Course Slides

Legal capacity and the right to decide *(continued)*

Recovery and the right to health

WHO QualityRights training – humanitarian edition

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Topics covered in today's training

Module 3. Legal capacity and the right to decide (continued)

- **Topic 3** Informed consent
- **Topic 4** Avoiding involuntary detention and treatment

Module 4. Recovery and the right to health

- **Topic 1** What is mental health?
- **Topic 2** Promoting the right to health in humanitarian setting: including the community
- **Topic 3** What is recovery?
- **Topic 4** Promoting recovery
- **Topic 5** The role of MHPSS services and staff promoting recovery

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Recap of Module 3 so far

Yesterday

- **Topic 1** Understanding the right to legal capacity – what are the key points?
- **Topic 2** Supported decision-making and advance planning – what are the key points?

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Module 3.
Legal capacity and the right to decide *(continued)*

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Topic 3. Informed consent

Presentation. What informed consent for treatment means

- **The person has enough information about proposed treatments to make an informed decision, including:**
    - possible benefits and negative effects/risks of the proposed treatment;
    - possible alternatives to the proposed treatment;
    - possible benefits and risks of not accepting the proposed treatment and/or of choosing one of the alternatives.
    - information is given in a way the person can understand and is adapted to their needs;
    - the information is given in a way that is culturally acceptable to the person.
- **The consent to treatment is given voluntarily:**
    - without threat or coercion or undue influence;
    - without deception, fraud, manipulation or false reassurance.

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

The right to informed consent includes the right to refuse treatment!

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Exercise 3.4 Informed consent, Halima's story

Halima

Halima is an 18-year-old young woman who had to flee her home city because it was bombed. She lost her father and her little brother in the bombings. She doesn´t know where her mother is. She sought shelter with her older sister, who is living with her family in an IDP camp. That was one year ago.

Since then, Halima has become tired of life. She is not speaking more than the necessary and refuses to go out of the tent, except when forced to do so by her family. She has stopped helping with the household, refuses to study – something she used to really enjoy – and she spends most of her time laying in her bed. The only things she likes to do is listen to music through her headphones and to play with her little cousins.

As Halima is not getting better, her sister is very worried and decides to bring her to the mental health services in the camp, where she meets a counsellor and a psychiatrist.

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Exercise 3.4 Informed consent, scenario A

After listening to her story (the sister does most the talking), the counsellor and psychiatrist explain that they can help Halima. Because Halima is not saying much, they explain to the sister that Halima should take medication, which they say will help to activate her - and they instruct her to come once per week to see the counsellor.

Halima looks hesitant and so they explain that it is very important that she follows the treatment recommendations very carefully if she wants to become better. They tell her sister that she is responsible for making sure Halima is taking her pills every morning and comes to the counselling sessions. Her sister agrees because she wants Halima to get better.

The counsellor takes an Informed Consent form and explains that Halima must sign it, to state that she understood everything, and that she agrees to the treatment being provided. The counsellor tells Halima and her sister that Informed Consent forms are required before the service can provide treatment. Her sister tells Halima to sign the form, which she does.

Exercise 3.4 Informed consent, scenario B

After the counsellor and psychiatrist hear the whole story (the sister does most of the talking), they explain they can help Halima, if she would like, and that normally it is necessary to talk with Halima alone first if she feels comfortable to do so. Halima agrees, and they explain to her sister that they will call her back in soon, if she would like.

After a few questions to get comfortable, they ask Halima what she thinks could help her. Halima is not sure. They explain that she could come and talk with a counsellor. They explain the counselling process and why they think it could be useful. And they explain why medication might also be useful.

Halima doesn´t know if she wants any of it and seems scared. The counsellor says this is completely fine and that she does not need to agree to anything she doesn't want. The counsellor suggests some ways to support Halima to feel more comfortable. If Halima would like, the counsellor and somebody from the community mental health team could come by next week to visit her at home and get to know her cousins and talk with her a bit more.

Alternatively, Halima could come to the weekly open women's café. After thinking a while, Halima asks if they could visit her at home, because she feels uncomfortable in new places. The psychiatrist asks Halima if it is ok to call her sister back in to explain to her the support that Halima would like to receive.

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Exercise 3.4 Informed consent, discussion

- **If you were Halima, which scenario would feel better for you – and why?**

Exercise 3.5 Informed consent in humanitarian settings and MHPSS programmes

Plenary discussion

As a general rule, MHPSS and mental health treatment guidelines require informed consent before treatment.

In practice, however, this is not always done, or is not done in line with CRPD principles, or is not done systematically through established procedures with mechanisms to monitor the process.

- Have you implemented Informed Consent approaches in your project? How are you obtaining this?
- Do you have mechanisms to monitor the process of obtaining informed consent?
- What challenges, including safety, do you encounter in your efforts to obtain informed consent?

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Exercise 3.5 Informed consent in humanitarian settings and MHPSS programmes

Plenary discussion

- Guidelines for MHPSS in emergencies have always required informed consent in all activities. Informed consent is a tool to make sure we fulfil the right to decide. This right needs to be fulfilled during humanitarian emergencies, as well as during normal times.
- Whatever your scope of work is, think about how you can ensure that people (including people with disabilities) are informed about, understand, and can genuinely consent to treatment care and support.
- A signed form or a box that is ticked is not consent unless people coming to the service get the information they need, in a way they understand, and can make their own decision.

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Topic 4. Avoiding involuntary detention and treatment

Exercise 3.6 The experience of involuntary admission and treatment

- **How would you feel if you were detained and treated against your will?**
- **How did you feel when you were detained and treated against your will?**

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Exercise 3.7 Involuntary admission and treatment

Involuntary detention and treatment are often accompanied with terrible living conditions, violence and abuse, especially in situations where there is shortage of resources.

Watch this video on involuntary admission and treatment: *Chained and locked up in Somaliland (Human Rights Watch)*

https://www.hrw.org/video-photos/video/2015/10/25/chained-and-locked-somaliland

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Exercise 3.7 Involuntary admission and treatment

- People with psychosocial, intellectual or cognitive disabilities are often detained in mental health and social services against their wishes.
- Sometimes, people may voluntarily enter mental health and social services because no alternatives are available.
- Homeless people may be sent to services and institutions against their wishes because it is believed they are better off within a service.
- People detained against their wishes are very often given forced treatment.
- Involuntary detention and treatment can last for days, weeks, months and even years.
- Due to prevalent stigma and inadequate support services, families often feel they have no choice but to shackle people with psychosocial disabilities, but it also happens as a form of punishment or “treatment”.
- Involuntary admission and treatment also occurs in faith based or other private centres, where people may face punitive and prolonged chaining, confinement, seclusion, and severe restrictions on their movement.

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Exercise 3.7 Involuntary admission and treatment

- What might alternatives to involuntary admissions look like?

Presentation. What does the CRPD say about involuntary detention and treatment?

Article 5. Equality and non-discrimination (e.g., people treated for physical health conditions can not be detained in health services and treated without their informed consent)

Article 12. Equal recognition before the law (e.g. informed consent before involuntary admission or treatment)

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What does the CRPD say about involuntary detention and treatment?

Article 14. Liberty and security ("disability shall in no case justify a deprivation of liberty")

Articles 15 and 16. Freedom from torture, violence, abuse

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What does the CRPD say about involuntary detention and treatment?

Article 17. Protecting the integrity of the person

Article 19. Living independently and being included in the community

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What does the CRPD say about involuntary detention and treatment?

Article 22. Respect for privacy

Article 25. Health (care on the basis of free and informed consent)

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Exercise 3.8 Avoiding coercive measures

Avoiding involuntary admission does not mean no action

- The CRPD requires a shift away from coercion and towards support based on people's will and preferences.
- Avoiding involuntary practices does not mean abandoning people to their fate.
- People should not be sent home by themselves without any offer of support.
- They should be provided with options for support that respect their rights.
    - This might include support from someone they trust who can stay with/check on them.
    - It might mean listening and sometimes thinking creatively and "outside the box".
- Advance directives are useful to ensure people's choices, will and preferences are respected in situations of high emotional distress.

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Exercise 3.8 Avoiding coercive measures – a scenario

One night, George was feeling distressed, agitated and anxious, shouting and making wild gestures. He wanted to run out into the village. The family didn´t know what was happening and thought George was cursed. They wanted to stop him going out because they were afraid something might happen to him, but also because they didn´t want to bring shame on the family. So, his brother and father tackled him and tied him to a bed in a little room. George called out repeatedly that he wanted to be freed and to leave, but after a few hours he fell silent.

The next day, the family consulted a traditional healer, who confirmed their false belief that George had been cursed. He told the family to keep George locked up and away from others in order to prevent the curse from spreading. He also told the family to give George a certain herbal cure to eat to break the curse.

From that time on, George was forced against his will to stay inside the little room, tied by his feet to his bed. His parents brought him food and told him to eat his herbs to get better. George refused, so his father force-fed him twice a day. In the beginning George tried to resist, but after a week, he gave up. He stopped shouting and became increasingly sad and withdrawn, refused to talk to anybody and just lay on his bed. He showed no sign of improvement.

Exercise 3.8 Avoiding coercive measures

Discussion

- Which of George's CRPD rights were violated?
- As MHPSS worker, how could you intervene in this scenario?
- How could you introduce supported decision making and advanced planning to support Georges rights in the future?

Break

15 minutes

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Module 4.
Recovery and the right to health

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Topic 1. What is mental health?

Presentation. What does mental health mean?

"Mental health is a state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well and work well, and contribute to their community. It is an integral component of health and well-being that underpins our individual and collective abilities to make decisions, build relationships and shape the world we live in. Mental health is a basic human right. And it is crucial to personal, community and socio-economic development" *World Health Organization*

Having mental health is fundamentally personal and subjective. It might include:

- a sense of internal well-being
- feeling in line with one's own beliefs and values
- feeling at peace with oneself
- feeling positive and optimistic about life.

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Presentation. Factors affecting mental health and well-being

What can undermine mental health and well-being?

- **Poverty** – not having enough income to provide for basic necessities is damaging.
- **Inequality** – disparities and inequalities between different groups undermines mental health and well-being.
- **Social isolation and loneliness** – people living in communities that are not inclusive experience marginalization and exclusion.
- **Low levels of education** reduces opportunities for full and active participation in society.
- **Rapid social change** – shifts in societal values, beliefs and behaviours can affect our well-being and the way we live.
- **A sudden change in circumstances** – job loss, relationship break-ups, bereavement, displacement, or exposure to conflict and emergencies, can all cause distress and affect mental health and well-being. Even positive events (like having a child, starting a job), can strain mental health and well-being.

(…list continues on next slide)

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Factors affecting mental health and well-being

Continued…. What can negatively affect mental health and well-being?

- **Emergencies** – crises like natural disasters, conflict, or pandemics can cause severe stress, loss, and uncertainty, with long-lasting effects on mental health and well-being.
- **Stressful work conditions** – excessive demands, lack of support and encouragement, and health hazards can make a person feel vulnerable and unable to cope.
- **Discrimination and other human rights violations** impact on a person's feelings of self-worth, confidence, control over their life and hope for the future.
- **Violence and abuse** have important damaging psychological impacts.
- **Physical health, intellectual, sensory conditions** – these can present everyday barriers and challenges.
- **Non-existent or inadequate services or support** may worsen these problems, and may cause human rights violations.

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Factors affecting mental health and well-being

Humanitarian emergencies

- Humanitarian crises, including armed conflict, forced displacement and disaster, inevitably result in suffering and high distress, with many barriers to good mental health.
- As well as the stress of the events, situations like these disrupt families, communities, governmental and social support structures.
- Emergencies almost always lead to a reduced personal safety and increased risk of personal threats and violence and human rights violations.
- Emergencies frequently disrupt access to basic necessities, like food, clean water and shelter, and often separate people from employment, income or education.
- The most marginalized in a society are often the most heavily affected.

Exercise 4.1 What is possible in humanitarian contexts?

Plenary discussion

Humanitarian emergencies are so difficult, and so lacking in protective factors for mental health, that people sometimes think achieving mental health and well-being is simply not possible in these contexts.

So, let's challenge that:

- **What can good mental health mean in humanitarian crisis?**
- **What are the possibilities for protecting and promoting mental health and well-being in humanitarian settings?**

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Topic 2. Promoting the right to health in humanitarian settings: including the community

Presentation. Community and its role in MHPSS

- People should **never** have to live in institutions.
- Mental health facilities that are isolated from, and unconnected to, the community should be phased out and replaced with mental health and social services provided in the community.
- In humanitarian contexts, institutions and services might not be available and the community itself plays an important role as supporter, protector and sometimes healer.
- Traditional and cultural healing and support practices that are not harmful, and that respect people's rights, should be incorporated into a holistic care approach.
- After humanitarian emergencies it is necessary to think not only about people's individual recovery, but also to include a community perspective and explore how to facilitate community resilience and healing.

Community plays a crucial part in a holistic MHPSS response, including: avoidance of institutionalisation; building community inclusion; and offering recovery-oriented support.

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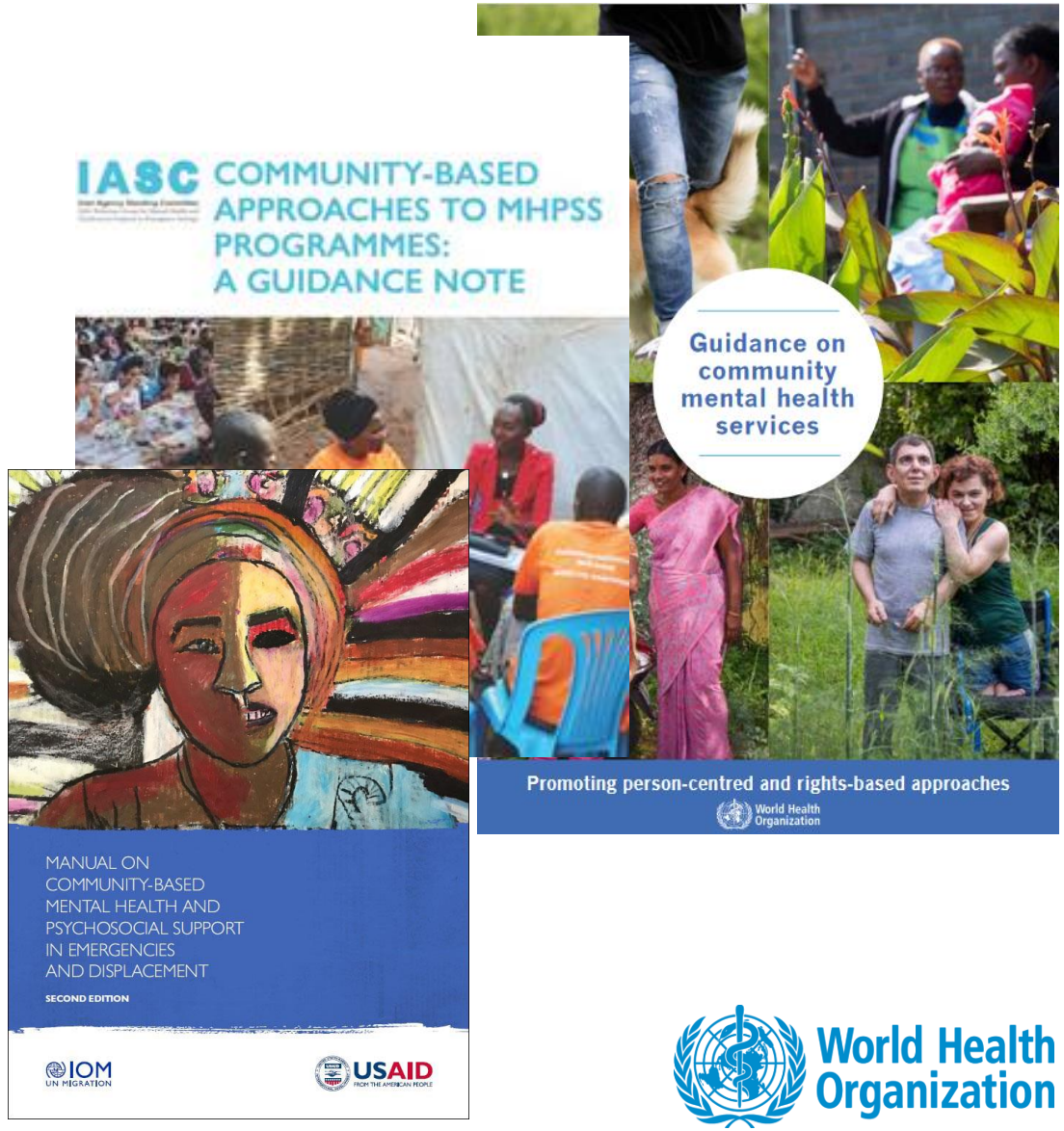
Community and its role in MHPSS

Key-elements of community approaches

- Community inclusion, participation and outreach (including for people with lived experience) at all levels of the MHPSS pyramid is key for ownership, empowerment, engagement and community resilience.
- Community has a key role in:
  - developing and implementing protection activities;
  - advocating for the rights of people with psychosocial, intellectual or cognitive disabilities;
  - establishing a range of community-based mental health and other services and supports.



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Example 1 Friendship benches

- The Friendship Bench initiative (created in Zimbabwe 2006) provides safe places in communities for people to talk.
- Trained lay counsellors provide support to people experiencing emotional distress.
- Most lay counsellors are older women as, in Zimbabwe, older people are seen as important guardians of the community and are respected.
- The friendship bench approach has been adapted and implemented in Zanzibar (United Republic of Tanzania), in Malawi and in New York City, USA.

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Example 2 The Green String Network

- The Green String Network (GSN) is a multi-disciplinary team of peacebuilders, community workers, mental health staff and researchers who design trauma-informed interventions, and ways to evaluate them. Their work addresses trauma as a root cause of violent behaviour.
- GSN is both a peacebuilding organization and a mental health organization
- GSN's approach to mental health is non-biomedical, non-Western, and linked to understanding the structural forces of violence, poverty, and power.

Key focus areas

- **Understanding stress and trauma.** The framework examines historical injustices and their ongoing impact, recognizing how trauma can be transmitted across generations.
- **Breaking cycles of violence.** The framework identifies the mechanisms, or "legacies and aftermaths," that perpetuate trauma responses, and seeks to break these cycles.
- **Empowerment and healing.** The framework emphasizes fostering resilience and healing at individual and community levels.

For more information, see https://www.green-string.org/

Exercise 4.2 Community based programmes and services

Sharing your experience with community engagement and community-based services

- Do you provide, or know of, community-based services that can promote mental health and well-being? This might include mental health and other services (for example support groups, livelihood and income generating programmes, social and sports activities etc.)

- What kind of support do these provide?

- How do they promote mental health and well-being and respect the rights of people with psychosocial, intellectual or cognitive disabilities?

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Topic 3. What is recovery?

Exercise 4.3 Feeling better

Silent exercise

Think about a time when you had to recover from something – now or in the past. It can be anything you can think of, not necessarily related to mental health.

- What helped you to get better?

Presentation. The meaning of recovery

- Recovery can mean different things for each person. It can be about
  - regaining control of identity and life
  - having hope
  - living a life that has meaning.
- This understanding of recovery moves us away from the idea or goal of “being cured” or “being normal again”.
- Recovery focuses on the whole person, addressing social, emotional, and physical aspects, including adversities like poverty, unemployment, discrimination etc.
- Recovery focuses on (re)gaining new meaning and purpose in life, being empowered and able to live a self-directed life, despite what one may have lived through.

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The meaning of recovery

- Recovery doesn't have the same meaning as 'cure' (recovery is a journey not an end point).

- Recovery refers to someone's internal conditions (perhaps their hope, healing, empowerment etc) but also external conditions that help or hinder recovery (such as whether rights are upheld, recovery-orientated services are available, and a healing culture is established).

Exercise 4.4 Youssef's recovery

Youssef has been experiencing deep and incapacitating sadness for several years and is not getting better. He has attempted suicide twice in the past 3 months. Youssef is seeing Dr Sharma.

Outcome 1. Upon arrival, Dr Sharma gives Youssef a prescription refill for his antidepressants. Youssef goes to the pharmacy to get his medication and leaves.

Outcome 2. Dr Sharma asks Youssef how he has been doing. When she hears he has been feeling worse in recent weeks, she asks why, and what might help. Dr Sharma also discusses Youssef's goals for the future as well as goals he could focus on right now to feel better.
Youssef tells Dr Sharma that he feels very alone. He is estranged from his family and friends who do not understand his situation. He has not been performing well at work and has had to take time off. He tells Dr Sharma that he would feel a lot better if he could reconnect with his family and friends and go back to work.
Dr Sharma suggests that, if Youssef wishes, they could meet with close family and friends to discuss what he is experiencing and how they can all best support him. She offers him a referral to a psychologist and asks if he wants to get information about medical treatment. She also connects him with a social worker and local support NGOs. She gives him a list of local peer support groups to help rebuild his support network. Youssef and Dr Sharma agree to meet regularly to work towards his recovery goals.

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Exercise 4.5 Recovery stories from your work

Plenary discussion

- **Do you have any recovery stories from your work?**

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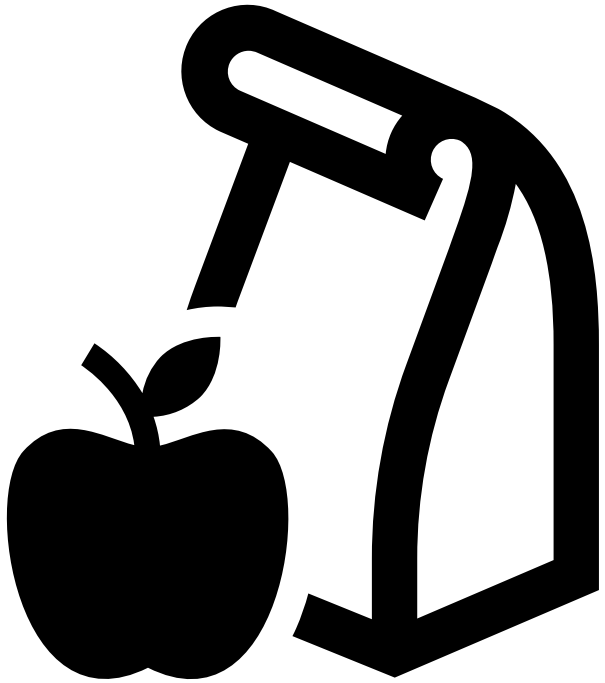

Lunch

Topic 4. Promoting recovery

Exercise 4.6 How can we promote recovery?

- **How can people promote their own recovery?**
- **How can families, caregivers and other supporters promote recovery?**
- **How can communities promote recovery?**

Presentation. What supports recovery?

Communication, trust and a shift of focus

Good communication and building a trusting relationship

- Using good communication skills (for example, active listening, using positive messages focusing on hope).
- Understanding that the person is an expert by experience and that this expertise is as valid as the expertise of practitioners.

A shift from *What is the matter with you?* to *What matters to you?*

- It is not up to mental health and other practitioners, families or others to decide what a person's recovery will look like. This must be the decision of the person who is going through the recovery journey.

"Instead of telling people to be resilient, we must create environments where resilience is possible, if not inevitable" *Green string Network*

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What supports recovery?

Recovery and social inclusion

- Taking part in social, educational, training, volunteering and employment can support individual recovery.

- Services should empower people gain or establish their place in the community and to live a life that has meaning to them (institutional models of care, which isolate people from the community, are incompatible with a recovery approach).

- We all have a role to play in fostering inclusion and openness that supports people in their recovery journey.

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What supports recovery?

Recovery plans

- A recovery plan can be a useful tool to:
    - support someone to work out a direction and steps for moving forward in life
    - help someone get the support of important people in their life, if they wish to do so.
- A recovery plan outlines the person's own goals in life.
- The plan outlines how the person and their chosen support network will work to achieve these goals.
- It may include a personal plan for dealing with acute distress.
- A recovery plan may also include an advance directive about care and treatment.

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Topic 5. How MHPSS services and staff can promote recovery

Exercise 4.7 Improving practices. What are you doing already?

Improving practices MHPSS services and staff use to promote recovery

Think about the MHPSS context where you work. How are you already promoting recovery?

(If you don't work directly in implementing MHPSS, what do you do to create an environment for the people you help that supports hope, empowerment and inclusion…..?)

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Exercise 4.8 Improving practices. What changes/improvements are needed?

Improving practices MHPSS services and staff use to promote recovery

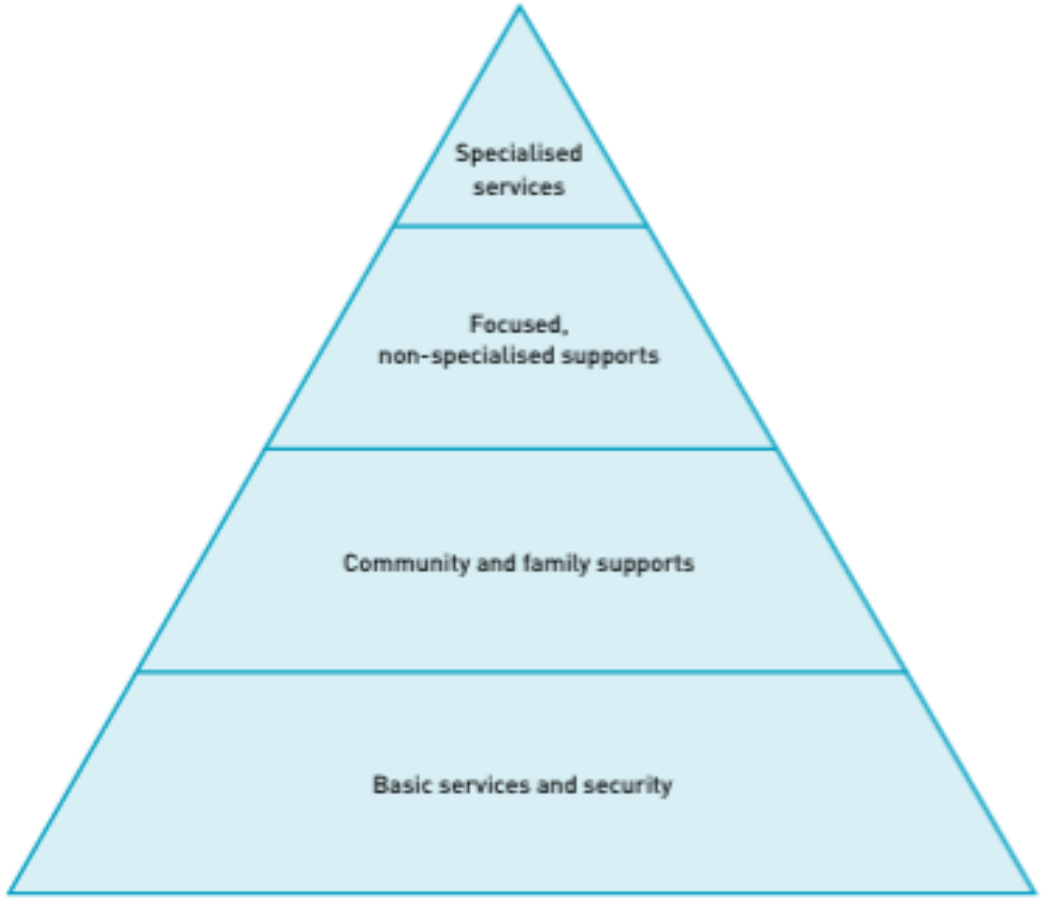

Image: Inter-Agency Standing Committee (IASC). (2007). *IASC guidelines on mental health and psychosocial support in emergency settings*. Geneva: IASC.

- Think about tangible measures that can be taken at the different levels of the pyramid to support recovery.
- If you are not MHPSS staff, think about the scope of the work you do in your sector, and how you can support recovery.

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Break

15 minutes

Exercise 4.9 Improving practices. Plenary discussion

Improving practices MHPSS services and staff use to promote recovery

- **Was it difficult to find ideas? If yes, what made it difficult?**
- **Was it easier to improve practices in some layers than others?**
- **Were some recovery actions relevant to all the layers?**

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Presentation. Changing the narrative

We will watch a video about Little Amal's journey: the larger-than-life puppet that travelled over 9000km from Syria across 13 countries in a project called *The Walk*, representing all children fleeing violence, conflict and persecution.

"….Yes, refugees need food and blankets, but they also need dignity and a voice. The purpose of The Walk is to highlight the potential of the refugee, not just their dire circumstances. Little Amal is 3.5 metres tall because we want the world to grow big enough to greet her. We want her to inspire us to think big and to act bigger."

Amir Nizar Zuabi, Artistic Director of The Walk

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Exercise 4.10 Improving practices. Action planning

Improving practices MHPSS services and staff use to promote recovery

- Continue building your QualityRights Action Plan.
- **Identify two to three concrete and realistic actions your project or organization could implement within the next six months to promote recovery-oriented practice.**
    - What specific changes in services or staff practices would support recovery?
    - What resources will you need?
    - What challenges might you face, and how can you address them?

- Record your ideas in the Day 3 Action Planner (Recovery) section.

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Daily wrap up and rapid end of day evaluation

Please provide some quick first impressions on how you found the second part of module three on *Legal capacity and the right to decide*, and module four on *Recovery and the right to health.* You'll have the opportunity to give more detailed feedback at the end of the entire course too.

1. What is/are the most important point(s) you learnt from today's training?
2. Any remarks? Wishes for tomorrow?

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