QualityRights

Improving mental health and related service environments and promoting community inclusion

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

(PILOT VERSION)

Contact Information:

Michelle Funk, Coordinator
funkm@who.int
Natalie Drew, Technical Officer
drewn@who.int

Prepared by
Mental Health Policy and Service Development
Department of Mental Health and Substance Abuse
World Health Organization, Geneva

World Health Organization

WHO/MSD/MHP/17.3

Suggested citation. Improving mental health and related service environments and promoting community inclusion - WHO QualityRights training to act, unite and empower for mental health (pilot version). Geneva: World Health Organization; 2017 (WHO/MSD/MHP/17.3). Licence: CC BY-NC-SA 3.0 IGO.

Cataloguing-in-Publication (CIP) data. CIP data are available at http://apps.who.int/iris.

Table of Contents

Acknowledgments

Coordination, conceptualisation and writing:

Michelle Funk (WHO, Geneva)

Natalie Drew Bold (WHO, Geneva)

Advisors and contributing writers

WHO would like to thank the following individuals in their advisory role and for writing contributions:

Marie Baudel (France), Celia Brown (USA), Mauro Carta (Italy), Sera Davidow (USA), Theresia Degener (Germany), Catalina Devandas Aguilar (Switzerland), Julian Eaton (United Kingdom), Rabih El Chammay (Lebanon), Salam Gómez (Colombia), Rachel Kachaje (Malawi), Elizabeth Kamundia (Kenya), Diane Kingston (United Kingdom), Itzhak Levav (Israel), Peter McGovern (United Kingdom), David McGrath (Australia), Peter Mittler (United Kingdom), Maria Francesca Moro (Italy), David Oaks (USA), Soumitra Pathare (India), Dainius Pūras (Switzerland), Sashi Sashidharan (United Kingdom), Greg Smith (USA), Kate Swaffer (Australia), Carmen Valle (Thailand), Alberto Vásquez Encalada (Switzerland).

Reviewers

WHO would also like to thank the following reviewers for their expert review and inputs:

Robinah Alumbaya (Uganda), Carla Aparecida Arena Ventura (Brazil), Anna Arstein-Kerslake (Australia), Lori Ashcraft (USA), Rod Astbury (Australia), Josef Atukunda (Uganda), David Axworthy (Australia), Sam Badege (Rwanda), Amrit Bakhshy (India) Jerome Bickenbach (Switzerland), Pat Bracken (Ireland), Simon Bradstreet (United Kingdom), Patricia Brogna (Argentina), Aleisha Carroll (Australia), Ajay Chauhan (India), Facundo Chavez Penillas (Switzerland), Louise Christie (United Kingdom), Oryx Cohen (USA), Jillian Craigie (United Kingdom), Rita Cronise (USA), Lucia de la Sierra (Switzerland), Paolo del Vecchio (USA), Alex Devine (Australia), Christopher Dowrick (United Kingdom), Ragia Elgerzawy (Egypt), Alva Finn (Belgium), Susanne Forrest (United Kingdom), Kirsty Giles (United Kingdom), Margaret Grigg (Australia), Cerdic Hall (United Kingdom), Steve Harrington (USA), Renae Hodgson (Australia), Frances Hughes (Switzerland), Maths Jesperson (Sweden), Titus Joseph (India), Dovilė Juodkaitė (Lithuania), Abu Bakar Abdul Kadir (Malaysia), Jasmine Kalha (India), Yasmin Kapadia (United Kingdom), Manaan Kar Ray (United Kingdom), Brendan Kelly (Ireland), Akwatu Khenti (Canada), Mika Kontiainen (Australia), Sadhvi Krishnamoorthy (India), Anna Kudiyarova (Kazakhstan), Laura Loli-Dano (Canada), Eleanor Longden (United Kingdom), John McCormack (United Kingdom), Colin McKay (United Kingdom), Emily McLoughlin (Ireland), Roberto Mezzina (Italy), Peter Mittler (United Kingdom), Pamela Molina (USA), Andrew Molodynski (United Kingdom), Gaia Montauti d'Harcourt (Switzerland), Raul Montoya (Mexico), Fiona Morrissey (Ireland), Lucy Mulvagh (United Kingdom), Carrie Netting (United Kingdom), Michael Njenga (Kenya), Abdelaziz Awadelseed Alhassan Osman (Sudan), Gareth Owen (United Kingdom), Elvira Pértega Andía (Spain),Thara Rangaswamy (India), Mayssa Rekhis (Tunisia), Julie Repper (United Kingdom), Genevra Richardson (United Kingdom), Jean Luc Roelandt (France), Eric Rosenthal (USA), Marianne Schulze (Austria), Tom Shakespeare (United Kingdom), Gordon Singer (Canada), Mike Slade (United Kingdom), Natasa Spasic (Australia), Michael Ashley Stein (USA), Anthony Stratford (Australia), Charlene Sunkel (South Africa), Shelly Thomson (Australia), Simon Vasseur Bacle (France), Alison Xamon (Australia).

WHO Administrative Support

Patricia Robertson (WHO, Geneva)

WHO Interns

Gunnhild Kjaer (Denmark), Jade Presnell (USA), Kaitlyn Lyle (USA), Yuri Lee (Republic of Korea), Stephanie Fletcher (Australia), Paul Christensen (USA), Jane Henty (Australia), Zoe Mulliez (France), Mona Alqazzaz (Egypt), Peter Varnum (USA).

WHO Staff

Global coordination of the QualityRights initiative is overseen by Michelle Funk and Natalie Drew (WHO Geneva).

QualityRights implementation is being supported across the world by Nazneen Anwar (WHO/SEARO), Darryl Barrett (WHO/WPRO), Daniel Chisholm (WHO/EURO), Sebastiana Da Gama Nkomo (WHO/AFRO), Dévora Kestel (WHO/AMRO), Dr Maristela Monterio (WHO/AMRO), Khalid Saeed (WHO/EMRO) and Shekhar Saxena (WHO, Geneva).

Donors

WHO would like to thank Grand Challenges Canada, funded by the Government of Canada, and CBM International for their generous financial support towards the development of the QualityRights training modules.

What is the WHO QualityRights initiative?

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

1. Build capacity to understand and promote human rights, recovery and independent living in the community.
2. Create community based and recovery oriented services that respect and promote human rights.
3. Improve the quality of care and human rights conditions in inpatient, outpatient and community based mental health and related services.
4. Develop a civil society movement to conduct advocacy and influence policy-making to promote human rights.
5. Reform national policies and legislation in line with best practice, the CRPD and other international human rights standards.

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

WHO QualityRights - Guidance and training tools

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

Service assessment and improvement tools

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

Training tools

Core modules

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

Advanced modules

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

Guidance tools

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

About this training and guidance

This document provides training and guidance on the key standards related to the physical and social environment within mental health and related services that need to be met to promote good outcomes, independent living and community inclusion.

Who is this training workshop and guidance for?

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

Who should deliver the training?

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

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

Guidance for facilitators

Principles for running the training programme

Participation and interaction

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

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

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

Cultural sensitivity

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

Open, non-judgmental environment

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

Use of language

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

Operating in the current legislature and policy context

During the training, some participants may express concerns about the legislative or policy context in their countries. Indeed, some of the content may contradict national legislation or policy. For example, the topic on supported decision making may appear to conflict with existing national guardianship laws. Similarly, laws that provide for involuntary detention and treatment contradict

the overall approach of these modules. This can raise issues and concerns, particularly around professional liability.

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

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

Being positive and inspiring

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

Group work

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

Facilitator notes

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

Preliminary note on language

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

Above all, a diagnosis or disability should never define a person because we are all individuals, with a unique personality, autonomy, dreams, goals and aspirations and relationships to others.
The choice of terminology adopted in this document has been selected for the sake of inclusiveness.

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

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

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

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

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

Learning objectives, topics and resources

Learning objectives

Participants will:

- Develop an understanding of what are good standards of living in the context of mental health and related inpatient and residential services.
- Understand the right to live independently and be included in the community.
- Explore how mental health and other practitioners, families and others can support people to engage in community life and community living.

Topics covered

Topic 1: What makes a good living environment?

Topic 2: The right to an adequate standard of living in mental health and related services

Topic 3: Living independently and being included in one's community

Resources required

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

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

Additional resources needed include:

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

Time

Approximately 2 hours and 30 minutes

Number of participants

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

Welcome and Introduction

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

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

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

Reflective exercise: (10 min.)

Ask participants to reflect on the following:

How does realising the right to make one's own decisions facilitate independent living and community inclusion?

Allow participants to share their answers in small groups of 5 people. After a 5-minute discussion, ask each group to nominate a spokesperson to share their answers with the rest of the participants.

Some responses from participants may include:

- If people with psychosocial, intellectual and cognitive disabilities have their rights respected in the same way as everyone else they will have the same opportunities to live fulfilling and enjoyable lives, on an equal basis with others, including exercising choices; participating in leisure activities, employment activities, political engagement and roles; becoming financially independent; fighting stigma.
- By being able to make decisions about where to live, as all other citizens are able to, people will have the choice to remain within their community and live in their own homes.
- People will play important and more active roles within their community if their decisions are respected and valued.
- It enables people to feel empowered and more confident about their skills to live independently.

Topic 1: What makes a good living environment?

Exercise 1.1: Grand designs (30 min.)

The purpose of this exercise is to ask participants to think about what aspects of their home environment should be integrated into mental health inpatient or residential services to make these a better place to stay. This exercise will allow the group to think about what is important in a living environment.

Make clear to participants that:

- The purpose of this exercise is **not** to imply that psychiatric hospitals can become good places to live. People should never have to reside in institutions.
- Large scale mental health facilities which are isolated from and unconnected to the community should be phased out and replaced with mental health and related services provided in the community.
- People should have access, on a voluntary basis, to short term and community-based services such as respite houses, halfway homes, supported flats/apartments, mental health units in general hospitals, etc.

Ask participants to divide into two groups and provide everybody with paper and pens.

Then explain the following:

Your task is to discuss and create a list of the differences between your home environment and the environment of a mental health inpatient or residential service. Each group will be given different areas to think about and we will combine the ideas at the end.

Group 1 will concentrate on the physical environment of their home compared to a mental health inpatient or residential service (which they are currently staying at, have stayed at in the past, or have visited). Try to include the structure of the home including the bedrooms and shared living spaces. Think about privacy, safety and what makes a happy, comfortable home.

Here are some questions which can be used to start the conversation:

- Is the building in good physical condition?
- Is the building located in the community and easily accessible (e.g. through public transportation, etc.)?
- How accessible is the building? Could anyone gain access? What about people who have mobility issues, use wheelchairs etc.?
- Do people have comfortable sleeping areas?
- Do they have private spaces including places to keep property?
- Do people have a clean toilet and shower or other bathing facility, that allow for privacy?
- Is the environment hygienic?

- Is the environment designed to be safe, secure and without any risks to the person's health or wellbeing?
- Where and how is food prepared? Is the food prepared by people themselves?
- Is there the possibility for people to personalise the environment based on their culture, interests and personal preferences? Are people able to add decoration and personal items?

Group 2 will focus on comparing the general atmosphere of their home and that of the mental health inpatient or residential service. Think about any unspoken or formal rules for behaving and communicating in these two different environments. Also consider how each environment relates to and interacts with the local community.

Here are some questions to start the conversation:

- How would you describe the general atmosphere?
- Are there any rules about respecting privacy?
- How do people behave towards one another?
- How do people speak to each other in this environment?
- Are people able to speak freely and openly, whenever they want?
- Are there opportunities to develop friendships or close social contacts?
- Is there a uniform or can people wear what they like? Do people have to wear pyjamas during the day?
- How are residents spoken to and addressed?
- Are people able to carry out religious, leisure or cultural activities?
- Are people able to come and go as they please?
- Are there rules around visitors and visiting times?
- Are there regular interactions with the local community? Do people engage in local community activities?
- Are there social and family events?
- Are there differences in terms of power dynamics? (For example, does everyone have equal status or are there hierarchies in terms of power e.g. within the service, between people using the service and staff? Are people, who may usually be responsible for making decisions for their household, being denied this opportunity within the service, thus creating feelings of powerlessness?)

Make a column on the flip chart for the differences between the home environment and the environment of the mental health inpatient or residential service.

On reporting back allow participants to freely discuss the reasons for the differences (if any) between their home environment and that of the mental health inpatient or residential service.

Topic 2: The right to an adequate standard of living in mental health and related services

Presentation: The right to an adequate standard of living (15 min,)

The right to an adequate standard of living is protected by article 28 of the Convention on the Rights of Persons with Disabilities (CRPD) (1). The WHO QualityRights toolkit (2) sets standards to ensure this right is respected, protected and fulfilled.

What is considered a good standard of living may differ across cultures and vary depending on people. For example, living with one's extended family may be the norm for some people and in some countries, while having a place of one's own may be very important to others. However, many basic requirements are likely to be common to everyone.

The WHO QualityRights toolkit, highlights key standards that need to be met in inpatient mental health and related services to ensure that people are able to enjoy their right to an adequate standard of living when they are staying in a mental health and related services (Annex 1).

The standards are:

1.1 The building is in good physical condition

A building in good physical condition is necessary to create an environment where people can be and feel safe and comfortable.

- The building is in a good state of repair (e.g. windows are not broken, paint is not peeling from the walls).
- The building is accessible for people with physical disabilities.
- The building's lighting (artificial and natural), heating and ventilation provide a comfortable living environment.
- Measures are in place to protect people against injury through fire.

1.2 The sleeping conditions of service users are comfortable and allow sufficient privacy

Sleep is an essential part of everyday life and is essential to good physical and mental health. Often this is one of the most neglected aspects of life in inpatient mental health or related services where there is overcrowding and where privacy is limited.

- The sleeping quarters provide sufficient living space per service user and are not overcrowded.
- Men and women as well as children and older persons have separate sleeping quarters.
- Service users are free to choose when to get up and when to go to bed.
- The sleeping quarters allow for the privacy of service users.
- Sufficient numbers of clean blankets and beddings are available to service users.
- Service users can keep personal belongings and have adequate lockable space to store them.

1.3 The facility meets hygiene and sanitary requirements

Just like homes in the community, inpatient mental health or related services must be clean and healthy environments. This allows people to feel comfortable and means that their health is not being put at risk.

- The bathing and toilet facilities are clean and working properly.
- The bathing and toilet facilities allow privacy, and there are separate facilities for men and women.
- Service users have regular access to bathing and toilet facilities.
- The bathing and toileting needs of service users who are bedridden or who have impaired mobility or other physical disabilities are accommodated.

1.4 Service users are given food, safe drinking-water and clothing that meet their needs and preferences

Good quality food, water and clothing are all basic requirements for good physical and mental health.

- Food and safe drinking-water are available in sufficient quantities, are of good quality and meet with the service user's cultural preferences and physical health requirements.
- Food is prepared and served according to culinary requirements and under satisfactory and hygienic conditions, and eating areas are culturally appropriate and reflect the eating arrangement in the community.
- Service users can wear their own clothing and shoes (day wear and night wear).
- When service users do not have their own clothing, good-quality clothing is provided that meets their cultural preferences and is suitable for the climate.

1.5 Service users can communicate freely, and their right to privacy is respected.

It is essential that people feel comfortable to speak and communicate freely and privately. Often people staying in mental health or related services lose these rights.

- Telephones, letters, e-mails and the Internet are freely available to service users, without censorship.
- Service users' privacy in communications is respected.
- Service users can communicate in the language of their choice, and the facility provides support (e.g. translators) to ensure that the service users can express their needs.
- Service users can receive visitors, choose who they want to see and participate in visits at any reasonable time.
- Service users can move freely around the facility.

1.6 The facility provides a welcoming, comfortable, stimulating environment conducive to active participation and interaction.

Interaction with other service users, visitors and staff has a therapeutic benefit and supports recovery, as well as being an essential part of everyday life.

- There are ample furnishings, and they are comfortable and in good condition.

- The layout of the facility is conducive to interaction between and among service users, staff and visitors.
- The necessary resources, including equipment, are provided by the facility to ensure that service users have opportunities to interact and participate in leisure activities.
- Rooms within the facility are specifically designated as leisure areas for service users.

1.7 Service users can enjoy fulfilling social and personal lives and remain engaged in community life and activities.

The social and personal life of every person using mental health or related services should be maintained and they should remain engaged in community life and activities.

- Service users can interact with other service users, including members of the opposite sex.
- Personal requests, such as to attend weddings or funerals, are facilitated by staff.
- A range of regularly scheduled, organized activities are offered in both the facility and the community that are relevant and age-appropriate.
- Staff provide information to service users about activities in the community and facilitate their access to those activities.
- Staff facilitate service users' access to entertainment outside the facility, and entertainment from the community is brought into the facility.

The standards in the WHO QualityRights toolkit are important aspects of any person's life. Where we reside, even for a short time, should be comfortable, stimulating and a positive experience.

Social interaction is the cornerstone of what makes most people happy. People's role and engagement in the community contributes to feeling that one's life has purpose and matters. So just as these factors are important for all people, these are also important for people staying in inpatient mental health and related services. Social interactions, activities and involvement in the community can also be therapeutic and help people in their recovery.

Topic 3: Living independently and being included in your community

The purpose of this topic is to help participants understand the content and implications of the right to live independently and be included in the community (Article 19 of the CRPD).

Presentation: The right to live independently and be included in the community (20 min.)

This presentation explores Article 19 of the CRPD and what is meant by living independently and being included in the community and why it is such an important right.

The right to live independently and be included in the community is protected in Article 19 of the CRPD.

According to Article 19, people with disabilities have a right to:

- Live in the community
- Be included in the community
- Participate in the community

In particular countries must make sure that people:

- Can choose their place of residence, decide where to live (their city/ town/village, neighbourhood, apartment, but also whether they should live in a place where they can receive specific support or not) and decide with whom to live (alone, with their family, with friends, etc.).
- Cannot be forced to live somewhere if they don't want to. This means they cannot be forced to stay in a mental health or related service.
- Have access to a wide range of support and services to enable them to live in their chosen community (in-home, residential and other community support services, personal assistance, etc.)
- Have access to the same services and facilities in the community as the rest of the population.

Article 19 of the CRPD has 3 key dimensions (3):

1. **Choice**: Being able to exercise choice is essential to community inclusion. This mean for example, the opportunity to exercise one's choice about one's place or residence, living arrangements, the type and supply of services and supports one wishes to receive, and so on. It also means having choices concerning daily activities, education, employment, friends, clothing, etc. These choices make life meaningful and worth living. In addition, having choice also means being able to choose from the same range of options (e.g. housing or service options) as other members of society, or to reject those options.

    - To be able to make choices, people need to be able to exercise their legal capacity. Article 12 is very important to the realisation of article 19 (See Module on *Protecting the right to legal capacity in mental health and related services).*

- Choice also means that people cannot be forcibly admitted to institutions. It doesn't matter whether the institutions are big or small or where they are located – if they do not respect people choices on a day to day basis (who can visit, what to eat, what activities to do) they are not in line with article 19.

2. **Support**: A wide range of support services should be available to enable people to live in the community.

    - Services or supports may include: information and advice, training for independent living, housing programmes, on the job training schemes, personal assistance, habilitation and rehabilitation programmes, social assistance services, disability benefits, peer support, sign language interpreters, family crisis services, respite services, mediation, support for transportation, as well as general and specific health services.

3. **Availability of community services and facilities**: All community services must be inclusive and accessible. In other words, people with disabilities should have access to all the services available to the general population. For example people with disabilities have the right to go to public school, to use the general transport system, to access the open job market, access to health services, access to social, cultural, leisure or other events and activities etc.

Having a place and a role in the community, being accepted, valued and included within it, is not only a right, but also an important component of a person's well-being and recovery.

The WHO QualityRights toolkit also includes a number of standards which mental health and related services need to meet in order to promote the right to independent living and community inclusion. The standards are:

- Service users are supported in gaining access to a place to live and have the financial resources necessary to live in the community.
- Service users can access education and employment opportunities.
- The right of service users to participate in political and public life and to exercise freedom of association is supported.
- Service users are supported in taking part in social, cultural, religious and leisure activities.

It may be necessary to explain that "freedom of association" means the right to become (or not) a member of an association or organisation, the right to create an association or organisation and the right to gather with other people for example during meetings or events.

Housing and financial resources to live in the community:

In some countries, people tend to live with their families with, in some cases, several generations living under the same roof. In other countries having a place on one's own is an important component of what being independent means.

The right to live independently in the community is not about imposing an ideal way of life. It is about making sure that people have the same **choices** in terms of living arrangements as all other members of their community.

People with psychosocial, intellectual and cognitive disabilities should have the possibility to have a place to live outside the mental health and other services either on their own, with their family or with other people of their choosing.

Therefore staff in mental health and related services have an important role to play in supporting people to gain access to a place to live and to the financial resources necessary to live in the community. The WHO QualityRights toolkit provides the following guidance:

- Staff inform service users about options for housing and financial resources.
- Staff support service users in accessing and maintain safe, affordable, decent housing.
- Staff support service users in accessing the financial resources to live in the community.

For example, mental health and other practitioners can connect people with social workers so they can find a good place to live – this may be in an independent house, with one's family, or even extended family or friends if it is not possible for the person to live with their immediate family.

Staff should also connect people to other community based services and supports they may need to live independently, including social services, peer support, personal assistance, and other social benefits that would enable them to be more independent and have more living choices on all aspects of their lives.

Feeling included in the community and having a place to call "home" which is not a mental health or related service is very important for most people, as is being able to make choices about how to live their life overall. Choice also means being able to choose who provides care and support to them.

It is important to note that sometimes even *community* residential services replicate the institutional culture of mental health and related services. For example, staff members continue to make all the daily decisions (about meals, activities, visits, medication, etc.) for the residents. These types of residential services are not respectful of people's right to live independently.

At this point in the presentation, ask participants if they have any questions.

Education & Employment:

People with psychosocial, intellectual and cognitive disabilities must be able to access education and employment opportunities:

- Staff give service users information about education and employment opportunities in the community.
- Staff support service users in accessing education opportunities, including primary, secondary and post-secondary education.

- Staff support service users in career development and in accessing paid employment opportunities.

Education and employment are important aspects of everyone's life. Reasonable accommodations should be provided (e.g. part time job, flexible hours, working at home) to enable people to access education and employment. Having a job and an education improves self-esteem and helps people contribute to their local community.

Ongoing education and employment keeps people's lives moving forward and ensures that their lives are defined by more than a mental health diagnosis.

Employment gives people money that can help maintain their independence and contribute to the household. These are also protective factors that can aid recovery.

Participation in political and public life

Participation is an important component of the right to live independently and be included in the community. Many people with psychosocial, intellectual and cognitive disabilities live in the community but are nevertheless in a situation of social isolation and segregation. It is important to make communities more inclusive by supporting people's participation in all areas of political and public life.

This may include voting in elections, joining an association or religious group and running for an election if people wish to.

The WHO Quality Rights toolkit gives guidance on the role of staff in helping people exercise this right:

- Staff give service users the information necessary for them to participate fully in political and public life and to enjoy the benefits of freedom of association.
- Staff support service users in exercising their right to vote.
- Staff support service users in joining and participating in the activities of political, religious, social, disability and mental disability organizations and other groups.

Participation in political and public life should be guaranteed to people with psychosocial, intellectual and cognitive disabilities on the same basis as all other groups. This ensures that people can contribute and campaign for change in society.

In addition, people with psychosocial, intellectual and cognitive disabilities should be specifically consulted and inform the political decision making process. This is because many aspects of the lives of people with psychosocial, intellectual and cognitive disabilities are significantly impacted on by the political process. Also, they have critical knowledge and expertise in matters that affect their lives (e.g. employment, health, education). Staff should enable people to link up with advocacy groups.

Social, cultural and leisure activities

People should be supported to take part in social, cultural, religious and leisure activities. This helps people to maintain their interests and life. This is also an aid to recovery as well as a right.

- Staff give service users information on the available social, cultural, religious and leisure activities.
- Staff support service users in participating in the social and leisure activities of their choice.
- Staff support service users in participating in the cultural and religious activities of their choice.

Social, cultural and leisure activities help people to enjoy their lives. Interaction with the natural environment encourages mental wellbeing and physical activity is essential for good health.

These activities allow people to meet other persons and form friendships and relationships. It promotes social inclusion and reduces isolation and is an essential part of the human experience.

Cultural and religious beliefs may also be deeply important to a person especially if they have been practiced for many years. These should be respected and supported by staff in mental health and related services.

All of these factors – housing and financial resources, education and employment, participation in political and public life as well as in social, cultural and leisure activities – are critical factors in promoting community inclusion and independent living.

They are also important therapeutic factors that promote recovery.

Promoting community inclusion also means educating the community to understand and respect the rights of people with psychosocial, intellectual and cognitive disabilities. This can be achieved through can be raised through awareness raising campaigns, public events and other activities that create links and engagement between services and the community.

What can a good standard of living and community inclusion look like?

At this point, show participants the videos *"Croatia: Out of Institutions, Into the World"* and *"Back Home: A supported mental health residence in Cerrik, ALBANIA".*

Introduce the first video by explaining to participants:

- This Human Rights Watch video highlights efforts being undertaken in Osijek, Croatia, to move people out of institutions and residential care facilities, and into the community.
- In the film, people talk about the benefits they have experienced in moving into the community after living in segregated institutions, some of them all their lives.

Introduce the second video by explaining to participants:

- In December 2008 twelve men and women, former residents of the psychiatric hospital of Elbasan in Albania moved into a supported residence at the nearby small town of Cerrik.
- Social workers and nurses supported the daily living of those who had been institutionalized for quite some time and had therefore lost touch with their community. The supported home was part of the WHO support to the Albanian Mental Health reform, with funding from the Swedish and Irish development Agencies (respectively SIDA and Irish Aid).

Croatia: Out of Institutions, Into the World. Human Rights Watch 2014 (4.46 mins)
https://www.youtube.com/watch?v=Gf9LVjdILvQ

Back Home: A supported mental health residence in Cerrik, ALBANIA (4) (15:10 min.):
https://www.youtube.com/watch?v=bnRtk5DjDr4 Date accessed 07/06/2016

After watching these videos, ask participants about some of the positive and negative aspect of the house shown in the video.

Exercise 3.1: Independence and community inclusion (20 min.)

The purpose of this exercise is to explore how the inclusion of people with psychosocial, intellectual and cognitive disabilities in their communities can be encouraged.

Ask the group the following questions:

Can you give examples of some activities and roles that people with psychosocial, intellectual and cognitive disabilities undertake in the community?

Possible answers include:

- Be in paid employment or other income generating activities
- Participate in educational activities; go to school, college, university, or engage in other forms of skills-based learning and professional courses.
- Vote during elections
- Stand for elections
- Have a family life, marry, have children
- Engage in recreational activities such as going to the movies, going to the park etc.
- Make important decisions for the household, such as managing the finances, etc.
- Undertake household activities such as cooking, going to the market, looking after the children
- Participate in advocacy organisations and/or campaigns
- Establish and/or participate in peer support groups
- Participate in vocational training activities

- Attend functions/ events in the community such as festivals, religious events, etc.
- Participate in family events, gatherings and occasions such as weddings etc.
- Support others in similar situations
- Become role models for others
- Any other activity…

Once this question has been discussed, ask the group:

- How could different actors, including service staff, family members, people with psychosocial, intellectual and cognitive disabilities or others, encourage and facilitate engagement in the local community and community life?

Remind participants that "staff" in a mental health and related service may include a wide range of people, not only psychiatrists and mental health nurses. It may include, for example, peer workers, social workers, occupational therapists, cleaning staff, attendants and so on.

Encourage the participants to consider:

- How could staff, family and others support people to gain employment, education or vocational training?
  - E.g. create links and liaise with employment services, employers, income generating NGOs etc. as well as schools, universities, and vocational training services. Educate relevant persons in the employment and education sector about mental health and human rights issues

- How could people be supported and assisted to find a place to live in their communities?
  - E.g. create links and liaise with housing services. Organise and accompany service users to visit potential accommodation options in the community. Provide people with administrative, emotional or other support in moving and settling into new housing/living arrangements.

- How could people encouraged and assisted to take part in a variety of activities of their liking in the community? How could people be supported to develop social interests in the community, such as attending local festivities or visiting places of worship if they so choose?
  - E.g. Keep abreast of current events and activities in the community. Establish links and liaise with people or organizations providing cultural, religious, social and other services in the community. Ask people what activities they enjoy and facilitate their access to these activities.

Having heard the different opinions, ask the group the following questions:

- Do you think that people using this service are able to enjoy the right to live independently in the community?

- What does the service <u>do</u> to support people to live independently and be involved and included in the community?

- What does the service fail to do, to encourage and promote independent community living?

Follow this discussion with the following questions:

- What more can be done by staff, families and others to make sure people are more engaged in community life while they are staying in an inpatient mental health and related service and after their stay?

- What more can be done to promote and empower people residing in inpatient or residential mental health and related services to transition towards living an independent life in the community?

This is an opportunity for the group to draw up an action plan on how to improve the situation. It may include recommendations and advocacy for new services which are community based and have a 'home-like' environment.

Concluding the session (5 min.)

Ask participants if they need any clarification or wish to ask further questions.

Then ask participants:

What are the three key points that you have learned from this training session?

Once participants have had the time to provide answers, show these take home messages:

- People with psychosocial, intellectual and cognitive disabilities have the right to an adequate standard of living.
- People with psychosocial, intellectual and cognitive disabilities have the right to live independently in the community and to make choices about their lives.
- People with psychosocial, intellectual and cognitive disabilities have the right to participate in their community including, social, public and political life.

Reflective exercise (5 min.)

Ask participants the following:

Now we have explored how people can live independently and get involved in their community:

- How does independent living and active involvement within your community benefit your life?
- How would you feel if you could not live independently and/or be involved in your community?

Annex 1: The WHO QualityRights toolkit standards (2)

1.1 The building is in good physical condition

A building in good physical condition is necessary to create an environment where people can be and feel safe and comfortable.

- The building is in a good state of repair (e.g. windows are not broken, paint is not peeling from the walls).
- The building is accessible for people with physical disabilities.
- The building's lighting (artificial and natural), heating and ventilation provide a comfortable living environment.
- Measures are in place to protect people against injury through fire.

1.2 The sleeping conditions of service users are comfortable and allow sufficient privacy

Sleep is an essential part of everyday life and is essential to good physical and mental health. Often this is one of the most neglected aspects of life in inpatient mental health or related services where there is overcrowding and where privacy is limited.

- The sleeping quarters provide sufficient living space per service user and are not overcrowded.
- Men and women as well as children and older persons have separate sleeping quarters.
- Service users are free to choose when to get up and when to go to bed.
- The sleeping quarters allow for the privacy of service users.
- Sufficient numbers of clean blankets and beddings are available to service users.
- Service users can keep personal belongings and have adequate lockable space to store them.

1.3 The facility meets hygiene and sanitary requirements

Just like homes in the community, inpatient mental health or related services must be clean and healthy environments. This allows people to feel comfortable and means that their health is not being put at risk.

- The bathing and toilet facilities are clean and working properly.
- The bathing and toilet facilities allow privacy, and there are separate facilities for men and women.
- Service users have regular access to bathing and toilet facilities.
- The bathing and toileting needs of service users who are bedridden or who have impaired mobility or other physical disabilities are accommodated.

1.4 Service users are given food, safe drinking-water and clothing that meet their needs and preferences

Good quality food, water and clothing are all basic requirements for good physical and mental health.

- Food and safe drinking-water are available in sufficient quantities, are of good quality and meet with the service user's cultural preferences and physical health requirements.
- Food is prepared and served under satisfactory conditions, and eating areas are culturally appropriate and reflect the eating arrangement in the community.
- Service users can wear their own clothing and shoes (day wear and night wear).

- When service users do not have their own clothing, good-quality clothing is provided that meets their cultural preferences and is suitable for the climate.

1.5 Service users can communicate freely, and their right to privacy is respected.

It is essential that people feel comfortable to speak and communicate freely and privately. Often people staying in mental health or related services lose these rights.

- Telephones, letters, e-mails and the Internet are freely available to service users, without censorship.
- Service users' privacy in communications is respected.
- Service users can communicate in the language of their choice, and the facility provides support (e.g. translators) to ensure that the service users can express their needs.
- Service users can receive visitors, choose who they want to see and participate in visits at any reasonable time.
- Service users can move freely around the facility.

1.6 The facility provides a welcoming, comfortable, stimulating environment conducive to active participation and interaction.

Interaction with other service users, visitors and staff has a therapeutic benefit and supports recovery, as well as being an essential part of everyday life.

- There are ample furnishings, and they are comfortable and in good condition.
- The layout of the facility is conducive to interaction between and among service users, staff and visitors.
- The necessary resources, including equipment, are provided by the facility to ensure that service users have opportunities to interact and participate in leisure activities.
- Rooms within the facility are specifically designated as leisure areas for service users.

1.7 Service users can enjoy fulfilling social and personal lives and remain engaged in community life and activities.

The social and personal life of every person using mental health or related services should be maintained and they should remain engaged in community life and activities.

- Service users can interact with other service users, including members of the opposite sex.
- Personal requests, such as to attend weddings or funerals, are facilitated by staff.
- A range of regularly scheduled, organized activities are offered in both the facility and the community that are relevant and age-appropriate.
- Staff provide information to service users about activities in the community and facilitate their access to those activities.
- Staff facilitate service users' access to entertainment outside the facility, and entertainment from the community is brought into the facility.

References

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

2. World Health Organization (WHO). WHO QualityRights tool kit to assess and improve quality and human rights in mental health and social care facilities [online publication]. Geneva; WHO; 2012. (Available from: http://apps.who.int/iris/bitstream/10665/70927/3/9789241548410_eng.pdf?ua=1, accessed 2 February 2017).

3. United Nations Human Rights Council (UNHRC). Thematic study on the right of persons with disabilities to live independently and be included in the community. Report of the Office of the United Nations High Commissioner for Human Rights, A/HRC/28/37, 12 December 2014 [UN Report]. Geneva; United Nations (UN) General Assembly; 2014. (Available from: http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session28/Pages/ListReports.aspx, accessed 2 February 2017).

4. World Health Organization (WHO) Country Office in Albania. Back Home: A supported mental health residence in Cerrik, Albania [video]. Tirana; WHO; 2015. (Available from: https://www.youtube.com/watch?v=bnRtk5DjDr4, accessed 2 February 2017).