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For all.

May 2024

Policy brief

**Co-creation as a path to
transformation towards better
mental health for all**

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Introduction: The State of the Union on Mental Health

According to the [Eurobarometer \(2023\)](#), 62% of European Union citizens think that recent world events (the COVID-19 pandemic, the Russian aggression against Ukraine, the climate crisis, unemployment, and the food and energy costs) affected their mental health. More than half of respondents to the last EU Barometer survey experiencing a mental health problem have not received help from a professional. The situation is likely to be similar in the wider European region.

As recognised by the [World Health Organisation](#), “now, more than ever, **business as usual for mental health care simply will not do**. The need for wide-ranging transformation towards mental health for all is indisputable and urgent”. Mental Health Europe agrees with this analysis and thinks that this applies also beyond care. In this brief, Mental Health Europe presents to policy makers and other relevant stakeholders a way to kick start this wide-ranging transformation: *co-creation*.

The concept of co-creation in mental health is innovative, when it involves a shift in attitudes, culture and power within a rigid system which historically has been hierarchical in nature and when it expands beyond services. Traditionally, people experiencing mental health problems have lacked a voice. Neither they nor their families have been involved in decision-making on mental health. They have been viewed as recipients, as opposed to active partners in care. The empowerment of people with lived experience is a key pillar of co-creation. Yet, co-creation goes a step further because it establishes that all the actors – within and beyond the health sector - have to be empowered to work together on an equal basis.

Mental Health Europe calls for **co-creation to be adopted as a path of transformation**, moving away from systems where non-participation and tokenism are the norms, towards one which is based on collaboration, partnership, and true understanding of needs. Mental Health Europe believes in the transformative power of co-creation not only in relation to the provision of services, but also in promotion and prevention.

Co-creation – applied in policies, practices, research and communication - has the potential to bring us closer to our vision of societies that promote positive mental health for all, intervene early when problems develop, and provide accessible, comprehensive and community-based mental health services for those who need them.

In this policy brief, we explain Mental Health Europe’s concept of co-creation in mental health and its guiding principles, as well as the relevance of this approach to promote human rights and bring economic and social advancements to the entire society for the benefit of all. The policy brief then focuses on the beneficial effects of adopting a co-creation approach in mental health promotion and prevention. Finally, it presents concrete recommendations and actions on how to apply the co creation approach in practice.

What is co-creation?

Mental Health Europe defines co-creation as “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**”.

The concept of co-creation emphasises the **redistribution of powers** of all participants in the process and the attribution of **equal value** to the different expertise of all the participants.

Co-creation should be applied at individual level, at organisational level or at broader level in policy and decision-making, it should support rethinking service provision, research, communicating about mental health and much more. As mental health is shaped by life events and socio-economic and environmental determinants, we can't adequately address the challenges that our societies are facing by exclusively acting within the health sector. Depending on what we are co-creating, we may have to engage actors from other sectors, beyond health.

The principles of co-creation

The principle	How to apply it
Inclusivity	Think outside the box, involve all the stakeholders.
Equality	Keep diversity in mind, adopt intersectional thinking.
Respect	Value and acknowledge both formally and informally the contribution that everyone involved has made.
Reciprocity	Facilitate genuine sharing of experiences between the involved actors, so that mutual learning occurs, and shared meanings develop.
Power-sharing	Give equal value to different expertise, by recognizing the assets that people bring, beyond their roles. This includes having the same possibility to influence the process.
Accessibility	Provide information related to the co-creation activity in a friendly format for everyone involved. Put in place reasonable adaptations to enable everyone to participate.
Transparency	Be transparent about the constraints limiting co-creation (e.g. resources, timeframe).

For more information about the principles of co-creation, see [Mental Health Europe Co-creation toolkit](#).

Why do we need co-creation in mental health?

Mental Health Europe defends a vision of co-creation where everyone can sit at the table and participate equally. For this to happen, barriers to participation for persons with disabilities should be removed and the rights of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) fully applied.

The human rights argument- Nothing about us

without us

International human rights law unequivocally recognizes persons with disabilities, including psychosocial 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 pillar of international human rights law, enshrined in the United Nations Convention on the Rights of People with Disabilities (UN CRPD). The EU and all its members states, and many countries outside the EU, are parties to the UNCRPD. This means they have committed to realising all the rights of persons with disabilities under this framework, including their meaningful participation in the processes concerning them. This requires ensuring not only the mere participation and ability to be heard, but also and more significantly, the opinions of people with lived experience must have an impact on the outcomes of any process that concerns them on the equal basis with those traditionally holding more power, such as professionals or service providers.

Social and economic benefits

Co-creation is a journey of discovery and growth where **the change during the process is as important as the outcome**. During the process, relationships, perceptions and attitudes are challenged and transformed and new knowledge is created.

By allowing everyone to remove the labels attached to them, co-creation entails more equal¹, collaborative and effective partnerships. It can also facilitate social justice and support community development, as it allows the creation of egalitarian relationships within society. This makes space to expertise by experience, thus bringing back the focus on what people need and contributing to improved health systems².

¹ Co-creation transforms the therapeutic relationship so that it is more user inclusive thus providing ownership of one’s recovery journey (Petroff 2013).

² Co-creation has been noted to improve service delivery, which improves service outcomes (OECD 2011). It 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). 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).

Hence, co-creation has both social and economic benefits. Socially, there is the potential for empowerment to be strengthened, equality to be increased and responsibility to be shared. Economically, it is an efficient approach because it incorporates the perspective and preferences of both service users and providers, thus ensuring a more useful allocation of public resources.

The value of co-creation, an example

A good practice of co-creation is the experience of recovery colleges, successfully implemented, among other countries, in Ireland. Recovery colleges involve supporting people experiencing mental health problems through adult education. A key feature is that people with lived experience co-create all aspects of the college, from curriculum development to course delivery and quality assessment. Studies evaluating the impact of recovery colleges featuring co-creation have reported positive outcomes upon service-user well-being such as [improved self-esteem or confidence](#), [improved employment opportunities](#) and [reduced use of mental health services](#). These colleges can also [benefit staff](#) with key outcomes, including experiencing and valuing co-creation, changed perceptions of service users and increased passion and job motivation. At the societal level, recovery colleges provide opportunities to engage more people in [learning alongside people with mental health problems](#) and tackle stigma through social interaction.

Co-creation as a pillar of the psychosocial model of mental health: focus on promotion and prevention

Mental Health Europe calls for the mainstreaming of the co-creation approach beyond the empowerment of persons with lived experience and to apply this tool also to promote and prevent mental health problems, according to a psychosocial model of understanding mental health. In this case, the concept of co-creation is intended in a broader way and is related to the right of every person to be involved in decision-making processes that involve them³. This is the cornerstone of every democratic process and the original meaning of co-creation, i.e. the highest form of engagement of beneficiaries of policies and practices (the “doing things with citizens” rather than for them). The emphasis is on combining different expertise, with a focus on shared decision-making and information exchange within a mutually equitable relationship.

Recommendations

When applying co-creation in mental health, the following barriers can be envisaged: lack of **commitment**, a **culture** not conducive to co-creation; lack of **infrastructure** and lack

³ The right to participate in public affairs is set out in article 25 of the International Covenant on Civil and Political Rights and is further elaborated in other provisions under international human rights law. For instance, Article 12 of the Convention on the Rights of the Child states that children have the right to participate in decision-making processes that may be relevant in their lives and to influence decisions taken in their regard.

of **resources** (time, human resources and finances). Mental Health Europe puts forward recommendations to the EU and to European countries on how to overcome these barriers, complemented by examples of concrete actions.

Recommendations to the European Union

In the European Union there is an increasing momentum around mental health. The [Communication on a comprehensive approach to mental health](#) – with its ambition to put mental health on par with physical health and leave nobody behind - added a new pillar to the EU Health Union. Since the publication of the Communication in June 2023, the Council of the European Union, the European Parliament, the European Economic and Social Committee have also taken a position on the topic of mental health (see Mental Health Europe briefing [here](#)). These are important steps in the right direction, but the path ahead is still long. The next EU legislature must take a stronger commitment to mental health and ensure that the increased value given to mental health is matched with concrete actions, having a psychosocial model of understanding mental health and human rights as cornerstone.

COMMITMENT to pave the way to co-creation

- 1) Develop a **long-term action plan on mental health** based on the commitment taken in the Communication. The action plan should have concrete **targets, objectives, and budget** as well as a clear **timeline** and **indicators** to monitor progress. Establish **monitoring and evaluation of the implementation of the EU's comprehensive approach to Mental Health**.
- 2) Establish a role of **Vice-President with a clear mandate on (mental) health**, links with other policy areas (social rights, environment, human rights, digitalisation, etc) and resources to develop, implement and monitor initiatives on mental health.

CULTURAL CHANGE towards co-creation

- 3) Deliver a **European Year dedicated to mental health** to increase literacy around mental health and its drivers.
- 4) Develop comprehensive and accessible **campaigns through co-creation to increase knowledge about the UN CRPD** and combat prejudice and discrimination against people with psychosocial disabilities.
- 5) **Support awareness raising initiatives** and campaigns among the general public and professionals, such as the [European Mental Health Week](#).
- 6) Use **language** and terminology that reflects on the variety of mental health experiences and frames the topic in an **inclusive and non-stigmatising** way. See Mental Health Europe's co-created [glossary](#).

STRUCTURE for co-creating with of all relevant stakeholders

- 7) Support the implementation of the Communication on a comprehensive approach to mental health, by setting up **joint meetings between the Member States Expert Group and the HPP Stakeholders Network** and by including

again **civil society as main partners in Joint Actions**. Rather than working in parallel, co-creation requires for different expertise to mix, as the encounter between different sets of knowledge is the condition for new knowledge to arise.

- 8) Further efforts to create a **structure for mainstreaming the meaningful and regular engagement of key stakeholders, across all policies** that have an impact on mental health.
- 9) Ensure that all **structures and processes are fully accessible to persons with disabilities**, persons with lived experience and other groups that are usually excluded from policy debates and that **all barriers to their participation are removed**.
- 10) Adopt and implement a **co-creation approach in the development of political programmes after the European Parliament elections** to ensure that stakeholders, in particular persons with lived experience and their supporters, are involved and meaningfully engaged.
- 11) Consider and **address potential conflicts of interest** and/or industrial interests when dealing with stakeholders, particularly business and corporations.

RESOURCES for co-creation

- 12) Support **Member States' efforts in reforming their mental health systems** towards quality recovery-oriented and human rights compliant services, notably by developing capacity building on co-creation through the Technical Support Instrument.
- 13) Make available or increase resources and tools – including **public funding and sustainable financing mechanisms** – for the effective participation of persons with mental health problems, their families and supporters and their representative organisations in EU public affairs, including in the preparation and negotiation of EU laws and initiatives, and the next EU budget.
- 14) **Monitor co-creation in practice**, by collecting disaggregated data on participation of diverse groups of stakeholders in EU public affairs.
- 15) Allocate **sustainable funds to the EU Health Union and to the European Social Fund +**. Ensure that the redeployment of a large amount of funds within the Multiannual Financial Framework to respond to current health threats [does not undermine the efforts to build and maintain EU public health and social capacity](#).
- 16) **Fund research** to increase evidence on the benefits of and good practices on co-creation.

Recommendations to European countries

1. COMMIT to co-creation in policies, practices, communication and research

The example of countries where co-creation has successfully been implemented shows that key drivers for change is political commitment, the vision at policy level, combined with champions of co-creation. Good leaders can encourage their staff to be trained in and adopt co-creation, enabling the concrete implementation of a new vision.

Concrete actions:

- ✓ **Include people with lived experience in making decisions** and shaping the design, implementation, and monitoring of actions **in any sectors that impact mental health outcomes**, such as in decisions related to building housing policy, social care policy, or actions to reduce poverty or problematic debt, and in research.
- ✓ **Reform legislation** to ensure that mental health systems are **human rights compliant, recovery oriented and integrated** in a network of services at community level. Reform should be properly funded and drafted in co-creation.

2. Facilitate a CULTURAL SHIFT in mental health, valuing lived experience and challenging the “us” vs “them” mindsets

Co-creation requires a redistribution of power among all relevant actors. If it is clear why those traditionally holding the power may be resistant to change, it is worth noticing that those whose voice is currently not present enough - people with mental health problems and psychosocial disabilities and their supporters - could refrain from engaging in co-creation. This reluctance to change can be explained – among other reasons- with self-stigma (internalised belief that they have nothing to contribute), fear of being discriminated or be involved in a tokenistic way. Other key stakeholders have been absent from the policy debate as they might not feel involved in creating this change. Mental Health Europe call for all actors to have the power to influence the processes that impact on them.

Concrete actions:

- ✓ Transform mental health services in such a way to **reflect the value of lived experience in the professional workforce** (e.g., by including peer support) and in different working practices, founded on co-creation and shared decision making at all levels.
- ✓ Implement **standards and guidelines for the participation of various stakeholders** in policy, service delivery, training and research.
- ✓ Provide **incentives to increase the participation of people with lived experience** in policy development, service delivery, training initiatives and research. Provide incentives for those managers that have demonstrated actions towards transformative change.
- ✓ Co-create and implement with health and different sectors community **campaigns and prevention and promotion programmes to tackle social and structural determinants** and society wide issues impacting mental health and wellbeing.
- ✓ **Work with traditional media** to educate actively about the stereotypes and **stigma and discrimination**.
- ✓ Include **co-creation training** as part of the mandatory training regimes of different stakeholders, across sectors.

3. Create the STRUCTURE to co-create with all stakeholders, ensuring that no one is left behind

Co-creation is a process, not an event. For it to be sustained, organisational capacity needs to be in place.

Concrete actions:

- ✓ Establish **coordination structures/mechanisms within the mental health sector and across sectors** to enhance collaboration (e.g. joint budgets), by clearly articulating who is accountable.
- ✓ Invest in multi stakeholder fora **supporting diversity of participation**, with particular emphasis on underrepresented sections of civil society. Ensure that the information and the working process are fully accessible and adapted to the needs of this diverse audience.

4. Sustain co-creation by allocating RESOURCES

If co-creation is not supported by investment in time, human resources and finances, people will not have the proper access and conducive environment to be able to contribute.

Concrete actions:

- ✓ Establish mechanisms to allow **independent financing** to support the development/growth of organisations of people with lived experience. Launch an independent **co-creation grant scheme** to sustain co-creation.
- ✓ Find ways to **value and acknowledge** both formally and informally the **contribution that everyone involved** in the co-creation process **has made**.
- ✓ **Funds research** to monitor and **evaluate the value of co creation** to have evidence base.

Recommendations to civil society

- 1) **Share resources, data and promising and evidence-based approaches** relevant to a mental health in all policies approach and that can further help the co-creation transformation.
- 2) **Collaborate and partner up with organisations across sectors** to create communities of practice and exchange learnings on mental health.
- 3) **Work together to normalise the conversation around mental health**, open conversation and support awareness raising campaign to reach out the community your work with, notably by engaging around European Mental Health Week and opening the debate.
- 4) Pave the way to **empowerment of the communities** you represent, so that they can be heard and have choice and influence in every decision that impacts on their mental health.
- 5) **Advocate for mental health considerations to be included in the policies you work on** and services, within and beyond the health sector.

Conclusions

Mental Health Europe's vision is that of a Europe where everyone's mental health can flourish across their life course. This vision must be cross-cutting across all EU and national government levels as well as sectors and must be grounded in engaging all our communities.

With the upcoming EU institutional renewal in mind, Mental Health Europe calls on everybody to realise that mental health concerns us all and that **we all have a role to play in relation to creating a better future for all.**

Co-creation is a path of transformation, towards better mental health for all. Everybody will benefit from it. It is worth it.



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Co-funded by
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