



Toolkit:

Co-Creating in Mental Health

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Disclaimer

These materials are intended to assist any stakeholder – individuals and organisations - as they strive to co-create in mental health. The use of these materials should include a formal acknowledgement to the source.

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What is the <u>purpose</u> of this Toolkit and how to use it

Introduction

The aim of Mental Health Europe (MHE) Toolkit Co-creating in Mental Health is to provide a variety of stakeholders in the field of mental health and psychosocial disabilities with a framework that includes both the theory and practice of implementing a co-creation approach in mental health. This framework is shaped according to MHE vision, values and approach that are primarily based on human rights and the psychosocial model of mental health.

Whether you are a person with lived experience, a practitioner, an academic, a charity, a policy or decision-maker or other type of stakeholder wishing to engage in co-creation in mental health, this toolkit provides an overview of what co-creation is, its benefits and advantages to all actors in mental health and practical tools for working in co-creation.

Through a set of principles that underpins co-creation activities, a methodology for facilitating training on co-creation and several tools for planning and evaluating co-creation, the toolkit will guide stakeholders in creating an environment conducive to successful and impactful co-creation. The toolkit can be used in many different contexts. It can for instance support policies' development, re-thinking services, planning an awareness campaign, producing an education manual, organising a training. Whatever the activity or project, it is always possible to do it in co-creation provided the commitment and investment are there.

As rewarding as co-creation is in terms of results and ownership, it also presents challenges and issues to consider. The toolkit is meant to help its users understand what the implications of working in co-creation are, identify potential problems, prevent or address them, think of the practical aspects and plan accordingly.

The toolkit content was developed by MHE Co-creation Task Force consisting of members with diverse profiles: persons with lived experience, service users, advocates, practitioners, academics, service providers. It was developed building on available resources and literature and the experience and expertise of co-creation within MHE.

The toolkit is a living document; it will be reviewed and updated over time building on learning and knowledge generated through the implementation of co-creation activities by MHE, its members and other stakeholders at country, regional and European level.



MHE Co-Creation Approach

2.1 Why is co-creation in mental health important?

There are two fundamental reasons that make of co-creation an important approach in the area of mental health: the first one is linked to human rights and the second to the benefits it brings in terms of results, impact and ownership of those.

The human rights perspective

The right to participation is the basic and fundamental right of people to have a say in how decisions that affect their lives are made. Political and public participation is a cornerstone of every democratic system. There are also participation frameworks and instruments for other contexts and for specific groups, e.g. several provisions in the Convention on the Rights of the Child are about children's participation. Article 4 of the 1978 Declaration of Alma-Ata on Primary Health Care states that "people have the right and duty to participate individually and collectively in the planning and implementation of their health care."

When it comes to mental health and participation, it is primarily about the right to participation of people with mental health problems and psychosocial disabilities that we naturally focus on without forgetting their supporters¹.

The full and effective participation and social inclusion of people with mental health problems and psychosocial disabilities is primarily reflected in the general principles of the United Nations Convention on Rights of Persons with Disabilities (UNCRPD). This principle is intrinsically connected with other human rights in the applicable international law; of particular interest for this toolkit are those of equality and non-discrimination and participating in political and public life. The UNCRPD Committee recognizes that the active and meaningful involvement of persons with disabilities resulted in achieving a ground-breaking human rights treaty and established the human rights model of disability. Consequently, international human rights law now recognizes unequivocally persons with disabilities as "subjects" of all human rights and fundamental freedoms and demands their meaningful participation in all the processes concerning them. The notion "Nothing about us, without us" is now a cornerstone of international human rights law.

Co-creation holds the participation and empowerment of people with lived experience as its pillar. It does however go further affirming the principle that also other actors playing a role in mental health need

Supporters are people who provide support – emotional and/or practical – to someone who is experiencing a mental health problem. Supporters can be family members, friends, neighbours, colleagues at work, teachers or others. Some organisations also call professionals who support people with mental health problems 'supporters' and distinguish between 'formal' and 'informal' supporters. MHE Glossary "Mental Health – the power of language"

to participate and be empowered to work not only with experts by experience, but also with each other.

Evidence on benefits

Co-creation provides a range of benefits to all concerned (Social Care Institute for Excellence 2015). These benefits come from a macro or organisational level and a micro or personal level. Additionally, some benefits can impact both.

Advantages to the Person

Co-creation has many advantages for the individual (Boyaird and Loeffler 2013). For example, co-creation supports the personal growth of the individual, as well as supporting them to reach their career goals despite the presence of mental health problems (Boyle et al. 2006; Salisbury 2020). Co-creation is a mechanism by which service users are appreciated and valued within mental health services (Brudney and England 1983; NHS England 2015). Alford (2014) suggests that there are multiple motivators for engagement in co-creation which are altruistic in nature. Beebeejaun et al. (2013) suggests that these altruistic benefits occur due to the use of experiential knowledge to create new knowledge that can inadvertently cause positive social change. This not only empowers and provides confidence to service users, but it also supports individuals to rewrite and successfully navigate their own recovery journey (Spencer et al. 2013; Ewert and Evers 2014; Thorneycroft and Dobel-Ober 2015; Fisher et al. 2018; Norton 2021). Other advantages of co-creation from a person's perspective includes improved health outcomes and increased mental health literacy (Piper & Emmanuel n.d.). Such literacy also relates to staff who must also learn how to successfully communicate with service users, something which co-creation can help to improve (Jones et al. 2020). Finally within relationships, co-creation allows everyone to remove the labels attached to them so that all are welcome at the table (Ewert and Evers 2014; NHS England 2015). This is supported also by the conclusions of The Lancet Report on Reducing Stigma and Discrimination that states that the involvement of people with lived experience reduces stigma and discrimination².

Advantages to the Organisation

CCo-creation also benefits the organisation it is being implemented in. Firstly, co-creation is flexible/fluid. Academically, such fluidity is represented through the lack of a universally acceptable definition for the term. This lack of a clear definition can also be advantageous as such fluidity allows for multiple opportunities to arise. Other advantages of co-

creation from an organisation perspective are observed through hospital admission statistics. Spencer et al. (2013) identified a 30% reduction in emergency presentations and a 50% decrease in hospital admissions as a direct result of co-creative activity. In this way, co-creation has been noted to improve service delivery which inadvertently improves service outcomes (OECD 2011). This is possible as co-creation transforms the therapeutic relationship so that it is more user inclusive thus providing ownership of one's recovery journey (Pestoff 2013). In this way, co-creation is a mechanism by which power is passed from service provider to user (Bovaird and Downe 2008; Spencer et al. 2013; Beresford et al. 2021).

Dual Benefits

Additional to the above, there are some benefits that apply to both the organisation and those within it. Co-creation is inclusive of all contributions made within mental health service provision (Bovaird and Loeffler 2013). It is through such contributions that service users can better understand the strengths, limitations, and functions of the system (Locke and Schweiger 1979; Hsu et al. 2012). Through this, service users can better vocalise their needs to services (Hsu et al. 2012). Additionally, co-creation allows staff to become more engaged in their work (Marks 2008), which increases job satisfaction (Spencer et al. 2013). This inclusivity arises from co-creation's ability to create a safe space where they can freely express themselves and their difficulties (Norton 2021). This has the advantage of providing insight into gaps in medical knowledge, health care needs and service improvement that would otherwise not have been filled (Filipe et al. 2017). Interestingly, co-creation also has economic and recovery benefits (Department of Health 2006). Finally, co-creation enhances the learning experiences for all concerned. This is illustrated in recovery colleges where co-creation forms an essential aspect of the design, delivery and evaluation of recovery programmes (Hopkins et al. 2018).

Advantages to the Health Care System

The co-creation process enables the development of customised solutions for the healthcare system (Stock, C., Dias, S., Dietrich, T., Frahsa, A., & Keygnaert, I. 2021). No standardised procedures can be used optimally to adapt new care services to the needs and lived experiences of people as well as to the increasing demands of healthcare institutions in a flexible and effective way.

The involvement of decision-makers, health professionals and health institutions in the development phase is the decisive advantage. This collaborative adaptation of methods, processes and solutions to the health system, orientation towards lived experience, continuous focus

on needs, linking of thought and work processes as well as testing for practicality under real-life conditions allow for improved implementation of services (Dias et al. 2021; Choi et al. 2021; Onasanya et al. 2021). This ultimately benefits the health system and society.

2.2 What do we mean by co-creation?

Co-creation is relatively a new term compared to the more known and used 'coproduction'. Coproduction concepts and related definitions started appearing in the literature as far as 1977 in relation to goods and services in general as well as more specifically with regard to public services and also healthcare. With time the concept has been enriched with principles, values and other criteria to define different types or levels. According to the literature co-creation is a component of the broader concept of coproduction.

Due to this diversity of definitions and frameworks and to the lack of one capturing Mental Health Europe's vision of co-creation, MHE has endeavoured to develop its own definition and framework. Very importantly, this work falls within MHE's overall approach of promoting positive and empowering language and communication on mental health.



Mental Health Europe's definition of co-creation

A collaborative approach involving all actors in mental health working together on an equal basis to develop and implement policies, services, programmes and communication that foster positive mental health according to a psychosocial model and human rights-based approach.

2.3 Principles of co-creation

MHE's definition of co-creation is underpinned by seven principles.

1	Inclusivity	Co-creation is representative of all groups having a stake and ensures diversity
2	Equality	Everyone's perspective is acknowledged as essential and valued, and each participant brings their own experience, expertise, skills and insights
3	Respect	Due regard is paid to working together and communicating in a respectful and constructive manner
4	Reciprocity	Reciprocity is a genuine sharing of thoughts, feelings, and experiences between a group where mutual learning occurs, and shared meanings develop
5	Power-sharing	Sharing of power recognises different areas of expertise resulting in democratic shared ownership of decisions
6	Accessibility	Everyone involved has equal opportunities to participate and contribute to the process
7	Transparency	The whole process is jointly and clearly outlined and understood

2.4 Translating principles into practice

In this section you will find suggestions and tips on how to put the principles outlined above into practice and create an environment that is conducive to co-creation.

- Inclusive mapping of stakeholders Stakeholders' mapping is a common practice in many contexts, however the way the mapping is approached could influence the process in very different ways. Consider:
 - Think out of the box there may be stakeholders you have not considered to involve for many reasons: e.g. you may believe they have no role to play in what you plan to do, or you do not know where to find them, or you need to broaden your perspective on the project / service beyond the mental health area. It is important to be mindful there are different perspectives; you could: ask several people to contribute to the mapping, get inspiration from similar initiatives, put out a call for expression of interest (you may get surprised by the return!);
 - Keep diversity in mind whatever you do in co-creation you have to bear in mind that the results will have to meet the needs of your targeted beneficiaries, and that these will include people with diverse needs and coming from diverse backgrounds. Think of different types of lived experience of mental health problems, their family and supporters, service providers, community members, age, gender, socio-economic background, religion, etc. and the interconnection between these and the project / service. Make sure that your co-creation approach is as inclusive as possible from the start.
- 2. When liaising with stakeholder to engage them in the co-creation activity check what they need to be enabled to fully participate.
- 3. Make sure you have the necessary resources to co-create properly based on the needs you assessed: time, human resources, finances, venues, etc. Factor in that some flexibility will be needed because co-creation can be a bit messy and time consuming, but the result will be worth it! Be transparent about the resources allocation, particularly if funding is involved.
- 4. Identify what expertise, experience, skills and knowledge every participant brings and where they can contribute most effectively.
- 5. Inform participants about what co-creation is and how it works.

- 6. Jointly identify and agree on the focus and expected outcome of the piece of work to be done in co-creation. Where a piece of work is somehow already defined (e.g. a strategy) agree on how co-creation can be applied within the existing framework.
- 7. Establish a group agreement on how you will be working together, this should include:
 - Agreement on elements that create a safe environment for everyone;
 - A plan for managing the communication between participants and strategies for addressing challenges to participate that some people may face;
 - A process for managing conflict;
 - · Agreement about how decisions will be reached.

You should check/review the group agreement regularly and adapt as needed. It could for instance be done at the beginning of every meeting as a group or people could send written suggestions individually (this may be a more comfortable option for some).

8. Outline an action plan describing the steps of your co-created activity so that everybody is clear about the process, but keep it simple and, obviously do it in co-creation too. Acknowledge that in reality not everybody may be able to contribute to each single step and that this is accepted by all as long as outcomes are shared with everybody. If funding is involved in the project, be transparent about the budget allocation.

Having an action plan should not lead however to a too rigid and formal process. After all co-creation is about "creating" together, so leave space for creativity, out-of-the box ideas and informality.

- 9. Co-create the evaluation plan and tools to be used for checking whether your way of working is in line with the co-creation approach.
- 10. Provide information and documents related to the activity/project in a friendly format for everyone involved. If the language used is too technical for instance or only in one language not everyone will have the same opportunity to contribute.
- 11. Be mindful of participants with diverse needs; e.g. need for signs interpretation.

- 12. Plan tasks and activities according to everyone's professional and personal circumstances, e.g. should some meetings be planned during the weekend to enable participation of those who are involved on a voluntary basis and cannot take time off their week job?
- 13. Pay attention to practical aspects if a meeting is online does everyone can and know how to join and participate? If it is face-to-face, is the venue easy to access via different transport means?
- 14. Find ways to value and acknowledge both formally and informally the contribution that everyone involved has made.



Facilitating training on co-creation

3.1 Setting objectives and learning outcomes

Co-creation – A new priority in MHE Strategic Plan 2022-2025

MHE identified co-creation as one of its new strategic priorities for the period 2022-2025. The development of this toolkit aims at contributing to the objective of "increasing co-creation in policy and services development, implementation, and evaluation across the European region".

The objectives of a training programme on co-creation should be framed with that strategic objective in mind.

For anyone interested in undertaking this training, we recommend setting the following objectives for the training:

Overall aim

To increase Knowledge, Skills and Confidence for putting co-creation into practice

Objectives

- 1. Improve understanding of what co-creation is and why it should be applied
- 2. Learn about MHE's co-creation approach
- 3. Strengthen skills for translating theory of co-creation into practice.

In line with a true co-creation approach, prior to facilitating training ask participants about:

- Their pre-existing knowledge and experience of co-creation;
- Their expectations of the training;
- Any specific barriers they face in their work context in relation to cocreation;
- What specific aspects of co-creation they wish to learn about;
- A couple of ideas for an activity they will implement in co-creation following the training.

The template in Tool 1 can be adapted and sent to participants prior to the training.

Tool 1 - Training needs' assessment template

Understanding your training needs for co-creation in mental health

Please answer the following questions to help us shape the training programme for you:

- **Q1.** Do you have any prior experience with/knowledge of cocreation? Please provide details.
- **Q2.** What are your expectations regarding the training?
- Q3. Describe any barriers you have been facing in working with a co-creation approach
- **Q4.** Is there anything specific you would like to be addressed during the training?
- **Q5.** Let us know about any need/requirement that will help making this training a positive experience for you (e.g. allocating several breaks; organising it during the weekend, etc.).
- **Q6.** Please describe a couple of ideas for an activity you will implement in co-creation as a follow up to the training.

3.2 Training plan and methodology

Tool 1 - Training programme - Annotated version for training Facilitators

This agenda version is meant for the training facilitators. Participants may receive the same but without the part related to methodology.

Facilitators should address all of the topics; the methods may be adapted as long as they provide similar dynamics and results.

We recommend holding the training with approximately 12-15 people. Should you have more participants, make sure there are no more than five people in the group work settings.

The duration of the training should ideally be one and a half days and, in any case not shorter than one day. The following training plan is meant for one day and a half; coffee and lunch breaks are not indicated but should be foreseen.

Topic	Objectives	Methodology
1. Welcome, Introductions & Setting the Scene (45 mins) 1.1 Participants' introductions	Participants get to know each other Participants are clear about what will be achieved	1.1 You can ask participants to say a) who they are b) what they do and c) one characteristic they have that can help them to work in co-creation. Depending on your audience there are different ways in which you can run this part. You can find some examples and tips for icebreakers here, here and here.
1.2 Training objectives & Expectations 1.3 Group Agreement	Group Agreement to work together in a constructive and respectful way are agreed	1.2 Show a slide summarising the input received through the training needs' analysis (tool 1) / If there are expectations that do not fit the purpose of the training clarify that these can be put in what you will call the "garden of ideas" as they do not relate to this specific training / Show a slide with the objectives set for the training
		1.3 Give participants a couple of A4 sheets and ask them to write one item for the group agreement in each and stick the sheets on the wall / Once done read them out, make adjustments if and as needed and get the group to agree to those terms.
		As the training facilitator you can have a few things already on your notes to suggest if the group finds it difficult to come up with ideas. This usually gets the conversations going. It is really important that participants understand the importance of the group agreement and how it may be revisited as the training progresses.

Topic	Objectives	Methodology
2. Co creation: What and Why (60 minutes)	Participants explore their understanding of co-creation	2.1 Give participants a flipchart paper and ask them to individually create their vision of co-creation (this can be in words or pictures) / Ask them to share it with the whole group / Facilitators summarise the common elements at the end on a separate flip chart sheet
creation 2.2 Discussion about	background on the history of co-creation	Separate rip chart sinest 2.2 With 2-3 slides give an overview of existing co-creation frameworks (from the literature) – this may have to be shorter
the Benefits of and Barriers to co-creation	Participants understand the benefits of co-creation and the barriers	or longer depending on circumstances (e.g. participants' prior knowledge, requests from the training needs' assessment, their role in co-creation)
		2.3 Split participants in 2-3 groups and ask them to go through the benefits and barriers pre-identified through the training needs' analysis (have this ready on a slide to show participants or give them on paper version) and then using a flipchart paper ask them to a) add anything they think is missing and b) mark the items they have direct experience of and also the ones they consider a priority/ Each group feeds back in plenary / Facilitators sum up and relate it to key features of MHE's approach on benefits and barriers, particularly the human rights' perspective.

Topic	Objectives	Methodology
3. MHE's co-creation approach (90 minutes)	Participants learn about MHE's approach to co-creation	3.1 In a couple of slides show the definition & principles / ask participants feedback and compare with outcome of the group work in session 2.1
3.1 Definition & Principles	Participants practice skills and learning	3.2 Split participants in 2-3 groups and ask them to work with the flipcharts from session 2.3 and to identify actions to address the barriers / Each group feeds back in plenary
theory to practice		3.3 Implement 2 role plays to enact potential dynamics in a co-creation activity - see details of the methodology and some examples of role plays in section 3.3 of the toolkit
		3.4 Facilitators present some slides on section 2.4 of the toolkit
4. Learning from others(60 minutes)4.1 Case studies	Participants practice skills and learning	4.1 Divide participants in 2-3 groups and ask each to review the case study you will give them on paper / They should identify what worked well and what were the shortcomings of the case study / Each group feeds back in plenary and facilitators encourage discussions on ways to address shortcomings identified

5. Evaluating co-	Participants learn how	5.1 Split participants in 2-3 groups and ask them to write on a
creation (45 minutes)	to evaluate co-creation	flipchart paper a) 2 objectives of the evaluation, b) 2 key items
(42)		(20 minutes)/ Ask each group to present that in plenary / Show
5.1 Evaluation plan		on some slides the outline of the toolkit evaluation plan and
5.2 Evaluation indicators		
6. Preparing the post-training (60 minutes)	Participants go home with an action plan to further put in practice	6.1 Give participants an A4 sheet with a template for them to fill in and define who they will involve in the info-session, what they will present and the timeline
6.1 Info-session for colleagues (2-3 hours)	tne learning acquired	6.2 Facilitators will have asked participants to arrive to the training with an idea about an activity to implement back
6.2 Implementing an activity in co-creation		nome / Give participants an A4 sneet with a template for them to describe an action plan. Questions and concerns arising from the action plan are discussed in plenary.
		Facilitators make copies of all these documents.
7. Next steps & Closing (30 minutes)	Participants agree on next steps and provide feedback on training	7.1 The group agrees on a date to meet online to share their experience of implementing an activity in co-creation after the training
7.1 Online post-training session		7.2 For immediate feedback send participants a Slido (www.
7.2 Evaluating the training		feedback on a screen. For more comprehensive feedback send them the form provided in section 3.5 of the toolkit.

3.3 Role-plays

Role-playing is the act of portraying the character and behaviour of someone who is different from us in a specific role and situation. In other terms, in a role-play people play certain roles without a script, and in a situation and setting determined by the role-play facilitator. Role-play involves two or more people who act out how a conversation would look and sound among actual people in an actual situation.

The benefit of recreating real situations through scenarios that include "problematic" elements is that participants are given the opportunity to see the situation from perspectives other than their own. Furthermore, the 'experiencing' aspect makes of role-play an effective method to learn and gain skills.

In a training setting the participants and the facilitators have an opportunity to see difficulties that may arise in dealing with a particular situation and can then explore alternative ways of addressing them and evaluate how effective the approaches played out during the role-play were.

The toolkit proposes a few scenarios that can be used as they are or that can be adapted. Facilitators may as well want to outline and propose different scenarios in the training sessions. To get the most from a role-play the proposed scenarios should be as close to reality as possible and there should be a specific objective behind the scenario, e.g. solving a conflict, finding a solution to a problem, practicing a specific skill.

Steps to conduct a role-play

- Describe the scenario Describe to the participants the scenario that will be played, but do not give too many details, in particular about the 'problematic' situation that is going to be represented. In this way participants are not influenced by the explanation and will be more attentive and observing of what happens and doing their own analysis of the interaction.
- 2. Assign roles Once you have established a scenario, assign roles to participants for the various fictional characters involved in the role-play. As a role-play should last a maximum of 10 minutes it is preferable to involve a maximum of five participants; the rest of the group will watch the performance and provide feedback at the end.
- 3. Have participants act out the scenario Whereas some participants will enjoy getting into the role and improvising, for others it may feel awkward. It is good to propose participants to volunteer for this.

Another thing that can help is to leave a few minutes to participants to prepare and give each of them a card prepared in advance with more details about their specific role (details should not be shared with others though). At this stage facilitators should refrain from intervening unless some participant is feeling uncomfortable. Even if the play may not be going as planned, there is always some lesson to be learned.

4. Provide feedback – Once the role play is over it is important to get feedback, possibly from everyone. Facilitators may ask individual roleplayers why they acted in a certain way or made a specific statement; it is also helpful to ask them how they felt throughout the play and what made them feel/experience certain emotions/attitudes. Feedback should be sought also from participants who watched the play; would have they done something differently and why? Finally, facilitators should discuss the dynamics and summarise a few lessons learned from the exercise.

Tool 3 – Role-play scenarios

Role-play 1: Peer support

Setting: a meeting at hospital X with representatives of the mental health service (the head of the service and a psychiatrist), the local mental health association and persons with lived experience. Purpose: The purpose of the meeting is to start discussions for having peer support included in the service. The mental health association has initiated the contact with the mental health service. Problematic aspect/s to be shared only with participants acting the role play; each participant should receive only the card specific to their own role with the following description:

Card 1 - The psychiatrist: you are not in favour of peer support and you are attending only because the head of the service made you Card 2 - Person with lived experience: you are very annoyed by the attitude of the psychiatrist

Card 3 - Head of the mental health service: you are quite interested in discussing peer support and you have an open mind about it Card 4 - Representative of the mental health association: you are eager to leave the meeting with some positive outcome so as to be able to continue discussing this project.

Role-play 2: Mental health reform

Setting: a meeting at the Ministry of Health involving representatives from the ministry, psychiatrists, mental health associations, families' associations, hospitals, psychologists.

Purpose: The purpose of the meeting is to discuss the mental health reform that is being planned for the country.

Problematic aspect/s to be shared only with participants acting the role play; each participant should receive only the card specific to their own role with the following description:

Card 1 - Advisor to the Minister of Health (MoH): this meeting has been organised simply to show that stakeholders were consulted; in reality the Ministry already has well defined plans for the reform and is not very open to significant changes. You try to keep everyone in the meeting happy without committing to anything or giving concrete replies

Card 2 - Representative of the mental health association: you know that several consultation meetings have already taken place before this one and that mental health associations were not invited. You complain about the lack of transparency and the tokenistic approach and want reassurance that your recommendations are going to be taken into consideration

Card 3 - Hospital representative: you tend to 'dominate' the discussion and focus on the need for more hospital beds and funds for infrastructure to respond to the increase demand on mental health services. You interrupt several times the representatives of the mental health and families associations and the psychologist Card 4 - Representative of the families' association: you have never participated to this kind of meeting and you feel unprepared and unsecure. You try to take the floor a couple of times but you soon give up and remain silent for the rest of the meeting Card 5 - Psychologist: you believe that a holistic approach to mental health requires involving stakeholders in other sectors: social policy and services, education, employment, etc. You are keen to understand form the MoH Advisor if they are going to involve these sectors in the reform, but you do not get clear answers and have the impression that the Advisor is not interested in your opinion.

Role-play 3

Setting: a meeting organised by a national mental health association and involving representatives of its membership: service providers, NGOs, individual advocates, academia.

Purpose: The purpose of the meeting is to agree on the communication campaign messages for World Mental Health Day; the focus of the campaign is migration. The Communications Officer of the mental health association secretariat has sent participants some draft messages before the meeting.

Card 1 - Communications Officer of the mental health association secretariat: you lead this campaign and your objective is to leave

the meeting with an agreement on the three key messages. Card 2 - Service provider: you are on call and need to leave the meeting after a couple of minutes to go back to work. The meeting date and timing should have been agreed with all participants. Card 3 - NGO representative: you believe the focus of the campaign should have been young people, so you are not too happy about the fact that the topic has already been chosen and that draft messages were already proposed. You think membership should have been involved much earlier in the process. Card 4 – Person with lived experience: you have no perspective on this topic and you feel like you cannot contribute. The mental health association should have involved someone with a migrant background.

3.4 Case Studies

Reviewing some case studies from real experience of co-creation work will help participants to the training understand how the theoretical elements of MHE's co-creation approach may be applied in practice.

The case studies have been taken from real examples but adapted and anonymised for training purposes; they are examples to be used to gauge the extent participants have understood the principles of co-creation.

Each group will have a separate case study to review. Ask them to identify the following:

- · What were the elements that facilitated a successful co-creation?
- What where the elements that were missing and/or could have been improved to lead to a successful co-creation?
- What could have been done differently?

Co-creation Case Study 1 - Festival "Arts for Wellbeing"

This was initiated by NGO X working on mental health to develop a week-long festival to promote the benefits of arts for wellbeing. A group of people came together which included NGO X staff, local community groups' representatives, artists and local authorities.

A kick off session was held to agree on the aim and objectives, as well as people to be involved. An initial project plan and time line was developed. Agreements were made on meetings time and frequency.

While the project management process was pre-defined to an extent, it was flexible, allowing for learning and change along the way. Work was distributed between members and it was agreed upon who would take on specific roles. Everyone's knowledge and opinions were taken into consideration and peoples' skills were exercised/executed in this activity. From an initial group of 12 people managing the plans, 9 remained towards the end of the project.

As per the agreement with the group, along the way corrections and adjustments were made. The perspective of people with lived experience was carried on throughout the entire project, developing an actual aim for the festival. Just as well, lived experience was used in all decisions, including how the results of the festival will be promoted afterwards.

In this co-creation activity, almost everyone received compensation for their time and contributions.

Co-creation Case Study 2 – Integrating experts by experience into academic teaching

This was initiated by University X to integrate the experience of people with mental health problems in BSc and MSc degree programmes such as nursing, physiotherapy and medicine, by redesigning teaching modules and having experts by experience as educators. Individual institutions in country X have single teaching assignments through persons with lived experience.

At University X however, persons with lived experience have the competences to design their curriculum themselves and are part of the team as other educators are. Therefore, they contribute to defining the structures and development of the health department from their perspective.

For this purpose, at first a group of students, lecturers, Professors and researchers of the University X, experts from the clinical field of mental health, experts in technology development, experts for methodological design, and cantonal representatives was established. Before the first meeting representatives of University X conducted a literature review and a survey among different mental health institutions in the country to assess demands towards education of future students. Those results were presented during the first meeting and used as discussion baseline.

To understand each one's perspective and needs during the meeting an empathy map was used for empathetic target group analysis. It was used it to identify feelings, thoughts, and attitudes of participant and understand their needs among them. As result of the first meeting, all participants summarize their key findings and inputted them on a pre-prepared document. During the second meeting the 6-3-5 method was briefly described and the goal explained. The project members were asked to creatively work on the question: "What is needed to implement persons with lived experience as lecturers in academic education"? using that method. The results were used as a basis for further discussion.

During the third meeting those results and subsequent questions were worked on together and solutions as well as alternatives were developed using a digital mind map. This provided guidance for all members on what they had to achieve before the last meeting. The fourth and last meeting was used to summarize the results of the process, and to discuss the findings using a SWOT analysis. It was decided to have persons with lived experience as educators with the support of the jointly developed framework conditions. After that, persons with lived experience developed according to their own assessment the forms of delivery of course content, further choosing of topics, setting learning objectives, and creating assessments for the students.

Co-creation Case Study 3 - Mental health reform

The Association for Mental Health in country X has applied cocreation in the process of a mental healthcare reform in the country. In each region of the country (with app. 700.000 citizens each), one coordinator with lived experience of mental health problems was hired to organize meetings with other people with lived experience and family members to map the needs of service users across the country. The meetings have been organized as group meetings, but some individually as well.

Meetings were structured according to a methodology by which they would be repeated with the same people and adding new participants - initially starting with people with lived experience and family members, later on inviting service providers, psychiatrists, psychologists, social workers, and representatives of the local municipality or a region etc.

The coordinators organizing the meetings were asking three basic questions:

- What are your needs?
- What does not work in the existing health care system on local level?
- How would you design a local mental health care system to fulfil all needs in the mental health area?

The coordinators were paid, the meetings' participants were volunteers. The coordinators had one manager for support and organizing. The coordinators have organized more than 200 meetings over nine months with thousands of people present.

At the end, all the data was analysed and presented to the government as recommendations for the healthcare system reform design.

The aim of using a cocreation approach for this work was not only to get the information on local levels but also to engage people with lived experience in designing the system and facilitate their participation within the system. The expected results were therefore not only to prepare the recommendations to the government but also to engage service users as drivers of recovery education later on.

3.5 Evaluating the training and follow up

Participants feedback at the closing of the training

It is always helpful to get immediate feedback from participants right at the end of the training. A quick and nice way to do this is via Slido, a tool to engage your participants with live polls, Q&A, quizzes: www.slido.com There are certainly other similar tools you may use instead of this one.

Participants feedback after the training

In order to get more qualitative feedback from participants it is recommended to send them a more comprehensive evaluation form with a majority of open-ended questions. Trainers should have printed copies to give out in case someone prefers that; otherwise the form below can be shared via an online tool like SurveyMonkey or Google forms.

Tool 5 - Training Feedback Form

- 1. Were the aim and objectives of the programme achieved for you? (Yes / No)
- 2. What are the key learning points on co-creation you got as a result of the training?
- 3. Which skills you acquired/strengthened to support your work in co-creation?
- 4. My Trainer/s was/were prepared and familiar with the programme (rate from strongly agree to strongly disagree)
- 5. On a scale of 1 10 how would you rate this training?
- 6. What was the highlight of the programme for you?
- 7. What could be improved?
- 8. What one change would you make to the programme?
- 9. Please add any other comments that can help us improve the training.



Tools for preparing to co-create

4.1 Stakeholders mapping - Who should be involved?

Stakeholders' mapping is a common practice in many contexts, however, to support a true co-creation approach from the onset it is important to map the stakeholder groups to be involved in co-creation having in mind diversity and inclusiveness.

Stakeholder mapping is the visual process of laying out all the stakeholders of a project, activity or product on one map. The main benefit of a stakeholder map is to get a visual representation of all the people/groups who will be impacted, who have a stake, who can contribute and to arrive at prioritising the stakeholders to be engaged in your co-creation process. In any co-creation process there will be internal and external stakeholders.

Internal stakeholders are people on your team/organisation. Their levels of engagement, influence and contribution may vary.

External stakeholders are those who will be impacted by the co-creation process and/or who have influence and should be included.

To identify all relevant stakeholders and prioritize them, one of the best ways to do that is to use a matrix to analyse these elements in relation to the project/activity you plan to implement in co-creation. In the spirit of MHE's vision of co-creation whereby all stakeholders in mental health shall be involved and work together on an equal basis, the stakeholder mapping will be structured slightly differently from other existing tools. The tool in this toolkit will help putting into practice the principle of inclusivity of MHE Co-creation Approach as well as securing the best chances of co-creating successfully and meeting the other principles too.

4.2 How to use the Stakeholder Mapping for co-creation in mental health

Step 1 - Brainstorming List all stakeholders that come to mind in relation to the work on co-creation you will be implementing. At this stage try to think of as many as possible

Step 2 - Prioritise Using the following criteria start prioritising them according to their level of readiness, influence and importance for the project in co-creation to be a success.

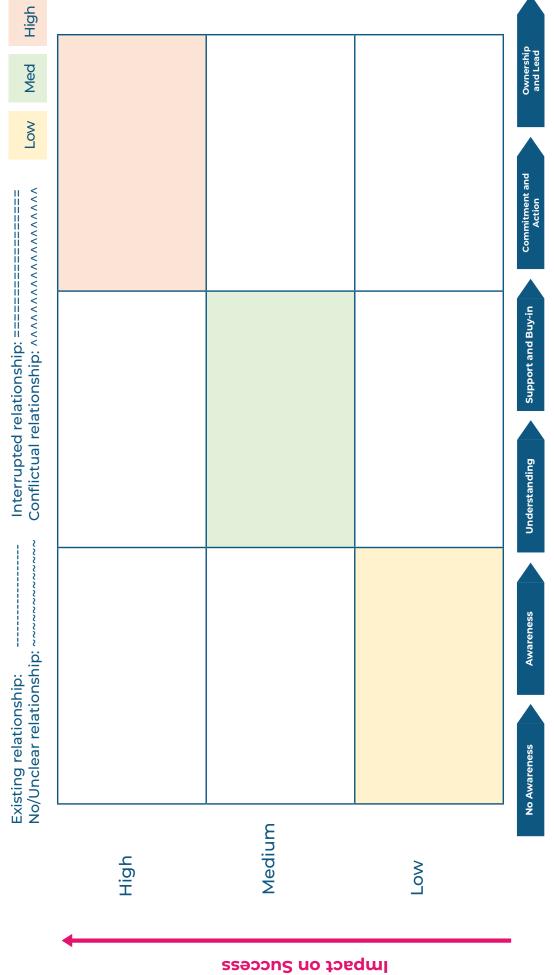
- Unaware:
- Awareness
- Understanding
- Support and Buy-in
- Commitment and Action
- Ownership and Lead

Step 3 – Relationships Stakeholders have certain relationships with each other. Use the stakeholder map to illustrate these relations. This will help you to see what stakeholders are connected, and to discover existing interactions, lack of synergies or potential challenging dynamics. Differentiate the link using the following lines (these can be adapted as needed):

Existing relationship:	
Interrupted relationship:	
No/Unclear relationship:	~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~
Conflictual relationship:	^^^^^^

Step 4 – Findings Once you have built your stakeholder map, it is time to analyse it. This analysis will help you understand which stakeholders are essential to get on board, the investment needed depending on their level of readiness, the existing synergies and the potential dynamics.

Tool 6 – Stakeholder Mapping for Co-creation in Mental Health



4.3 Participants needs assessment

After the stakeholder mapping you will have contacted the key stakeholders to engage them in the project in co-creation. Part of this conversation should be about what they need to be able to meaningfully participate and contribute. This could be done by asking them to fill out and send back the following form, but it would be preferable to go through it with them so that clarifications can be provided.

The result will be translated into Tool 8 – Checklist on resources requirements.

Tool 7 – Participants needs' assessment

Who (Organisation and/or individual)	What	When	Why

4.4 Resources requirements

In the preparatory phase of your work in co-creation it is important to assess what type of resources you need and also to secure them. A simple check list will be sufficient; make sure to update the list during the process should new needs arise.

Tool 8 – Checklist resources requirements

Type of Resource	Resource secured? (Yes/No/In progress) – Add comment
1. Human resources Who needs to be involved and who leads the process from the originator of the project / programme / service as well as from the others participating.	
2. Time When done properly co-creation may require time. It is important to define a realistic timeframe and to make sure that all those involved can commit to the required time investment.	
3. Finances Depending on the process you may need a budget for programme / project / service costs, meeting venues, travel, accommodation, design cost, printing costs, and compensation for participants.	
4. Diverse needs There may need specific things to be put in place. This could be in relation to accessibility – translation of documents, sign interpretation, helping people to use technologies like online meeting platforms – or enablers for participation, e.g. holding meetings during the weekend. The participants' needs assessment will have helped identifying them.	



Tools during co-creation

5.1 Co-creation Info session

The info session is the first meeting to be held with all the participants involved in the project. In this meeting agenda you will want to address the following items.

- 1. Introduction of participants Ask participants to not only say who they are and what they bring to the group, but also what their motivation to work in co-creation is and if they have any previous experience with that.
- 2. Working in co-creation This part is very important to set the scene. Go through what co-creation is, the benefits and challenges, the principles and the practicalities (Section 2).
- 3. Establishing the group agreement (Tool 9)
- 4. Focus and plans for the project Jointly agree on the focus and expected outcome of the piece of work to be done in co-creation. Sometimes you will be starting from a blank page and this part will be about brainstorming from scratch. In the cases where a piece of work is somehow already defined (e.g. a strategy) agree on how co-creation can be applied within the existing framework.
- 5. Reviewing of resources needed to make sure you can co-create (Tool 8)

 Take the opportunity to review the assessment done when engaging
 the stakeholders in the project and make adjustments. Be transparent
 about the resources allocation, particularly if funding is involved.
- 6. Outlining the action plan (Tool 10) Depending on how the meeting has been going and the dynamics within the group you may decide that this part should be left to a next meeting.

5.2 Group agreement - Co-creating a safe space

Whatever piece of work you will be doing in co-creation, it is important to ensure that all people engaged feel comfortable with the process and with the group's dynamics. This is particularly important in situations where there may be power imbalances - real or perceived - within the group.

- The best and easiest way to do this is by establishing a group agreement on how you will be working together, this should include:
- Agreement on elements that create a safe environment for everyone;
- A plan for managing the communication between participants and strategies for addressing challenges to participate that some people may face;
- · A process for managing conflict;
- Agreement about how decisions will be reached.

The agreement should be put in written and shall be checked and reviewed regularly and adapted as needed. This may for instance be done at the beginning of every meeting as a group or people could send written suggestions individually (this may be a more comfortable option for some).

Each group will define the content of the agreement, thus that will vary every time. The following is an example of items you may want to include in the agreement. They are defined bearing in mind the seven Principles of MHE's Co-creation Approach.

Tool 8 – Checklist resources requirements

We are all equal participants to this process and work

Everyone's opinions and contributions are valuable and valued

No idea or contribution is not good enough; we are here to cocreate!

We will actively listen to each other

We will respect opinions even if we don't all agree

We will interact in a respectful and constructive manner – both in written and oral communications

We will respect confidentiality when private matters are shared unless agreed otherwise

We will make our best to attend meetings and contribute in between meetings – we acknowledge that sometimes that won't be possible, and we will let the group know in advance

Documents in their different versions will be regularly shared and any change/contribution made will be visible in track changes

We will share the responsibility for drafting content and/or following up on actions we agreed

Decisions will be made by consensus; when that won't be possible the group will decide by majority. This relates to the process, content, logistics, etc.

What happens if the agreement is not respected?

The group should elect two people in charge of taking care of the group coordination. Naturally one of them will be from the organisation/entity who launched and leads the work done in co-creation.

If there are one-off cases a simple collective reminder (e.g. at the beginning of every meeting) of the terms of the agreement from the two people in charge should be sufficient.

However, in case of repeated breaches and, particularly in cases that undermine the safe space created – lack of respect, breaking confidentiality, aggressive attitudes, etc. – the two people in charge should discuss the situation with the individual/s in question bilaterally at first and, if needed with the entity they are representing. Should not be possible to resolve the situation positively, the group shall decide about the permanence of the individual/s in the group.

5.3 Action plan

It is important to outline an action plan describing the steps of your cocreated activity so that everybody is clear about the process, but keep it simple and, obviously do it in co-creation too. Acknowledge that, in reality not everybody may be able to contribute to each single step and that this is accepted by all as long as outcomes are shared with everybody. Having an action plan should not lead however to a too rigid and formal process. After all co-creation is about "creating" together, so leave space for creativity, out-of-the box ideas and informality.

The plan should be defined by the group at one of its first meetings and after the focus of the co-creation activity to be implemented has been agreed. An action plan should be a "living' tool, thus it should be monitored and revised regularly and updated as needed.

If the project in co-creation involves funding; the action plan should also include a budget that is shared in a transparent way with participants.

Tool 10 – Co-creation Action Plan

	Task	Assigned To	Due Date	Status (started/in progress/completed)
L.T				
T.2				
T.3				
T.4				
T.5				
T.6				
T.7				
T.8				
Comments:	ents:			



Evaluating Co-creation

Evaluation is an important step in co-creation; it helps to make sure that we are co-creating, make adjustments as needed and, very importantly gather lessons learned feeding not only our future projects but also the body of evidence on the practice and impact of the co-creation approach.

Often evaluation is something done at the end of a process without planning properly in advance. The downside of that is that some relevant data may not be collected any longer, that no resources were allocated and therefore some activities to collect feedback are not feasible; that input was not gathered from certain stakeholders groups and in the end the evaluation is partial, less informative and not owned by all those who contributed to the process.

6.1 Evaluation plan

It goes without saying that the evaluation plan too should be co-created. It is recommended to use the following elements when developing it.

Objectives

- · Monitor that the co-creation principles are being adhered to;
- · Make adjustments to the process as needed;
- Assess the quality of the process and the impact of the co-creation approach;
- · Gather lessons learned.

The group can decide if additional objectives should be defined.

Data collection methods

The data collection methods should be agreed in co-creation. It is suggested to focus on "qualitative" methods to collect feedback on the co-creation process and results. The choice will be determined by the capacity, resources, timeframe, type of activity implemented. Some of the methods that could be used are feedback forms after meetings; groups discussions, surveys, one-to-one interviews.

It is important to make sure that the tools are adapted to those providing feedback. An online questionnaire may work well for some but not for others; they may prefer to shar their views in an interview. Check this when you build your evaluation plan.

Timeline

The evaluation is meant to guide you during the implementation of your activity in co-creation so that if changes and improvements are needed you can make them in a timely manner. Therefore the collection of feedback needs to be built in different points in time; the milestones will depend on the specific context, but the structure of the Evaluation Indicators table presented further on could be the reference: before, during and after co-creation.

Informants

The stakeholders participating to the activity implemented in co-creation will naturally have to be involved in both carrying out the data collection and also providing it. In addition, you should think of other individuals or groups whose feedback is important to get. They may belong to the same organisations/entities that were involved in your co-creation activity, but who were not directly involved. Or they could be external to the activity but be impacted by its results.

Evaluation Report format

It is helpful to think in advance about the main structure for the evaluation report. A simple way of shaping it is by responding to three key evaluation questions:

- Are we doing what we said we would do?
 This question is used to check whether you have been efficient in putting in place what was needed to implement the co-creation approach successfully. It focuses on the process.
- 2. <u>Have we made any difference?</u>
 This question is meant to measure the impact of co-creation in terms of the results achieved.
- 3. Were these the right things to do?
 This question will help understand if the actions and strategies used to sustain the co-creation approach were the right ones in that specific context. Should have you done things differently?

You may want to use the report for different purposes and audiences and therefore have a couple of different formats to best convey what should be highlighted.

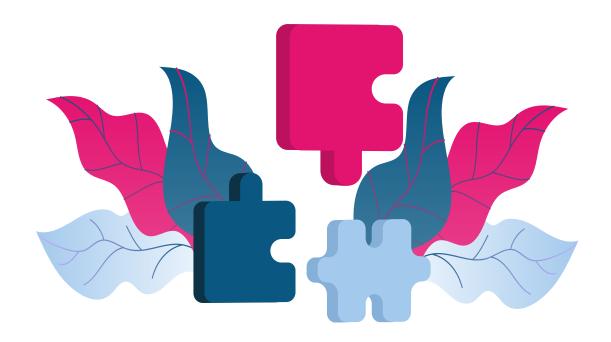
6.2 Indicators

Ш	Elements to review	As	Assesment	int	Principles	Next Steps
		Not done	Partially done	Fully done	addressed	What would improve and how?
PRE	PREPARING FOR CO-CREATION	ATIO	z			
-	Thorough stakeholder mapping done				Inclusivity	
2.	All relevant stakeholders are involved in the co- creation process				Inclusivity	
3.	Participants represent diverse profiles within their stakeholder group				Inclusivity	
4	There is a clear understanding of what participants need to fully engage in the cocreation activity				Inclusivity Accessibility Equality	
5.	All resources needed for everyone's full engagement are secured and they are allocated in a transparent way				Inclusivity Accessibility Equality	
DUR	DURING CO-CREATION					
9	Participants are aware of the expertise each brings				Equality Reciprocity Respect	

Transparency	Equality Reciprocity Power sharing	All principles	Respect Equality Reciprocity Power sharing	Respect	Power sharing Transparency	Power sharing Transparency
		SS:				
Participants understand what co-creation is and how it works	The focus and expected outcome of the piece of work to be done in co-creation has been jointly discussed and agreed	A group agreement is Yes: in place	9.1 The group agreement describes how a safe environment for co-creation will be established and maintained	9.2 The group agreement describes clear communication processes	9.3 The group agreement contains a procedure for managing potential conflicts	9.4 The group agreement establishes how decisions will be made
7.	ထံ	ര്				

All principles	Transparency Accessibility	Accessibility Respect	Inclusivity Accessibility	Inclusivity Accessibility	Respect Reciprocity	All principles
						No:
						Yes:
9.5 The group agreement is regularly checked and reviewed as needed	An action plan describing the steps of your co-created activity is in place	All info needed for the work of the group is provided in a format that is friendly and accessible to all participants	Diverse needs of participants are catered for	Practical aspects take into account everybody's circumstances influencing their capacity to contribute	There are formal and informal ways in place to value and acknowledge contributions	A plan for evaluating the co-creation experience is in place
	10.	II.	12.	13.	14.	15.

All principles All principles Inclusivity Equality	Reciprocity Inclusivity	Equality Reciprocity Inclusivity Equality	Reciprocity Power sharing	Equality Reciprocity Power sharing
16. The evaluation plan has been co-created 17. The evaluation plan is framed around the 7 co-creation principles EVALUATING CO-CREATION 18. All actors who were involved in co-creation	are able to contribute their perspective to the evaluation The tools for evaluation		purposes is done in co- creation 21. The evaluation report is	



Other Tools

7.1 MHE Glossary on Mental Health

Words can guide the change we want to make

Words have a big influence on how we think and act. We use words to categorise and make sense of the world. Depending on the society we live in and our personal experiences, we associate words with specific concepts, societal movements or opinions. These free associations of thoughts or images influence the way we feel and act, and make words a powerful tool for advocates, politicians and policy makers to guide thinking.

When we want to see the right change, we need to use the right words. The way we talk about mental health and people experiencing mental health problems can hurt, discriminate, and reinforce negative stereotypes, without us even realising it. De-stigmatisation in the field of mental health begins with the use of words, that is, with semantics.

Over the past centuries, and even over the past decades, we have seen language used about mental health change dramatically. The terms we use say something about where we want to move away from or where we want to go towards. When using words, it is good to understand their history and what they represent(ed) in a specific society or community.

MHE Glossary on mental health builds on MHE's <u>Words Matter</u> and <u>Mental Health Europe Explained</u> work. As language evolve along with our societies, this is to be considered a living document, which Mental Health Europe will review whenever the need arises.

The glossary can be seen as a menu: we describe a number of commonly used terms, together with a brief history and the connotations often linked to them.

We also explain how Mental Health Europe is cautious of the impact of certain words, and the interests these can protect. In short sections called 'Mental Health Europe's selected words' we describe why we choose to use certain terms that we think currently align best with our values and mission. We also advise our member organisations and others to refrain from specific stigmatising language that can lead to discrimination.

What is not covered by this glossary?

In the glossary, we have chosen to confine ourselves to terminology referring to mental health issues that can happen to anyone at any stage of life. We will not be discussing terminology referring to lifelong differences that people are born with or which develop in very early childhood such as learning disabilities or autism. A person who is on the autism spectrum may see the world differently to "neurotypicals" and the language used to describe these differences is very important if the social world is to meet their needs. However, it should not be confused with language used to refer to mental health issues. People on the autistic spectrum may also experience mental health problems. The same applies to people with intellectual disabilities, who have historically been equated with those with mental health problems – to the disadvantage of both groups. The task of constructing a glossary of selected terms for these groups is clearly very important but beyond our current scope.

The glossary was co-created by an ad-hoc working group comprising people with lived experience, supporters, mental health care and social service professionals, service providers, academics, and human rights and health experts relevant to mental health. 'Mental Health Europe's selected words' were proposed by the working group after in-depth reflections on the different options. The current final selection was agreed by our Board of Directors.

The MHE Glossary on Mental Health can be accessed here

7.2 MHE Toolkit on Promoting understanding of the Psychosocial Model of Mental Health

At Mental Health Europe we believe that as a society there is an urgent need to reorder our priorities in the way we deal with mental health problems. Humans are social beings and if you ask people where their mental or psychological distress has its origins, most will refer to events which have disrupted their lives, their relationships, and the way they view the world. And yet, the way mental health problems are presented to ordinary people is most of the time as diseases or medical problems which result from flaws in the brain or genetic makeup which can be controlled by drugs or sometimes even by using coercive practices. As well as being a profoundly pessimistic perspective, many people also find that the effects of this kind of treatment makes them feel worse and hope of recovery an ever more distant prospect.

If we want to improve the lives of people with mental health problems, and if we want to have better prevention of mental health issues, we need a different kind of approach, one which deals directly with the social determinants of mental health and the lived experiences of people. We call this a psychosocial model. At its heart is the recognition that we are

embedded in a network of personal, social and community relationships which may for a time not be working for us because of loss, grief, trauma, poverty or any number of factors that make us sad, anxious, desperate or lost, but which with the right help can, over time, be empowered to work enabling recovery and a better life.

In this toolkit we look at what the right help may consist of. The resource deals with important prerequisites to recovery, such as respect for the human rights of the individual and the principle of informed consent to treatment. It also gives examples of successful psychosocial approaches from many parts of Europe, illustrating what can be achieved if we reorder our priorities. We are under no illusions about the magnitude of this task. Powerful forces including the legal systems of most countries, global institutions and the financial might of the pharmaceutical industry influencing the mainstream media, policy, medical education and the information doctors receive about how to deal with mental health problems, all tend to overshadow the search for alternatives. Despite this, psychosocial approaches continue to thrive and change the lives of people who have the luck, the courage, and the support to try them. This Toolkit provides guidelines and good practices on the psychosocial model and how it works in practice in different sectors and for different actors.

The MHE Psychosocial Model Toolkit can be accessed here



www.mhe-sme.org

Mental Health Europe (MHE) is the largest independent network organisation representing people with mental health problems, their supporters, care professionals, service providers and human rights experts in the field of mental health across Europe. Its <u>vision</u> is to strive for a Europe where everyone's mental health and wellbeing flourishes across their life course. Together with members and partners, MHE leads in advancing a human rights, community-based, recovery-oriented, and psychosocial approach to mental health and wellbeing for all.



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