make impulse purchases. One thing Michael learned quickly was to ask Gavin what he wanted to purchase and why, rather than telling him what he should or should not do.

When Michael was able to engage with him in this way, they would have more productive conversations about what he wanted to spend money on and why, and Michael could understand the emotional needs he was trying to fill with purchases at certain times in his life.

These conversations also allowed Gavin to understand and consider other possible ways for his needs to be met.

Presentation: Challenging misconceptions and negative stereotypes in mental health – 19

The right to legal capacity in the CRPD

- The CRPD is an international treaty adopted by countries to ensure that **people with disabilities all around the world enjoy their rights on an equal basis with other persons in all aspects of life.**
- The CRPD aims to protect the human rights of people with disabilities, fight discrimination, stigma and stereotypes and promote inclusion and participation.
- It recognizes that people with disabilities must be able to achieve their potential on an equal basis with others.

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Presentation: Challenging misconceptions and negative stereotypes in mental health – 20

- According to article 12 of the CRPD, the right to legal capacity can never be taken away from people.
- Everybody has the right to legal capacity irrespective of their decision-making skills.
- A psychosocial, intellectual or cognitive disability can never justify denying people the right to legal capacity.
- The right to legal capacity is guaranteed to all people, no matter what their support needs are.
- Therefore people who have significant support needs (eg. people who do not communicate in traditional ways, who are isolated, who do not have support networks, or at risk of abuse) are protected by the provisions of article 12.

Formal and informal decision-making - 21

- The right to legal capacity concerns <u>all areas of life</u>
- The right to legal capacity concerns <u>all types of decision-making</u>
- Article 12 provides protection for both formal decision-making and informal day-to-day decision-making.
  - Formal decisions - often made by court-appointed guardians, mental health and other practitioners and families.
  - Informal decision-making - many day-to-day decisions (e.g. how to spend money, living arrangements, personal relationships, choosing which clothes to wear, choice of food) that people with disabilities face are often made by others (families or care partners).
    - This is particularly true in mental health and social services

Presentation: Challenging misconceptions and negative stereotypes in mental health – 22

Formal and informal decision-making (3)

- Women with disabilities may face multiple discriminations and may be more at risk of being denied the right to legal capacity.
- In some countries they may be prevented from making decisions about their sexual and reproductive rights.

Exercise 1.2: Examples of denial of the right to legal capacity – 1

João:

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

Rania:

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

Exercise 1.2: Examples of denial of the right to legal capacity – 2

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

Presentation: Settings where the right to legal capacity is denied – 1

- The denial of the right to legal capacity happens:
  - In communities
  - At home
  - In mental health and social services
  - In other places where people are detained (e.g. institutions, forensic services, police cells or prison).

Presentation: Settings where the right to legal capacity is denied – 2

- **At home,** people can be denied the right to make decisions about their own lives and daily activities.
- Family members may make all these decisions for them.
- Can be a consequence of their desire to (over)protect their relatives from potential harm and from communities which are not inclusive.
- Often, families fear that their relative will fail, be abused, get hurt or be taken advantage of.

Presentation: Settings where the right to legal capacity is denied – 3

Mental health and social services:

- Particularly true when people are involuntarily detained and treated because staff have (legal) authority to make decisions.
- Involuntary admission to services denies people free and informed consent and therefore denies them the right to legal capacity.
- Even when people are not involuntarily admitted and treated, staff assume that persons using the service cannot make decisions.
- The threat of involuntary admission and treatment may result in the acceptance of unwanted treatment.
- Staff often also make decisions for people because they think it is quicker, more convenient and less time-consuming.

- Decision-making power is taken away from people without talking or listening to them.
- The more the service is institutional in its nature, the more it deprives people of their right to make decisions.
- Mental health services may foster dependency and increase isolation and risk of exploitation.

Presentation: Settings where the right to legal capacity is denied – 4

In addition!

- People may face denial of their right to legal capacity on a day-to-day basis, in their community e.g.:
  - bank staff may refuse them access without a guardian/family member present
  - social services may refuse paperwork they need to access support.

Exercise 1.3: Everyday examples of decision-making – 1

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

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Exercise 1.3: Everyday examples of decision-making – 2

- Do you think that people are encouraged or discouraged to make their own decisions and choices?
- In what ways do these arrangements help/hinder recovery?
- Looking at examples from the table: what changes could be made so that people are able to make their own decisions and choices?

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Presentation: The consequences of denying the right to legal capacity – 1

- What are the harmful consequences of the deprivation or restriction of the right to legal capacity on people’s lives?
- How would you feel if you were deprived of your right to legal capacity?
- For people who have experienced this, how did it make you feel when you were deprived of your right to legal capacity?

Presentation: The consequences of denying the right to legal capacity – 2

- The right to legal capacity is fundamental to human personhood, freedom, dignity and autonomy.
- Any system that denies a group of people the right to legal capacity undermines their places in the community and society.
- The negative effects of denying people to make <u>major</u> life decisions are significant
- It can be also harmful to consistently deny people the opportunity to make the <u>small daily decisions</u> which shape their identity and world.
- Consistently taking away people’s right to make decisions can be profoundly disempowering

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Presentation: The consequences of denying the right to legal capacity – 3

- Without the right to make decisions, people have little or no control over their lives and are at higher risk of experiencing abuse and exploitation.
- Making decisions helps people to take responsibility for their lives
- They become less dependent on others, and able to develop positive and equal relationships.
- In summary, making one's own decisions:
    - shows that we are equal to others.
    - helps us develop relationships with others as equals.
    - allows us to be responsible members of our community.
    - allows us to defend ourselves against violence, exploitation and abuse.

Exercise 1.4: Decision-making as a means for empowerment – 1

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

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

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

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

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

Exercise 1.4: Decision-making as a means for empowerment – 2

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

- Amnesty International Ireland: Rory Doody on his experience of Ireland's capacity legislation and mental health services: https://youtu.be/63vK2F1ok7k

Presentation: The benefits of making decisions – summary

Benefits of making one’s own decisions :

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

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Reflective exercise

- Has your opinion about the ability of people with psychosocial, intellectual or cognitive disabilities to make decisions changed?
- Even if your opinion has not changed, do you think that people nevertheless have a right to make their own decisions?
- Are you aware of some practical ways to respect people's right to legal capacity?

Topic 2: Substitute versus supported decision-making

Exercise 2.1: Meaningful support

- What are some of the simple everyday actions that you may take in trying to be helpful and kind to someone?
- For example, buying your colleague coffee every morning.
  - How many people would appreciate having a coffee brought to you every morning?
  - How many people don't like coffee and prefer tea?

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Exercise 2.1: Meaningful support (cont’d)

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

Exercise 2.1: Meaningful support (cont'd)

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

Presentation: Why substitute decision-making is not a good model – 1

- People with psychosocial, intellectual or cognitive disabilities are often deprived of the right to legal capacity
- Substitute decision-making means that decisions are made for them by others.
- It may be members of the family, practitioners, or people appointed by a court.
- Sometimes substitute decision-making is a formal process.
- At other times it happens informally, with family members or practitioners automatically taking over all decisions.
- In yet other circumstances, laws (eg. courts, director of a service) allow others to make decisions for people, even when a guardian has not been appointed.

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Presentation: Why substitute decision-making is not a good model – 2

Why is substitute decision-making often used?

- People may think it brings clarity to decision-making.
- People may think this is the only way important decisions can be 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 they know what is best for the person.
- People may think that it is less time-consuming.
- People may think that the decisions made are necessary and good for people.
- Practitioners may feel they have responsibility for the person’s recovery.

Presentation: Why substitute decision-making is not a good model – 3

Problems with substitute decision-making

- Substitute decision-making
  - Is often based on misconceptions and negative stereotypes.
  - does not respect the person concerned as a decision-maker.
- People’s decisions are part of who they are and define who they become.
- To remove decision-making from a person means that their life becomes something that happens to them instead of them having the dignity and responsibility to drive their own life.

Presentation: Why substitute decision-making is not a good model – 4

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

Presentation: Why substitute decision-making is not a good model – 5

- A substitute decision-maker may make decisions which not only go against the person's will, but which are also bad for them.
- They may sometimes take advantage of the person
- Substitute decision-making results in a vicious circle: if people are deprived of the opportunity to make decisions, they can lose confidence in their ability and they stop trying.
- Some people who have never had a right to make decisions may sometimes prefer to defer this responsibility to others.

Presentation: Why substitute decision-making is not a good model – 6

- The more that people exercise decision-making skills, the more confident they become in those skills.
- People can and want to make decisions about their lives.
- Having autonomy to make decisions for oneself has a substantial impact on well-being.
- Despite the negative consequences and the huge potential for abuse, substitute decision-making continues to be the predominant practice in most countries.

Presentation: Why substitute decision-making is not a good model – 7

- 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/.

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Presentation: Supported decision-making, a new approach to decision-making – 1

- At times, we may all need support to make decisions in different areas of life.
- It can be useful to turn to trusted persons who can provide support in the process of making decisions.
- Article 12 of the CRPD introduces the concept of supported decision-making.
- Article 12 states that people must have access to a variety of support options, including the support of people they trust.
    - The CRPD recognizes that building on people's unique abilities and providing them with the support allows them to make their own decisions.

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Presentation: Supported decision-making, a new approach to decision-making – 2

- A person may need support to understand information, weigh up different options, understand the possible consequences and communicate their decisions to others.
- Some people are isolated and do not have trusted people in their lives.
- Even people who may not be completely isolated still lack people around them who they trust sufficiently.
- Supported decision-making might also involve providing the opportunity for people to form relationships of trust where these are absent.

Presentation: Supported decision-making, a new approach to decision-making – 3

- When persons have difficulties in expressing their will and preferences, they may want supporters to help others realize that they have the right to legal capacity.
- Support needs to be tailored to the individual.
- Decision-making skills and the level of support required can vary at different stages in a person's life.
  - At times people may not need any support at all, at other times low-level support is sufficient, and sometimes more intensive support may be required.
- It is important to remember that, unlike the need for support, the right to exercise legal capacity never fluctuates or varies.

Presentation: Supported decision-making, a new approach to decision-making – 4

Supported decision-making in mental health and social services

- The unequal power dynamics between practitioners and people using services act as an important barrier to supported decision-making in these settings.
- Laws allowing for involuntary admission and treatment contribute to this power imbalance.
- People using services often believe that practitioners are able to do what they want because of their authority
- Important to address and change power dynamics in order to respect people’s right to legal capacity.

Presentation: Supported decision-making, a new approach to decision-making – 5

- Practitioners are not “supporters” due to the risk of conflict of interest and undue influence.
- However, they must adopt a supportive approach.
- Sometimes practitioners believe that they are already implementing such an approach.
- Very often they identify a need, make a suggestion and ask for agreement from people using the service
- Directing the flow of information in this way is not a supportive approach.
- Practitioners often fail to account for the power differentials that exist between them and people using the service.
- By identifying needs and suggesting limited options, practitioners control the discussion and provide little opportunity for disagreement.

Presentation: Supported decision-making, a new approach to decision-making – 6

It is necessary to promote a new approach centred on support in which:

- People are empowered and provided with comprehensive information to enable them to make decisions about their lives, including their care and treatment.
- Power imbalances can be counteracted if practitioners pay attention to the values, expectations, will and preferences of the people they are working with.
- Practitioners' self-reflect on how their assumptions or behaviours may unintentionally be a barrier to decision-making by service users.

Presentation: Supported decision-making, a new approach to decision-making – 7

- Respect for the right to legal capacity also involves respecting people’s right to consent to or refuse treatment.
- Requires actively facilitating supported decision-making by ensuring that people can invite trusted persons to support and accompany them.
- Practitioners can facilitate contacts with formal support services.

Presentation: Supported decision-making, a new approach to decision-making – 8

Supported decision-making checklist
Do you do the following?

- Provide relevant information:
  - Give the person all the relevant information they need to make a particular decision.
  - Give the person all the information they asked for.
  - Give the person information on all the available options.
- Communicate in an appropriate way:
  - Explain or present the information in a way that is easier for the person to understand (e.g. by using simple, clear and concise language or visual aids).
  - Explore different methods of communication if required, including nonverbal communication.
  - Ascertain if anyone else can help with communication (e.g. a family member, support worker, interpreter, speech and language therapist or advocate) and whether the person accepts this help.
- Make the person feel at ease:
  - Identify if there are particular times of the day when the person's understanding is better.
  - Identify if there are particular locations where the person may feel more at ease.
  - Ascertain whether the decision could be delayed to see whether the person can make the decision at a later time when circumstances are right for them.
- Support the person:
  - Ascertain if anyone else can help or support the person to make choices or express a view.

Presentation: Supported decision-making, a new approach to decision-making – 9

Differences between supported decision-making and substitute decision-making

- In supported decision-making, a support person never makes decisions for/on behalf of/instead of another person.
- All forms of support are based on the will and preferences of the person concerned.
- A person's will and preferences are different from what others may perceive as being in a person's "best interest".
- Even if substitute decision-makers have good intentions, it does not mean that the person will perceive the situation in that way
- Unwanted or inadequate support may be felt by people as an unacceptable intrusion /harmful.
- The "best interest" approach needs to be replaced.

Presentation: Supported decision-making, a new approach to decision-making – 10

- Best interpretation of will and preferences.
- When the person is still unable to communicate their will and preferences after significant attempts have been made to communicate, decisions must be based on the best interpretation of their will and preferences.
- These can be determined by, for instance:
  - what is already known about the person;
  - advance planning documents

Presentation: Supported decision-making, a new approach to decision-making – 11

- Supported decision-making is different from existing systems such as guardianship, wardship and other substitute decision-making regimes.
- It is not a new term for existing models.
- It is about implementing a completely different approach in which the person always has the final say because decisions are made according to their will and preferences or the best interpretation of their will and preferences.

Presentation: Supported decision-making, a new approach to decision-making – 12

- Supported decision-making is voluntary.
- Supported decision-making means people can make real choices between acceptable options and are not coerced into making any specific decision.
- There must be no threat of coercion or punishment for exercising the right to make decisions.

Presentation: Supported decision-making, a new approach to decision-making – 13

- Many people express concern that if the person refuses support they may put themselves or others in danger.
- However, imposing or forcing treatment on a person can itself cause harm either immediately or later on.
- The harm caused can take many forms.
- Respecting people’s choices should not be used as an excuse to neglect or ignore someone in distress.
- The CRPD requires that supporters meaningfully engage with the person and provide options that are acceptable.

Presentation: Supported decision-making, a new approach to decision-making – 14

- In many countries, law and policy still provide for substitute decision-making models.
- Lobbying and advocacy are key to changing laws, policies and practices which are not in line with the CRPD.
- We can do a lot to support people to make their own decisions, even within existing legal or policy frameworks.
- It is also possible to support people to terminate their substitute decision-making regimes.

Presentation: Moving from substitute decision-making to supported decision-making

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

Exercise 2.2: Understanding support in decision-making – 1

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

Exercise 2.2: Understanding support in decision-making – 2

- Did you find this support helpful?
  - If yes, why?
  - If not, why not?

Presentation: Different forms of support – 1

- Most existing models of support are not yet fully compliant with the CRPD.
- Criticisms may include that:
  - some models are led and directed by professionals
  - they still use involuntary treatment (but to a lesser extent than other services).
- Important to acknowledge these limitations and that these services could be further improved to achieve full compliance with the CRPD.

Presentation: Different forms of support – 2

Providing full and complete information

- One form of support is to provide full and complete information in a format that the person understands.
- Many people do not have enough information to be able to make decisions.
- People must first be given all relevant information concerning the area or issue about which they want to make the decision.

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Presentation: Different forms of support – 3

Supportive communication skills

- Communication skills are necessary to accommodate people using diverse styles of communication or having communications difficulties.
- Supporters, including practitioners, should learn how to listen actively and attentively.
- Skills should also include helping the person to relax and giving the person breaks.
- Also respect how much or how little the person wants to share.

Presentation: Different forms of support – 4

Communication skills might include:

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

Presentation: Different forms of support – 5

Making reasonable accommodations

- reasonable accommodations may be required as part of the support process.
- “Reasonable accommodation” refers to removing barriers that persons with disabilities face, ensuring that they can exercise their rights on an equal basis with others.
- CRPD Art 5 requires that people with disabilities are provided with reasonable accommodation for their rights.
  - This means that other people must accommodate the person’s requirements and recognize the person’s potential need for supports in decision making.

Presentation: Different forms of support – 6

Reasonable accommodation:

- Can include providing people with understandable information.
- May involve practitioners accepting formal or informal assistance from family and friends & taking more time to communicate information
- Can be relevant whenever an individual interacts with other people (e.g. doctors explaining risk of a medical procedure, bank employees opening an account, etc.)
- Should be individualized and tailored to the needs of the person concerned

Presentation: Different forms of support – 7

Making decisions with the support of others

- Support can take many forms and can involve one trusted person or a network.
- Informal support, mostly provided by family and friends, is used by everyone in everyday life.
- As far as possible, informal support should be encouraged to limit formal intervention in people’s lives and to allow people to make decisions in a way which is similar to that used by people without disabilities.
- Formal support may sometimes be necessary for making complex or important decisions when informal support is not sufficient.
- When people decide to nominate their supporter(s) formally, they may nominate a relative that they trust.
- However, a person may sometimes nominate someone who is independent (e.g. an advocate) – eg.because the person is isolated or has experienced abuse in their family.

Presentation: Different forms of support – 8

Formal support

The Swedish Personal Ombudsperson (PO)

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

https://youtu.be/63vK2F1ok7k

Presentation: Different forms of support – 9

Formal support

Personal Ombudsperson (PO) system , Sweden

- Is a model of supported decision-making that is generally offered by NGOs.
- POs work at the request of the person needing services
- They help clients with a range of issues.
- POs only do what their client wants them to do.
- The model is based on long-term trust
- Designed mainly for people who are hard to reach.
- To avoid burdensome administration there is no written agreement
- POs have flexible schedules, adapted to the needs and wishes of their clients.
- POs work from their own homes, meeting clients in their homes or at neutral places such as a cafe.
- They have the skills to argue for a client’s rights before the authorities or in the courts.
- Sweden has a system of partial guardianship but the government does not see POs as an alternative to guardianship.
- POs are often asked to help clients end guardianship measure.

Presentation: Different forms of support – 10

Formal support

Personal Ombudsperson (PO) system (cont'd)

- The Swedish system has shown very positive results and benefits:
  - In 2014, 6000 persons were supported by a PO in Sweden.
  - 84% of Swedish municipalities included POs in their social service system.
  - Individuals with disabilities who are supported by a PO require less care and their overall situation improves.
  - In the long term the PO system reduces costs for the social system.

Presentation: Different forms of support – 11

Independent Advocacy (Scotland, United Kingdom)

Independent Advocacy, James' story (4:33 min.) (the video is available in several languages):
https://youtu.be/SSvorQMSn8Q

Presentation: Different forms of support – 12

Independent Advocacy

- A way to help people to have a stronger voice and as much control as possible over their own lives.
- Independent Advocacy organizations are separate from other types of services.
- Will not make decisions on behalf of the person/group they are supporting.
- The independent advocate helps the person/group to obtain the information they need to make real choices about their circumstances and supports them in putting their choices across to others.

Presentation: Different forms of support – 13

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.

Presentation: Different forms of support – 14

- Open Dialogue (Finland)

Short option: Daniel Mackler, **Jaakko Seikkula Speaks on Finnish Open Dialogue, Social Networks, and Recovery from Psychosis** (8:24) https://youtu.be/b5_xaQBgkwA

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

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Presentation: Different forms of support – 15

Open Dialogue

- Is a Finnish alternative to the traditional mental health system for people diagnosed with psychosis such as "schizophrenia".
- Respects the decision-making power of the person and engages the person’s network of family and friends.
- Team provides immediate help within 24 hours of the first contact.
- Seeks to engage social networks, rebuild relationships and, if possible, avoid medication and the alienating experience of hospitalization.

Presentation: Different forms of support – 16

Open Dialogue (cont’d)

- No exact treatment plan is prepared.
- The approach is flexible and adapts to the changing needs of each person.
- Place of the meeting is jointly decided.
- To counter stigma, meetings can take place at the home of the person seeking support.
- Person seeking support identifies the family and care partners to participate alongside the open dialogue team in daily meetings that are open, non-secretive and non-hierarchical.
- Everyone openly voices and reflects on their thoughts and feelings – particularly the voice of the person seeking support.

Presentation: Different forms of support – 17

Open Dialogue (cont’d)

- Language is an important part of creating an open dialogue.
- Team members do not interview the participants or use medical language.
- They do not seek to find solutions or to make decisions about treatment on behalf of the person concerned.
- Team members follow the themes and issues raised by the person and their family.
- Open Dialogue explores how they understand the situation and how, in their own language, the person and their support network have named and described the person’s distress.
- By speaking openly at all times, everyone understands what is going on and what is being talked about.
- A shared language and understanding is created

Presentation: Different forms of support – 18

Open Dialogue (cont'd)

- Study on first-episode psychosis showed that after 5 years
  - 82% of persons had no remaining psychotic symptoms
  - 86% had returned to their studies or a full-time job
  - only 14% were on disability allowance.
  - Only 29% had used neuroleptic medication in some phase of the treatment.
- In comparison, a 5-year follow-up study on people experiencing a first psychotic episode treated in Stockholm (1991 to 1992) reported that during the 5-year period:
  - mean length of hospitalization was 110 days
  - neuroleptic medication was used in 93% of cases.
  - 62% of the patients were living on a disability allowance after 5 years.

Presentation: Different forms of support – 19

Informal support

- Formal forms of support should not replace informal support networks which are essential in people’s day-to-day lives.
- When informal networks are nonexistent or weakened, it is very important to support the person to rebuild and/or consolidate these networks.
- It may also be necessary to advocate for a more formalized form of support networks for people who need and want them.

Presentation: Different forms of support – 20

Informal support

Support network

- e.g. Circle of support (Australia, United Kingdom)

Inclusion Melbourne, **Circles of Support** (6:19): https://youtu.be/fhF6mv03Cx0

Presentation: Different forms of support – 21

- Circle of Support (sometimes called a Circle of Friends) is a group of people who meet together regularly to help someone to accomplish their personal goals in life.
- The person concerned is in charge – decides who to invite to be in the circle & the direction that the circle's efforts should be employed.
- Members are unpaid and may include family, friends and other community members.

Presentation: Different forms of support – 22

Personal assistance

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

Presentation: Different forms of support – 23

Distinguishing elements of personal assistance :

- funding is controlled by and allocated to the person.
- Based on an individual needs assessment and the person’s circumstances.
- Led by the person concerned, who can contract the service from a variety of providers or act as an employer.
- Person concerned can custom design their own service - by whom, how, when, where and in what way the service is delivered).
- Person can choose their preferred degree of control over service delivery.
- The person always remains at the centre of the decision-making processes.

Presentation: Different forms of support – 24

- What is the role of a Personal Assistant? (12:10) https://youtu.be/Wdx9iTMsGyE

Presentation: Different forms of support – 25

Peer support

- Refers to the idea that people with psychosocial, intellectual or cognitive disabilities can help each other.
- Can come from an individual or a group of people with “lived experience” who have the knowledge and expertise to support others.
- Peers can provide valuable information about a wide range of issues and therefore enable the person to make informed choices.
- Peer support also supports the right to legal capacity.
- Peers offer relevant support as they know what challenges the person may face.
- Peer supporters should always be independent.

Presentation: Different forms of support – 26

Support from family and friends

- For many, the support and understanding of family and friends is extremely important in difficult times.
- Families and friends know a lot about the person and often provide the most direct support.
- They are generally aware of the person’s everyday life, the daily decisions they make and their usual choices and preferences.
- Family and friends are likely to be on hand to encourage and support the person to exercise their legal capacity.
- Family and friends can be a great source of information to enable others to understand the person’s background, values and objectives, or their previous experience(s) of services.

Presentation: Different forms of support – 27

Support from family and friends (cont'd)

- Potential conflicts of interest/attitudinal barriers :
- 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 overwhelming the person with support.
- Lacking knowledge about the person's values and preferences.
- Being unrealistic about what a person can achieve.
- Underestimating the person's decision-making skills.
- Fearing potential consequences for themselves.
- Being overprotective of the person.
- Feeling entitled to share part of their family member's story with others against the person's wishes

Presentation: Different forms of support – 28

Communities of support

- People who may appear to lack other kinds of support may find support in certain communities or community spaces and create a “family of friends”.
- Can include online communities, religious or cultural groups, political activist communities, groups focused on activities such as music or art, or communities based on gender or sexual orientation.
- Important that services recognize and take into account these forms of support even though they may be different from traditional support networks.

Exercise 2.3: Scenario – Understanding support in supported decision-making – 1

Example: Sunita

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

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

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

Exercise 2.3: Scenario – Understanding support in supported decision-making – 2

Considering what we have previously discussed, what went wrong in this case?

How could things have been done differently?

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Exercise 2.3: Scenario – Understanding support in supported decision-making – 3

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

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

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

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

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

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

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Topic 3: Supported decision-making in practice

Exercise 3.1: Scenarios – Deciding on supporters and support options – 1

Example: Ximena

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

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

Exercise 3.1: Scenarios – Deciding on supporters and support options – 2

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

Exercise 3.1: Scenarios – Deciding on supporters and support options – 3

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

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Exercise 3.1: Scenarios – Deciding on supporters and support options – 4

Ximena acknowledges that she does need some support but at this stage preferred to limit this to a small range of informal supports. She has automated all regular payments that need to be made, and she has automated reminder messages for routine tasks and appointments that need to be carried out. She has discussed her situation with her friends and they are more than happy to provide additional support to accompany her to appointments and to help her keep track of them.

After several discussions with a social worker, she has planned an advance directive that specifies her wishes for the long term. She has discussed this with her family and friends, which has brought a great deal of relief and reduced her anxiety about some aspects of the future. Ximena maintains a good relationship with the social worker who helped her to initiate an advance directive and who visits her once a month to see if everything is going well. Ximena knows that she (and her family and friends) can call the social worker at any moment.

Exercise 3.1: Scenarios – Deciding on supporters and support options – 5

Example: Jack

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

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

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

Exercise 3.1: Scenarios – Deciding on supporters and support options – 6

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

Exercise 3.1: Scenarios – Deciding on supporters and support options – 7

Jack (continued)

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

His friend Jane will check in on him on a regular basis in person or by phone.

Marlo says he will look into family supports that may be available for Jack and will help him fill in any forms that may be required or accompany him if any visits to social services are necessary.

The brother and friend will sometimes take the children for the weekend if Jack is feeling overwhelmed.

They also agree to be available to discuss any big decisions concerning the children (e.g. schooling, holidays, etc.).

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

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Exercise 3.2: Scenarios – Challenging situations – 1

Scenario 1: Claudia

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

Exercise 3.2: Scenarios – Challenging situations – 2

Scenario 2: Nasima

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

Exercise 3.2: Scenarios – Challenging situations – 3

Scenario 3: Christopher

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

Exercise 3.2: Scenarios – Challenging situations – 4

- Considering what has previously been discussed on the right to legal capacity (the right to make decisions for oneself) and supported decision-making, what would you do in this case?
- Could you suggest positive actions that could be taken in these situations that respect the right to legal capacity?

Presentation: System failures in supported decision-making – 1

- These cases depict challenging situations.
- In some situations, it seems impossible to find alternatives to substitute decision-making.
- It is even more complicated when it is necessary to protect the rights and well-being of others.
- In such situations people often resort to making decisions for the person rather than trying to find alternative solutions that respect the person's wishes.
- Important to make sure that challenging situations are not used to justify substitute decision-making.
- Services need to put in place clear processes to determine a person's will and preferences.
- If this is not possible, after serious attempts have been made, decisions should be made based on the best interpretation of the will and preferences of the person.

Presentation: System failures in supported decision-making – 2

- Making decisions on behalf of other people is not acceptable.
- It is a **violation of the individual's human rights and also a system failure**.
- Most of the time, this would not have occurred if support had been provided early on.
- Support should be provided to relatives who may also suffer adverse consequences in difficult situations.
- Support mechanisms should be discussed and agreed upon by all the people concerned.
- Each failure to respect people's right to legal capacity should make everyone involved review and question their current processes, practices and strategies to understand what went wrong.
- A meeting can be organized with all the stakeholders, including the person concerned, to discuss ways to avoid the same situation in the future.

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

Presentation: The role of nominated persons – 1

- A nominated person is a supporter who is trusted to communicate a best interpretation of the person’s will and preferences where it may be impracticable to determine the person’s will and preferences directly.
- People may or may not find it useful to have a nominated person.
- One specific person or a group can be nominated to determine and communicate the best interpretation of the will and preferences of the person.
- It is possible to nominate different people for different issues.
- The person can indicate that from a group of people, the opinion of one particular person should prevail.

Presentation: The role of nominated persons – 2

- Best interpretation approach can be used for eg. when a person becomes unconscious, unresponsive or has very severe and profound communication impairment.
- Best interpretation of a person's will and preferences should be made according to what the person has told the nominated person in the past or what the nominated person understands the person would want.
- Nominated persons are not "substitute decision-makers".
- They should not make decisions "instead" of the person.
- Nor should they make decisions according to what they think is in the "best interests" of the person concerned.

Presentation: The role of nominated persons – 3

- Before using the best interpretation approach, supporters should find out whether assistive technology or other forms of accommodation could help to determine will and preferences.
- Nominated persons can also play an ordinary support role in situations which do not require a best interpretation of will and preferences.
- They can help to clarify the person’s will and preference when others may not understand the person’s communication.
- They may also support the person in asserting his or her choices to others and can make sure these are respected.
- Nominations of representatives can be included in advance plans or directives or can be stated in a separate document.
- When nominating someone to communicate one’s wishes and preference, it may be helpful to include an alternative nominated person in case the preferred person is unavailable.

Presentation: The role of nominated persons – 4

The nominated person should:

- **Be a trusted person**: someone who knows the person well and is able to respect the person's rights, will and preferences, including their values and beliefs.
- **Be available**: who can make themselves available when necessary.
- **NOT be a mental health or social service staff member**: to avoid any conflict of interest.
- **Be revocable**: The nomination should be revocable and the person should be able to choose someone else.
- **Be subject to accountability mechanisms**: Safeguards should be in place to check on how nominated persons are applying the "best interpretation" approach and to ensure that they do not abuse their role.

Presentation: The role of nominated persons – 5

- It may also be useful to nominate a person who is able to navigate the medical and/or social system.
- Sometimes, little is known by service staff about the person’s will and preferences.
- If the person has come to the service, this would seem to indicate that the person is seeking support.
- People should be given time to express what kind of support they want.
- The fact that they have come to the service is not a reason to decide for them what treatment or support should be given or what action should be taken.

Presentation: The role of nominated persons – 6

- If no supporters can be identified, an independent person should be appointed.
- The appointed person should make every effort to identify the person’s beliefs and values and to make decisions on best interpretation of the will and preferences.
- However, because little is known about the person so far, the advocate’s best interpretation may not be completely correct.
- Such situations must only be temporary.
- The appointed person has a duty to take steps to get to know the person better and to help them to build a social network, so that the person can personally choose a supporter.

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

Presentation: Key principles of supported decision-making

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

Exercise 5.1: Personal action to promote supported decision-making

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

Presentation: Tips for supporters

- Take time to listen and to learn from the person to understand what they want. Use active listening to encourage communication without pressing for immediate answers.
- Get to know the person that you support as well as their social context.
- 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 they would like.
- Give people sufficient time to reach a decision on their own.
- Remain engaged with the person over time since their will and preferences may change.
- Pay attention to what might help or hinder a person to make certain decisions.
- Remain aware that other people may try to influence you. Always keep in mind that the person you are supporting is driving the decision.
- Find information about individuals, networks or services providing extra support and advice.
- Find support for yourself, identify people or services that can help you in your role as a supporter.
- Learn how to cope with frustration.

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Exercise 5.2: Action to promote legal capacity and supported decision-making at the level of mental health and social services – 1

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

Exercise 5.2: Action to promote legal capacity and supported decision-making at the level of mental health and social services – 2

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

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Topic 6: What is advance planning

Presentation: What is advance planning? – 1

- Supported decision-making can ensure that people take charge of decisions about their lives.
- Advance planning a tool to help ensure that will and preferences are considered and respected.
- Advance planning is about making a person's choices and preferences about future situations when the person may be experiencing difficulty in making their will and preferences known to others.
- Other people can refer to the person's advance plan to make sure they respect what the person wants.
- Advance plans can be useful for persons who are distressed, who experience psychosis or dementia, or who want to specify their wishes in advance.

Presentation: What is advance planning? – 2

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

Presentation: What is advance planning? – 3

- People may develop an advance plan for crisis situations as part of a recovery plan.
- A recovery plan is a document written by a person (on their own or in collaboration with others) that helps to guide their recovery journey.
- It is a tool designed to help people to live the life they want and to achieve their goals.
- Advance planning is 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.

Presentation: What is advance planning? – 4

- People should always have a choice on whether or not to make advance plans.
- In some countries, the law makes advance plans binding
    - This means that other people are legally bound to respect the directives stated in the advance plan.
- In many cases, laws also outline situations when binding advance directives can be overridden, as when the person requests something that is illegal.

Presentation: What is advance planning? – 5

Content of advance plans

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

Presentation: What is advance planning? – 6

Nominated persons

- For many reasons, some people may not want to write an advance plan.
  - They may be confident that, if they are unable to communicate their decisions in the future, their family or friends will make a decision based on their will and preferences and reflecting their beliefs and values.
- 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 in order to establish what is the best interpretation of the will and preferences.

Presentation: What is advance planning? – 7

Example:

When a decision needs to be made In Yasmin's family, people generally come together to discuss and find a solution which everybody agrees on. Yasmin does not think that she can anticipate all the decisions to be made if she becomes unable to communicate her choices in future. In the area of health, she also thinks that science and medicine are constantly evolving and new treatments may become available.

Therefore, she writes an advance directive stating that if one day she becomes unable to communicate her health decisions, she wants her husband, parents, brothers and sisters to gather and reach a decision based on what they think she would have wanted in these circumstances.

Presentation: What is advance planning? – 8

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

- Regarding health and mental health-related needs, people can specify:
  - which treatment, care and support options they want;
  - which treatment, care and support options they do not want.

Presentation: What is advance planning? – 9

- Advance <u>refusal</u> of a support, care or treatment option is different from advance consent to a support, care or treatment.
    - Advance <u>refusal</u> guarantees that a person will not be given that specific form of support, care or treatment.
    - Advance <u>consent</u> does not guarantee that the person will be given that form of treatment (eg. the service may not offer this option of treatment).
- Note that some people may want to develop and implement their advance plan outside the context of mental health or social services and may wish include forms of support which are not related to health care.

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Presentation: What is advance planning? – 10

Planning ahead – living with younger onset dementia: (5:08) Original video produced by Office for the Ageing, SA Health, Adelaide, Australia: https://youtu.be/8sVCoxYbLIk

Acknowledgement: Kate Swaffer, Co-founder, Chair & CEO of Dementia Alliance International www.infodai.org.

Presentation: What is advance planning? – 11

Directive for support in other areas of life

In their advance plan, people may also want to specify their wishes about other aspects of their lives, such as :

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

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Presentation: What is advance planning? – 12

“Ulysses clauses”

- Advance plans should not prevent people from changing their minds.
- Some people may wish to anticipate a future situation in which they may state a wish or preference which is not in accordance with their values and long-term will.
- They can explicitly specify that their advance plan should take precedence over their stated wishes and preferences during specific future events – “Ulysses clause”.
  - To be used with caution, especially if it authorizes others to use force.
  - Additional safeguard - have a group of supporters confirming that the Ulysses clause reflects the long-term will and preferences of the person.
- After the situation has occurred, the person should carefully review the Ulysses clause to make sure that the course of action taken was helpful and consistent with their long-term will.

Presentation: What is advance planning? – 13

Examples of the use of Ulysses clauses:

1. *Kwame has been diagnosed with bipolar disorder. He knows that a particular type of medication has extremely negative effects on him. It is very clear to him that he does not want this type of medication. However, he is concerned that when he feels really low, he would not be assertive enough to object to whatever medication staff might offer him.*

Therefore, he decides to write in his advance directive that he does not want to be given this type of medication in any circumstance, even if he agrees to it during a crisis.

Presentation: What is advance planning? – 14

1. *Li-Ming knows that at some time in the future she will find it increasingly difficult to make decisions about her life due to the progression of Alzheimer's disease. She trusts her cousin who knows her very well and is always supportive of her decisions. However, she does not want her brother involved in decisions related to her life because he is likely to overrule her will and preferences since he often thinks he knows what is best for her.*

She therefore develops an advance directive indicating who can communicate her will and preferences (i.e. her cousin) if she is unable to communicate them, and also specifying some of her choices for her future that she can already identify – e.g. she wants to live at home and receive support there rather than go into a retirement home, she specifies how her money can be spent, who can have keys to her house, what medical conditions she needs medication for, which medications she is not prepared to take etc.

Presentation: What is advance planning? – 15

When should advance plans come into effect?

Currently, in most countries:

- Advance plans come into effect when people are assessed as not having mental capacity.
- Once the advance plan comes into effect, the person is no longer allowed to make their own decisions directly or to change their mind.
- The law requires that people have "capacity" in order to make a valid advance plan:
    - people under guardianship cannot make a legally valid advance plan;
    - advance plans are not legally valid if they are made in a situations when the person is not considered to have the ability to make decisions.
- Advance plans are sometimes not be considered as having effect when a person is involuntarily admitted to a service.

Presentation: What is advance planning? – 16

- Although advance plans can allow people to assert a degree of control, the legal restrictions placed on their implementation reduces compliance with the CRPD.
- The CRPD requires a completely different approach:
  - According to article 12 of the CRPD, people have the right to legal capacity <u>at all times.</u>
  - People should retain their right to make decisions directly and to change their mind, even if an advance plan has been drafted.
  - The fact that people develop advance plans does not mean they are "legally incapable".

Presentation: What is advance planning? – 17

- People may wish to make their advance plan binding when they are unable to communicate their will and preferences directly.
- This guarantees that others respect the directives in the plan.
- The person should specify the situations or criteria in which the supporter should START and STOP putting the plan into effect.
- Advance plans should not prevent supporters from trying regularly to engage and communicate with the person directly

Presentation: What is advance planning? – 18

- When persons can communicate their will and preferences directly, advance plans can be useful communication tools to structure discussions:
  - Useful for exploring and discussing the possible scenarios requiring decision-making, the pro and cons of decisions, etc.
  - Help supporters to feel at ease with the plans and feel confident in putting them into practice.
  - Useful as a reference point for the will and preferences of the person.

Presentation: What is advance planning? – 19

Advance planning in countries

Example: German law (2009) (26)

- Germany has a law that makes advance directives binding, including in the context of mental health care.
- In their advance directives, people may nominate a supporter whose role is to assert the person’s will vis-à-vis the practitioner.
- If the person does not have an advance directive, the person’s presumed will and preference concerning treatment must be determined on the basis of concrete evidence such as previous oral statements.
- Following the entry into force of the law, users of mental health services have developed a model of advance directive (called *PatVerfü*) against any form of coercion in psychiatry.

Presentation: What is advance planning? – 20

- Even when countries do not legally recognize advance plans, this does not prevent supporters and practitioners from developing them.
- Mental health and social services can:
    - Put in place a policy to respect individuals' decision-making at all times.
    - Inform people about the opportunity to create advance plans.
    - Encourage people to make advance plans to anticipate future needs and scenarios and to nominate supporters.
    - Respect the directives stated in a person's plan.

Presentation: What is advance planning? – 21

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

Presentation: What is advance planning? – 22

The benefits of advance planning for service providers

- Advance planning can help service providers in their practice.
- Practitioners are often concerned that if people refuse care or support, and they do not use coercive measures – they will be held liable for bad outcomes.
- The law should make sure that practitioners are not held responsible if they follow a person's advance plan.

Presentation: What is advance planning? – 23

Examples of advance plan templates:

Advance PLAN example template

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

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

Presentation: What is advance planning? – 24

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

Health issue 1:
Management preference
Helpful:
Not helpful:

Health issue 2:
Management preference
Helpful:
Not helpful:

Health issue 3:
Management preference
Helpful:
Not helpful:

Presentation: What is advance planning? – 25

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

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

Presentation: What is advance planning? – 26

Health outcomes resulting from medical intervention that are unacceptable to me:

Presentation: What is advance planning? – 27

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

Children, Accommodation, Keys, Pets, Garden, Relationships, Social ties, Work	Important aspects about me that I would like people supporting me to know about (e.g. interests, daily routines, life history, etc.)

Presentation: What is advance planning? – 28

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

About me

Finances

Relationships

Daily routine tasks

Health matters

Presentation: What is advance planning? – 29

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

Exercise 6.1: Planning ahead

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

Topic 7: Making advance planning documents

Presentation: Steps for making an advance plan – 1

- No one should be forced to make an advance plan.
- An advance plan should reflect the will and preferences of the person, not those of other people.
- Practitioners, family members and care partners should develop their own advance plans in order to be familiar with and support more effectively others undertaking this process.

Presentation: Steps for making an advance plan – 2

Step 1: Think about it

- Do I want to prepare the advance plan by myself or involve other people?
- What is important to me in my life?
- What are my preferences for treatment and support in relation to different health conditions?
- Do I want to include a “Do not resuscitate’’ clause in my advanced plan?
- What are the different treatment, care and support options that can help my recovery in relation to health and life challenges?
- How do I want others to respond to me if I am unable to communicate my decisions and choices?
- Where would I like to be supported?
- What are the pros and cons of the different treatment, care and support options for my health condition, and of having none of these?
- Who can help me with daily life obligations?
- What are my rights concerning treatment, care and support?

Presentation: Steps for making an advance plan – 3

- Identify people who can be consulted for help when making or implementing an advance plan.
- Questions to think about include:
  - Are there specific people who I would like to support me to make decisions in different areas of my life?
  - Who are they?
  - Who can I trust to support me and communicate my will and preferences?
  - Who would be a good contact person if I experience a crisis?
  - Who knows me well?
  - Who shares the same beliefs/values/vision of life?

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Presentation: Steps for making an advance plan – 4

- The people to consult might include:
    - Partner/husband/wife
    - Friends
    - Family members
    - Care partners
    - Mental health and other practitioners
    - Trained facilitators
    - Someone in a peer role
    - Religious or community leaders.

Presentation: Steps for making an advance plan – 5

Step 2: Discuss

- Once persons have identified who to involve in advance planning, they can discuss the possible options with them.
- Alternatively they may wish to research the different options first and discuss these with potential experts or supporters.
  - Eg. practitioners or a peer can advise what treatments, care and support options are available, implications of accepting or refusing treatments.
  - People providing advice should be aware of the alternatives available.
  - They should be open to different options and not be fixed in their view.
- The person may also want to discuss with family and friends.
- Discussion should identify who would be ready to offer practical help to the person.

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Presentation: Steps for making an advance plan – 6

Step 3: Be aware of the legal framework

- In some countries, certain advance planning documents are legally binding.
- This may mean that a specific procedure needs to be followed.
- It may be necessary to ensure that the document is dated and signed.
- Witnesses may be required to sign the plan.
- Important to know whether there are specific circumstances in which other people will be authorized to override a binding advance plan.
- Lawyers, independent advocates, peer supporters or organizations of persons with disabilities may be able to provide the information needed.

Presentation: Steps for making an advance plan – 7

Step 4: Formalize the advance plan

- Document their choices in writing.
- If an advance planning form already exists in the country, that form should be completed.
- If no form currently exists, it is possible to record choices on a recovery plan or a separate document.
- Some people may require assistance in formulating the advance plan to ensure that that their will and preferences are clearly stated and are understandable to everyone.
- Some services or organizations may provide the support of independent trained facilitators or advocates for this process.

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Presentation: Steps for making an advance plan – 8

Step 5: Make others aware that the advance plan exists

- Others need to be aware of the advance plan.
- The person should retain a copy and other copies should be given to all relevant persons (family, friends and supporters, practitioners.
- Copies of the advance plan should be kept in the person’s medical records.
- In some countries, online registry or crisis card systems may also be available.
- With new technologies it is easier to make advance plans accessible.

Presentation: Steps for making an advance plan – 9

Step 6: Review the advance plan periodically

- People’s choices and preferences may evolve over time.
- Advance plans may need to be changed and updated to reflect new will and preferences.
- It is essential to ensure that copies of the new plans replace the old ones.
- As a person’s will and preferences are continually evolving, it is very important for supporters to remain engaged with the person.
  - Helps to ensure that they are considering not only what is stated in the document but also the current wishes of the person.

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Exercise 7.1: What others must know…

- Complete at least three sections of the advance plan template (Annex 8: Extract of a Recovery Plan template)

Presentation: Tips when making an advance plan

- When people make an advance plan, they may need to think about difficult past experiences.
- Here is some advice that may help:
  - People do not need to complete an advance plan all in one go. They can take or draft it over several days or weeks.
  - People should develop their advance plans when they are feeling good.
  - It can be useful for the person to ask someone they trust to support in developing their plan.
  - Supporter(s) may find it useful to create their own advance plan.
  - It can help to have support from someone who has already created their own advance plan.

Exercise 7.2: Discussion: Real-life examples of advance statements – 1

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

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

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

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

Exercise 7.2: Discussion: Real-life examples of advance statements – 2

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

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

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

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

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

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

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

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

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

Exercise 7.2: Discussion: Real-life examples of advance statements – 3

Do you think that these statements make good sense?

Can you understand why people have included these statements in their advance planning documents?

Exercise 7.3: Supporting people in making advance planning documents

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

Reflective exercise: Concluding the training

- What are the key points you will retain from this module?
- Has the way in which you think about people's ability to make decisions changed?
- Has your understanding of how people can be supported in making decisions changed?
- If yes, how has it changed? If not, why do you think it has not changed?

Acknowledgements (1)

Acknowledgements (2)

Acknowledgements (3)

Acknowledgements (4)

Acknowledgements (5)

Acknowledgements (6)

Acknowledgements (7)