Mm

Mental Illness

/ˌmen.təl ˈɪl.nəs/

an illness
that affects the mind

Mental Health

/ˌmen.təl ˈhelθ/

The Power of Language
A glossary of words and terms

Mental Distress

/ˌmen.təl dɪstres/

A State of extreme
mental anguish or sorrow

Table of Content

Introduction

Words can guide the change we want to make

Words have a big influence on how we think and act. We use words or similar constructs[1] 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 changes, 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. For example, the terms 'lunatic' and 'hysteria' were used regularly until the 1930's and 1980's respectively[2].

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.

This publication builds on Mental Health Europe's Words Matter and Mental Health Europe Explained work. As language evolves along with our societies, this is to be considered a living document, which Mental Health Europe will review whenever the need arises.

Choose the words that fit your values and experiences

Because words carry value, people choose particular words that fit their own mission, values, struggles and experiences. When talking about your own experience, you have your own preferences for your own reasons. It is very important to self-identify with terms that you think best describe your personal situation and experiences. When talking about other people's experiences, it is also essential to keep in mind that the words that you may think are most fitting may evoke hurtful or different associations for other people. Asking another person how they prefer to be addressed and referred to could prevent such unpleasant situations.

---

1   For example think about signs in sign language
2   Read about it in Taska, C. et al. (2012). Women And Hysteria In The History Of Mental Health. Clin Pract Epidemiol Ment Health (Link); And in this blog by the Royal College of Psychiatrists: 90 years ago: the Mental Treatment Act 1930 by Dr Claire Hilton; In the USA the word lunatic was only officially struck from federal law in 2012. See the 21st Century Language Act here

Mental Health Europe's work is underlined and guided by key international and European frameworks such as the UN Convention on the Rights of Persons with Disabilities (UN CRPD[3])

The UN CRPD is a United Nation human rights treaty. It is a binding document, adopted in 2006 and opened for signature in 2007. It is the first comprehensive human rights treaty of the 21st century and the first human rights convention to be opened for signature to regional integration organisations such as the European Union. It was signed and ratified by the European Union (EU) in 2010 and all the EU Member States. It reiterates that people with disabilities, including people with psychosocial disabilities, must fully enjoy their human rights.

Since its release, the UN CRPD has had a large positive impact on the mental health field, moving countries and organizations towards a more human rights-based approach. This glossary is written to reflect its principles.

This glossary can be seen as a menu

The glossary describes 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. Moreover, we 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 this 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 autism 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

---

3   See MENTAL HEALTH EUROPE's video to learn more about psychosocial disabilities and the UN CRPD: https://www.youtube.com/watch?v=NCIDkMbJslA

these groups is clearly very important but beyond our current scope. More information on autism can be found at www.autismeurope.org. For intellectual disabilities, please visit www.inclusion-europe.eu.

The process of creating this glossary

This 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.
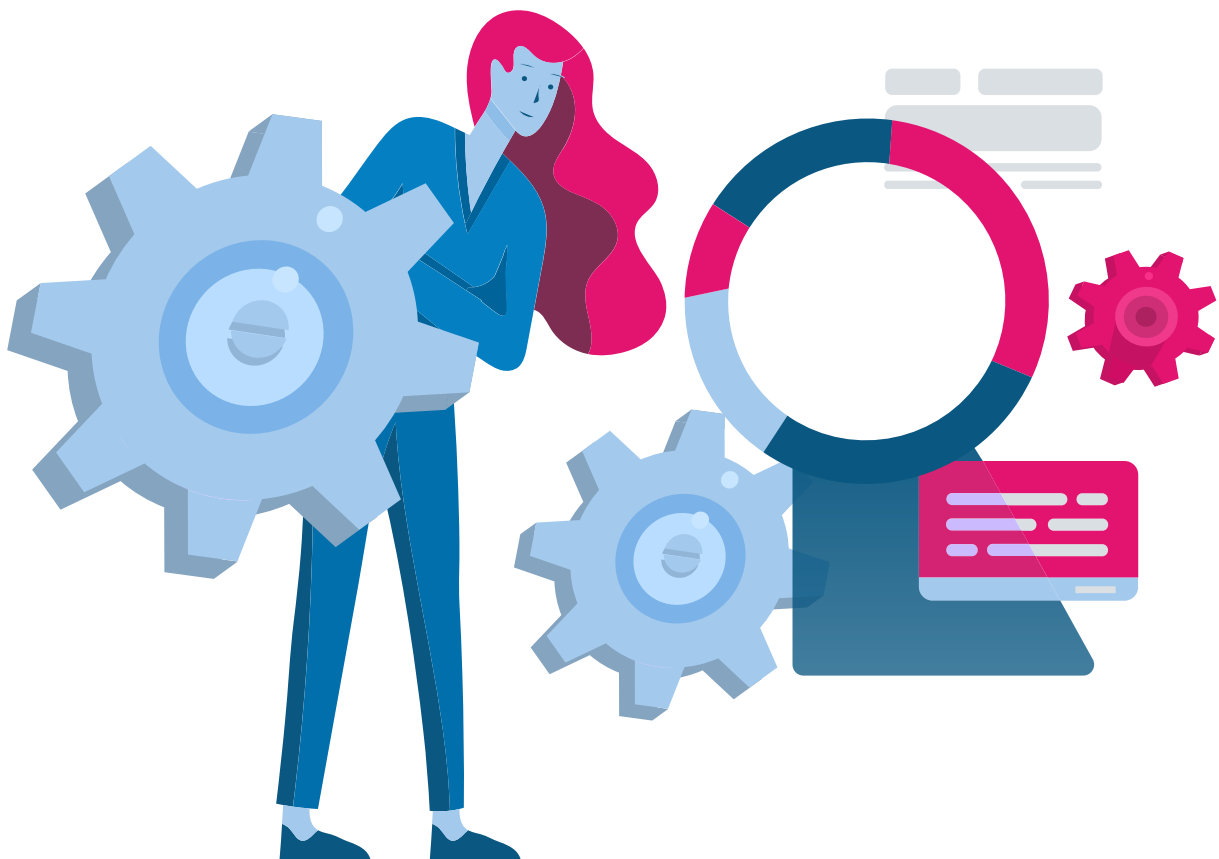
1

Stigma and discrimination related to mental health problems

Stigma & Discrimination

Lack of understanding, negative stereotypes, and misinformation about mental health issues lead to stigma and discrimination against people who experience, or have experienced, mental health problems.

Stigma is a negative connotation of a particular circumstance or quality. People with mental health problems can be stigmatised and viewed in a negative way because they experience or have experienced mental health issues. Stigma can come from different sources and can be present in different contexts. For instance, it can be practiced by others (social or public stigma), or by the person themselves (self-stigma) or it can even be entrenched in systems through policies and practices (in this case, it is defined as institutional or structural stigma).

Discrimination in the field of mental health is when people are treated differently because of a mental health issue they experience. This is prohibited under human rights treaties, such as the UN CRPD, and is in most cases against the law.

For more information, see Mental Health Europe's anti-stigma and discrimination campaign, Each of Us

2

What is

Mental Health

Mental Health

In contrast to the many different options that exist when talking about mental health problems (see section 3), more people appear to agree on using the term 'mental health'. When we dive deeper, however, we see that people actually have different understandings of what this term means.

The World Health Organization (WHO) defines mental health as "a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community."
This is quite a broad description, linking mental health to personal growth and participation in society. It is also broad in the sense that it allows mental health and mental ill-health to co-exist at the same time. The WHO describes this as:

"Mental health exists on a complex continuum with experiences ranging from an optimal state of well-being to debilitating states of great suffering and emotional pain. So mental health is not defined by the presence or absence of mental disorder. Even though people with mental health conditions are more likely to experience lower levels of mental well-being, this is not always the case. Just as someone can have a physical health condition and still be physically fit, so people can live with a mental health condition and still have high levels of mental well-being.[4]"

This is different from how other people address mental health, namely as the opposite of mental ill-health, or the absence of mental health issues.

At Mental Health Europe, we align with the WHO's definition of mental health, seeing it as something that is strongly linked to opportunities, and participation in the community.

3

Mental health disorder /
Mental illness /
Mental ill-health /
Mental health condition /
Mental health issues /
Mental health challenges /
Mental distress

What words do we use when our mental health is not in good shape? The terms used have evolved over time and their meaning depends on who uses them.

We introduce each of these terms and shortly discuss the history/connotations that are generally associated with them. Readers might have a different interpretation of these terms than we have described, which reflects the difficult nature of this exercise. Since language is diverse and constantly evolving, this glossary is only the current viewpoint of Mental Health Europe at this moment in time.

Mental Health Disorder

The DSM-5 (one of the main manuals for psychiatric diagnoses) describes a mental disorder as "a syndrome characterised by clinically significant disturbance in an individual's cognition, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or development processes underlying mental functioning."[5]

Mental Health Europe advises to refrain from using the term 'mental disorder' because this term puts a strong emphasis on dysfunction. It suggests an imbalanced relation, where medical professionals judge that someone's behaviour or feelings are abnormal or disruptive, and it leaves little room for personal recovery. It is therefore perceived as much more stigmatising than the other terms described in this section.

---

5   5 Stein et al. (2021), "What is a mental disorder? An exemplar-focused approach", Psychological Medicine (Link)

Mental illness or disease

These terms find their roots in the early 1900's. Darwin's theory of evolution was broadly accepted by that time, and people started approaching "mental deviations in society" as "unsuccessful genetic adaptations". Given the biological basis of their theory, physicians and psychologists chose the term 'mental illnesses or diseases', to designate what they saw as "the opposite of mental health"[6].

In current times, the term mental illness is often associated with a biological or biomedical approach. Some distinguish mental illness from terms such as mental distress or mental health issues, by saying that mental illness is diagnosed by a medical professional, such as a psychiatrist or psychotherapist[7].

Nevertheless, some people find it helpful or less stigmatising to use the term 'mental illness' to describe their experiences, because it puts them in the same category as other (physical) illnesses. This can help in validating what they experience and can make it easier to explain their experience to others. The term 'mental illness' also makes it easier to explain why support and/or care is sometimes necessary or may be a mandatory official category involved in receiving care. For example, comparing a mental health crisis to diabetes or a broken leg can help people understand the need for urgent support.

Other people do not like to use the term 'mental illness' because they associate it with an approach that is focused only on the biomedical model (and sometimes even only on prescribing psychiatric drugs) that does not account adequately for psychosocial factors. Additionally, while the original intention of the use of the term 'illness' was to minimise stigma, research has shown that it has often had the opposite effect and can be linked with "perceptions of dangerousness and unpredictability, and to fear and desire for social distance"[8]. Lastly, as many people experience mental health problems perhaps once or at different intervals of their lives, they may also not relate to these experiences as an 'illness'.

---

6   Wallace Mandell, 1995, 'Origins of Mental Health', Johns Hopkins University. Link.
7   See for example this, this and this website.
8   Lachlan et al. (2021). Why it's time to stop saying "mental illness": A commentary on the revision of the Irish Mental Health Act. HRB Open research (Link).

Mental ill-health

Although 'mental ill-health' sounds quite similar to 'mental illness', it has been used more recently in an attempt to provide a different connotation. Some sources make a distinction between the two by saying that mental illness must be diagnosed by a doctor, whereas mental ill-health also includes experiences that are not diagnosed[9]. Mental ill-health is thus sometimes seen as a broader, and less 'medical' term than mental illness.

Mental health condition

The Cambridge dictionary describes 'condition' as a "particular state that something or someone is in" and as "any of different types of diseases". This double meaning of the word 'condition' leads to people preferring or not preferring the term for different reasons.

Some people like the term because it describes a state: something that can be relatively constant and encompassing. Rather than, for example, the word 'issues' which is more transient and could be perceived as less serious. Other people have exactly the opposite preference because they do not experience a constant condition and find hope in thinking about it as something transient or fleeting.

People might also like the term 'condition' because it references health without seeming negative. For example, pregnancy or physical fitness are also often referred to as 'conditions', but never as illnesses. On the other hand, to others the term 'condition' can have negative medical connotations and they prefer not to use this term for that reason.

---

9   For example, this website

Mental health issues or problems

Many people describe 'mental health issues' or 'problems' as a broader category than mental illness or mental health condition[10]. They view 'mental health problems' or 'issues' as more universal and less specific, and use them to describe a broader variety of experiences.

There are people who like to use the terms mental health issues and problems, because these words do not carry a medical association. Other people do not like to use these words, because the words 'issues' and 'problems' may carry a negative connotation, which does not match their experience or feels stigmatising. Some perceive 'issues' as a broad term and a discreet and all-encompassing way of talking about the topic. Some think that 'issues' carrying a less negative connotation than 'problems', and therefore prefer to use the former and not the latter.

Lastly, there are also people who experience the terms 'issues' and 'problems' as dismissive of the validity of their experience or condition, because to them the terms suggest that the condition is brief or can be solved by the person themselves without support.

---
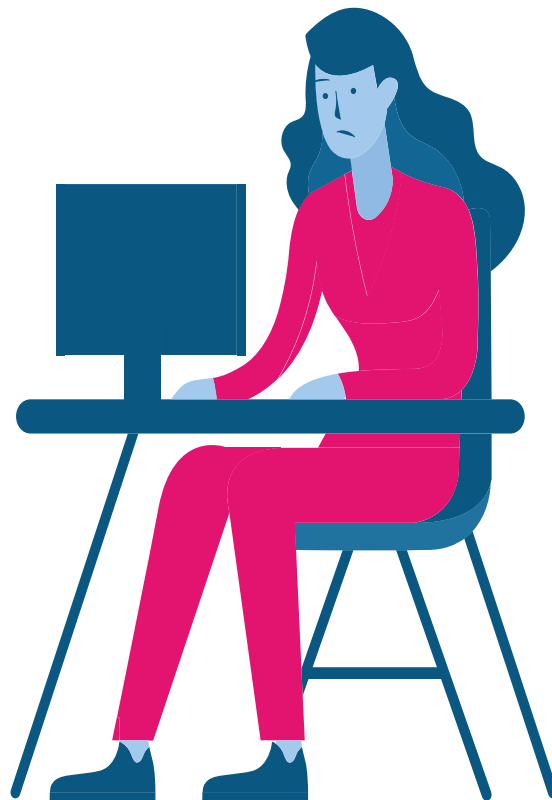
10   See for example this website

Mental health challenges or difficulties

The terms 'mental health challenges' and 'mental health difficulties' arose based on similar values as the terms 'issues' and 'problems' and, in particular, with regards to children. Again, these terms are broader and stray from a formal or medical terminology.

Some people prefer using the words challenges or difficulties, because they perceive them has having less of a negative connotation than the words 'problems' or 'issues'.

There are also people who do not like to use these terms because they feel they understate the severity of their experiences. Others may not like the term 'challenges' because they think it suggests that these 'challenges' are within the person, rather than related to external, psychosocial influences. There is also stigma attached to the term "challenged" in some languages, due to negative associations or usage to describe lower intelligence. The term 'difficulties' carries these connotations less.
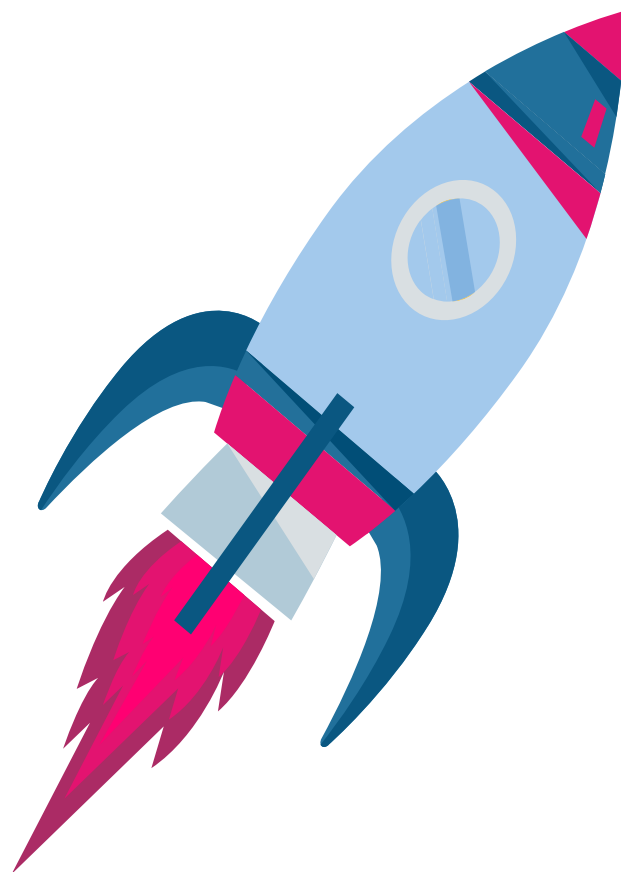
Mental distress

This term is used more and more often to describe a variety of experiences that negatively influence our wellbeing. The term 'distress' is interesting because it refers both to a feeling as well as to a situation. The Cambridge English dictionary describes it as "a feeling of extreme worry, sadness, or pain" and "a situation in which you are suffering or are in great danger and therefore in urgent need of help".

Some people like to use the term 'mental distress', because it is a broad term, including different unique and personal experiences without a medical connotation. Since everyone experiences distress at different times and in different situations, it is a term that is easy to relate to. People also like to use this term because of its double meaning (referring to feeling and situation) and associate it with concepts such as 'the psychosocial model of disability', both of which we will describe later in this glossary.

But there are also people who do not like to use the term 'mental distress' to describe their experiences. They don't find the term serious enough or think it is too general to describe the severity or specificity of what they are going through. For this reason, there are people who think that 'mental distress' is not the same as 'mental health condition', 'mental health problem' or 'mental illness', but rather something that can (but does not always) precede or co-occur with these.

Mental Health Europe's selected words

After much discussion, we have chosen to use the terms

mental distress,
mental health problems and
mental health issues,

recognising at the same time that it is up to each individual to determine the best way to express and relate to their own situation based on their own identity and what they feel is the best suited to describe their own experiences.

We have chosen these words because they align with the change that Mental Health Europe wants to bring about: a transition beyond a solely biomedical paradigm that takes into account all factors contributing to a lack of wellbeing. This is explained in more detail later in this glossary (see Section 5 'psychosocial model').

In very specific occasions, we may mention "mental ill-health", when the context requires this specific terminology. We are, however, trying to move away from this to avoid interpretations linked to pathologisation of mental health.

4

What do we mean by
'Psychosocial Disabilities'?

Psychosocial Disabilities

'Psychosocial disabilities' is an internationally recognised term, especially since the UN CRPD[11], to describe the experience of people who have mental health issues which, in interaction with various societal barriers, can 'disable' them and hinder the full realisation of their rights. It is an important term for Mental Health Europe in policy work because the UN CRPD, which also protects people with psychosocial disabilities, provides a legal framework to which the EU and its member states have to abide. People with mental health issues can meet discriminatory barriers that prevent them from being fully included in society and enjoying their rights. For example, some people with mental health issues experience difficulties finding work or are denied full legal capacity. These barriers thus 'disable' them in life and make it harder to pursue their future and to have full and equal rights.

Since the term 'disabled' may feel stigmatising for some people, we want to stress that it is not the person with a mental health issue we are talking about, but the barriers in society that disable that person and create a disability.
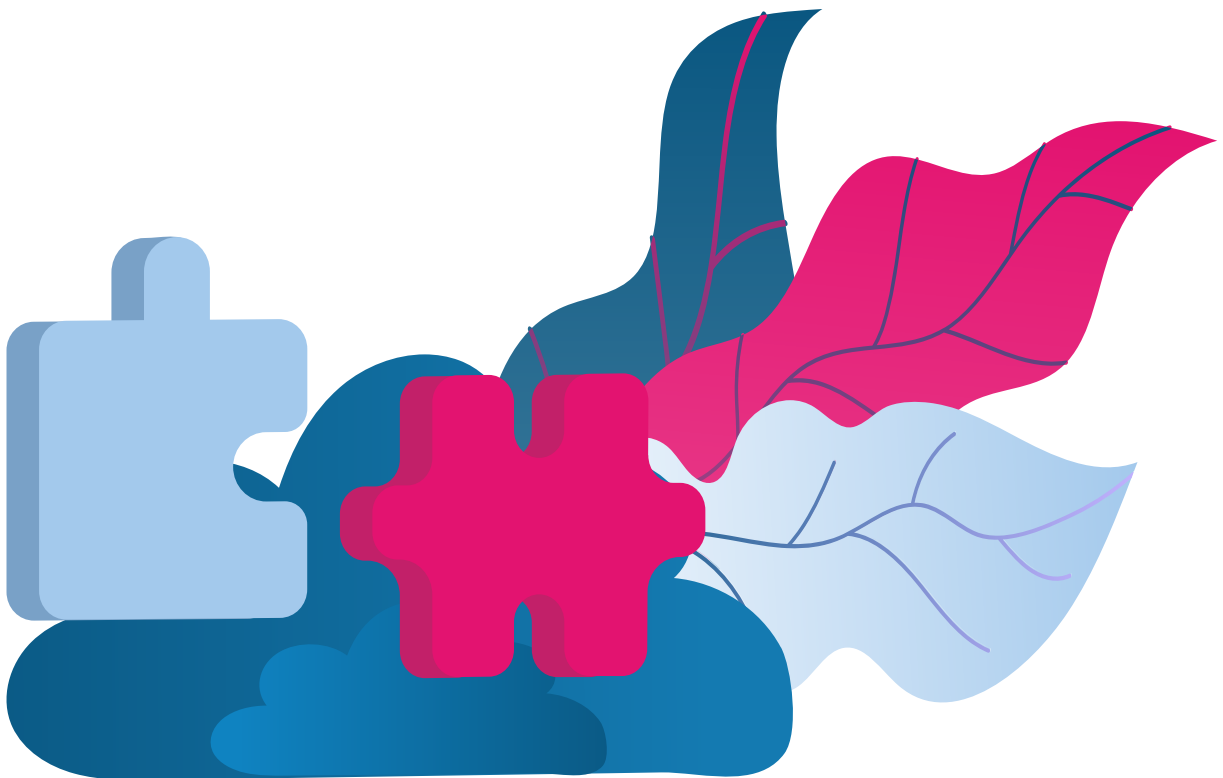

---

11   Link to The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)

5

What is the

Psychosocial Model of Disability?

Psychosocial Model of Disabilities

Mental health problems and psychosocial disabilities are affected by a wide variety of factors that can be classified in many ways. A distinction that is often made is between biomedical and psychosocial factors. Examples of biomedical factors are genes, brain structure or brain chemistry. Examples of psychosocial factors are socio-economic background, family environment or traumatic experiences. Some people choose to refer to a 'bio-psycho-social model' to stress that all factors have a role, and that they influence each other in complex, non-linear ways. Others feel that biology is at the root of all our experiences. However, there are no clear biomarkers of mental health problems. Focusing on these biomedical aspects, even when allegedly among others, has continuously overshadowed psychosocial factors.

The fact that the biomedical model of mental (ill-)health is currently the dominant model in many societies, can have negative consequences. For example, over-medicalisation and over-prescription, along with coercive measures occur, which can influence stigma and perceptions about mental health. It is not helpful if governments, mental health professionals, service users and citizens overlook the psychosocial factors at play and focus only on biological dysfunction and medications, such as psychiatric drugs, or institutionalisation.

At Mental Health Europe, we have therefore chosen to advocate for a 'psychosocial model' or, to refer to the rights described in the UN CRPD, for a 'psychosocial model of disability'.

6

What do we say?
patients /
clients /
(ex-)users /
survivors /
people with - /
people suffering from -

Patients

The Cambridge dictionary describes a patient as "a person who is receiving medical care, especially in a hospital, or who is cared for by a particular doctor or dentist when necessary". Many mental health services refer to people in their care as 'patients'. They see it as a fit description because people are receiving medical treatment and use the same terminology for people receiving care for physical health conditions. However, some people do not like the term patient because of its close connotation to the medical system.

There are also a lot of people who do not like to use the term 'patient', because the word patient refers to a passive or sick role. It is also associated with the adverb 'patient', which means "able to wait for a long time or to accept annoying behaviour or difficulties without becoming angry"[12]!

Clients, consumers

Some people prefer the term 'client', 'consumer' or even 'customer'. The Cambridge dictionary describes a client as "a customer or someone who receives services". People who like to use the word client think it is more active and empowering than the word 'patient', and like the fact that it emphasises that people have a choice on whether and where they receive care. The term 'client' is often used by mental health charities, community mental health services, and mental health professionals working in these services, for example.

There are also people who do not like to use the words 'client or 'consumer', because they suggest a commercial relationship between the service or professional and the person receiving care, which is not how they experience or want to describe this relationship. Additionally, some people do not like to use these terms because they refer to people who are on the receiving end of a service, rather than active players in their recovery journey.

---

12   Oxford dictionary

Service users, users and ex-users

The terms 'service users', 'users' and 'ex-users' refer to people who currently use or have used mental health services. Some people prefer the terms 'service users', 'users' and 'ex-users' because they are not associated with the medical system or with a passive role like 'patients'. They are also not linked to a commercial relationship like the terms 'clients/consumers/customers'.

There are also people who do not like these terms, because they – just like 'clients', 'customers' and 'patients' – describe people only in relation to how they use or used mental health services, instead of approaching them as whole persons with many different personal experiences. Another problem with this term is that it relies on access to services, which is not always possible, especially when services have restricted eligibility criteria or long waiting lists.

Lastly, some people find it confusing since these same terms mean something else in the field of addiction. They prefer to only use these terms combined with the adjective 'mental health' (mental health service user or ex-user, for example), or even a specification of the type of service used.

Survivors

The term survivor stems from the 'psychiatric survivors' movement' that arose out of the civil rights movement of the late 1960s and early 1970s. This movement defined the term 'survivors' as people who consider themselves survivors of psychiatric interventions. The term is sometimes associated with fighting for human rights and against coercion, stigma, and discrimination. It is also often associated with the anti-psychiatry movement, as well as the promotion of peer-run services as an alternative to the traditional mental health system.

Some people like the term 'survivors' because of its strong association with empowerment, recovery and standing up against involuntary and inhuman treatment. Other people do not like to use it, because they perceive its association with the anti-psychiatry movement as a rejection of support or services that they feel are useful and valuable to them. Also, some people don't like the term 'survivors' because it can be confused as describing 'surviving mental health issues', while many mental health issues are not (perceived as) life-threatening.
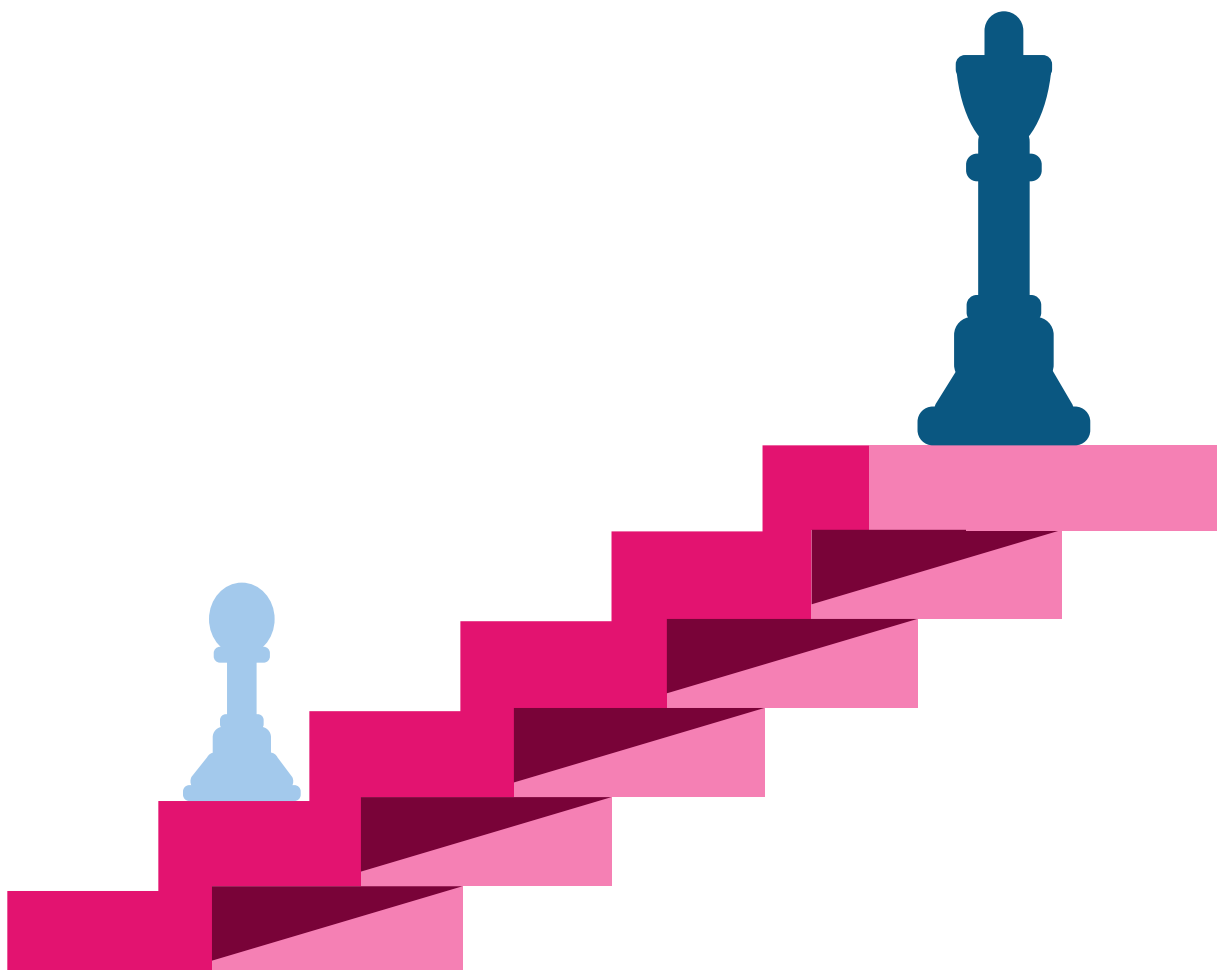
People with -, experiencing - or suffering from

Another approach is not to describe people in relation to the system but in relation to their mental health issues. For example, by saying 'people with mental health issues', 'people experiencing mental ill-health', 'people experiencing anxiety' or 'people suffering from depression'. Please visit Section 9 'How to talk about psychiatric diagnoses' for a short discussion on the use of diagnoses to describe people's experiences.

Some people take particular offense to the term 'suffering from -' because they feel that the word 'suffering' is stigmatising and describes people as passive. It associates with terms like sympathy and vulnerability, which can be validating and comforting to some, but can also make people feel objectified, patronised and unacknowledged as an active player who can recover, live, and thrive.

Some people like to use the terms 'people with - or suffering from' – because they are more person-focused than the previous terms we have discussed. On the other hand, just like with the term 'mental health challenges' we discussed in section 2, there are also people who perceive these terms as focusing too much on a chronic problem within the person, leading to the risk of overlooking the psychosocial factors at stake and the transient nature of many mental health issues. Some people therefore prefer the term 'people experiencing -', because this sounds more temporary and refers to more than just the individual alone.

Mental Health Europe's selected words

Above all, at Mental Health Europe, we respect peoples' choices in terms of how they prefer to refer to themselves, their identity and what they are experiencing. As can be seen, words used change over time and can have a big impact not only on the outlook of society, but on the people labelled with them.

We generally use the words

'service users',
'ex-service users' and
'people experiencing –',

depending on the context. We have chosen these terms because they align with the changes that Mental Health Europe wants to see happen: a transition beyond the biomedical approach to take into account all factors affecting mental health and empower people in their personal recovery. We prefer not to use the words 'clients, consumers, and customers', except when this is how people and organisations refer to themselves. Again, these choices are also often dependent on the language, history, and culture of the country.

This trend towards a more respectful and rights-based terminology can also be seen in the work produced by the World Health Organization (WHO) and has been influenced by the UN CRPD and the work of the UN Committee on the Rights of Persons with Disabilities and Special Rapporteurs. This represents a major step towards changing negative perceptions of persons with psychosocial disabilities and ensuring that countries recognize that all people with disabilities must be provided with opportunities to live life to their fullest potential on an equal basis with others, including how we refer to each other.

7
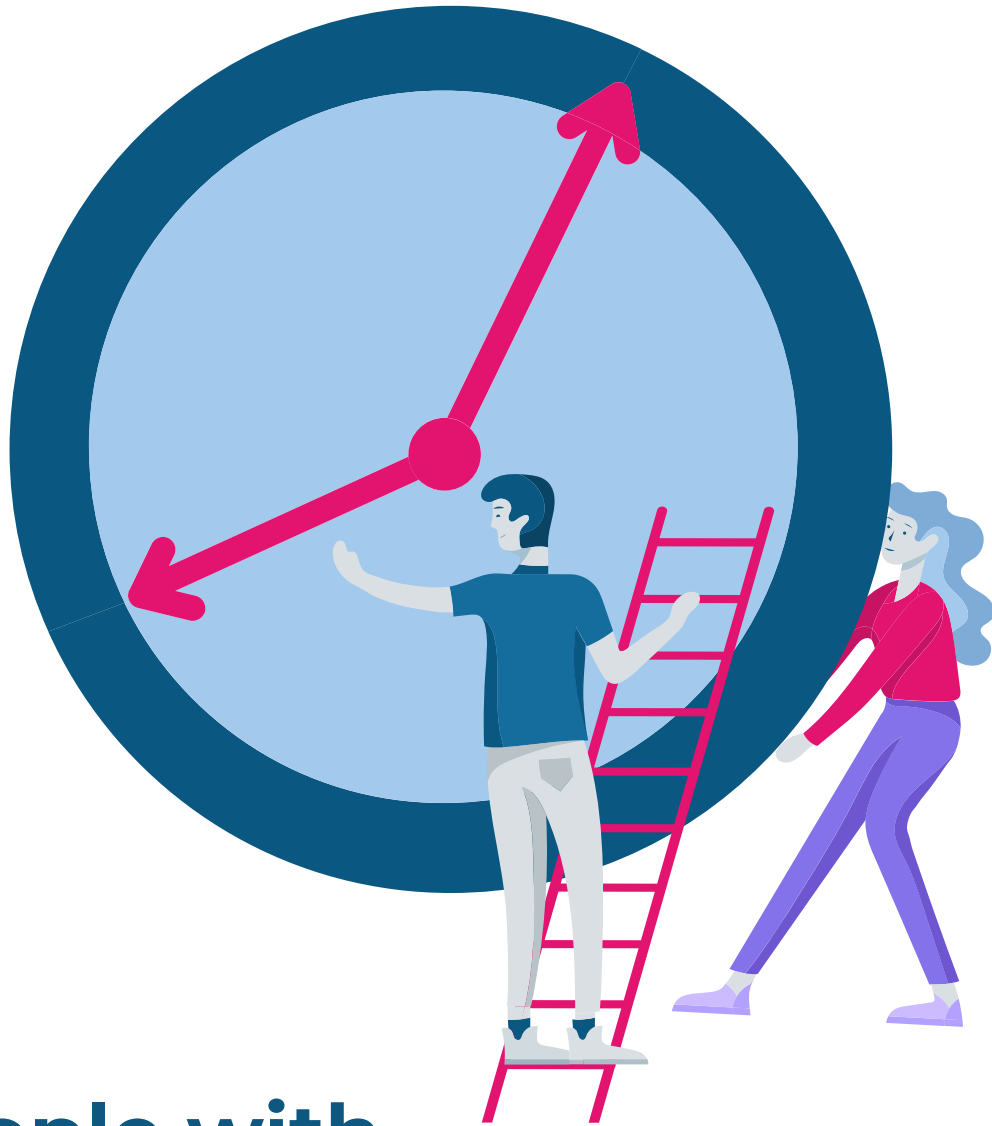
People with

Lived Experience

People with lived experience

In the mental health field, the term 'lived experience' is generally used to refer to people who experience or have experienced mental health issues. Given the wide variety of experiences people go through, this is one way of referring to many people.

Some people prefer to use the term 'living experience', as the term 'lived' implies to them that their mental health issues are something of the past, while they are still dealing with them on an ongoing basis. Others do not experience this connotation with the term 'lived experience'.
Lived experience is often understood more narrowly in specific contexts. For example, people might say they have lived experience of specific mental health issues, such as depression or hearing voices.

It is worth recognising that mental health and social service professionals, at any level, can also have lived experience. More attention has come in recent years to the value that this experience can bring to the support they offer[13].

The term 'lived experience' (of a mental health problem) has risen as part of a movement that sees mental health issues as meaningful human experiences and that persons with experience should have a seat at the table in policy making, decision-making and research, as provided for in the UN CRPD. It also refers to the importance of making sense of one's own experiences within the context of one's own personal story.

Experts by experience

This term refers to persons with lived experience who have gained expertise in their own experience and the mental health system. They often speak out and advocate for the rights of their peers.

All persons with lived experience have some expertise in their own experience and may want to share it. In certain countries, they may study and develop a broader outlook, allowing them to use their own experience to support others as professionals (also described as peer workers, mediators, or trained peers – see the next section for these terms) or they may be called on to contribute to policy and decision-making from a lived experience perspective.

---

13   For example, see this position statement by the Royal Australian and New Zealand College of Psychiatrists, this and this article

Mental Health Europe's selected words

At Mental Health Europe, we understand there is a distinction between **'people with lived experience'** and **'experts by experience'**. However, we want to stress that this does not mean that we think that people with lived experience who have not studied or been trained in the field do not have valuable expertise, or that training is necessary to support peers or have a say in the mental health policy field. We are also aware of the issues and risks that formalising the profession of experts by experience or peer workers (for example by requiring specific education or qualifications) brings to the diversity, professional freedom and inclusive culture of peer workers and experts by experience.

8

Supporters
&
Peer Supporters

Supporters

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.

Peer Supporters

Peer support is when people use their own experiences to help each other. Peer support is distinct from other forms of psychosocial support in that the supporter is someone who has been in a similar situation or position and can relate personally to the recovery steps that someone else wants to take. In peer support, everyone's views and experiences are equally valued, rather than considering the expertise of one person better or more important than another's.

Just like lived experience, peer support can sometimes focus on specific situations, positions, or experiences. For example, people can find it valuable to receive support and share experiences with people who have (had) similar mental health problems as themselves. Or people who find themselves in a specific dilemma, such as balancing mental health between work and home, can look for support from people who share this goal. In addition, peer support can also be an important relay and network for family members, friends, and informal carers of people with mental health issues.

There are many different types of peer support. Some examples include peer support groups, peer2peer trainings[14] or self-help groups, online forums, or one-to-one support[15], sometimes called mentoring or befriending. Peers may also act as mediators with professionals in the mental health care system and advocate for others' rights. What all types of peer support have in common is that they aim to bring together people with shared experiences to support each other and to provide a space where everyone feels accepted and understood.

---

14   See for example in this booklet practice 9 and 13
15   Also see this WHO Quality Rights guidance module on One-to-one peer support by and for people with lived experience (2019)

Peer Support workers or trained peers?

Just like with the terms 'people with lived experience' and 'experts by experience', some organisations distinguish 'peer support workers' or 'trained peers'. Peer support workers and trained peers can thus be described as people who have been trained to provide peer support to others or to organise peer-to-peer self-help groups. In this training, they have usually learned to reflect on their own recovery journey and incorporate the experiences of others as well in order to form a broader picture that can serve as a firm basis to provide support.

9

How to talk about

Psychiatric Diagnosis

Psychiatric Diagnosis

Medical diagnosis is the process of determining which disease or condition explains a person's symptoms and signs. The information required for a medical diagnosis is typically collected from a history and physical examination of the person seeking medical care.

A psychiatric diagnosis is different since physical symptoms are not necessarily present, nor are there biological tests conclusive for mental health problems. However, blood tests and other examinations can be important to rule out underlying physical causes when a person consults for a mental health problem[16]. Health professionals making a psychiatric diagnosis also have to rely on a person's own description of their thoughts and feelings, alongside observations of their behaviour. In this sense, the person best placed to make a diagnosis is often the person themselves, supported by information and empowered discussion with health care professionals. Enlightened professionals acknowledge this and can offer a therapeutic alliance with users of mental health services.

The main purposes of psychiatric diagnoses have always been to allow health professionals to communicate with each other, and to attempt to determine which forms of treatment would potentially be best to prescribe.

Some people find receiving a diagnosis helpful and reassuring, while others find it unhelpful, discriminating, unrelated to their problem or stigmatising. A diagnosis can be a way of recognising and recording a person's mental health problems and opening doors to obtaining help, but it can also narrow people's views and their feelings about their identity, which can lead to (self-)stigmatization, discrimination and marginalization. For example, people might interpret all of someone's behaviour and characteristics as expressions of a mental health diagnosis. Or they might think that someone's possibilities or opportunities to participate are limited because of the stigma and misconceptions that are related to psychiatric diagnoses.

---

16   See for example this, this and this article

"The philosophical school of Aristotle raises the difference between 'essence' and 'accident'. When a person is called by their diagnosis, their essence is being perverted; since in any case, that diagnosis could be an "accident", or a non-essential qualifier of that person."

Guadalupe Morales Cano, Director, Fundacion Mundo Bipolar – Spain

Member of Mental Health Europe

In general, people should not be referred to as a diagnosis (e.g., "he's bipolar"). Identifying individuals with their diagnosis is not helpful and can reduce a person's identity to a "problem". Instead, it is better to use 'person-focused language' and keep a holistic and humanistic view that refers to experiences (e.g., "he's experiencing anxiety").

We invite you to read our short guide on psychiatric diagnoses, available in various languages. This guide was prepared to help people who are given a diagnosis navigate and understand mental health care and approaches.
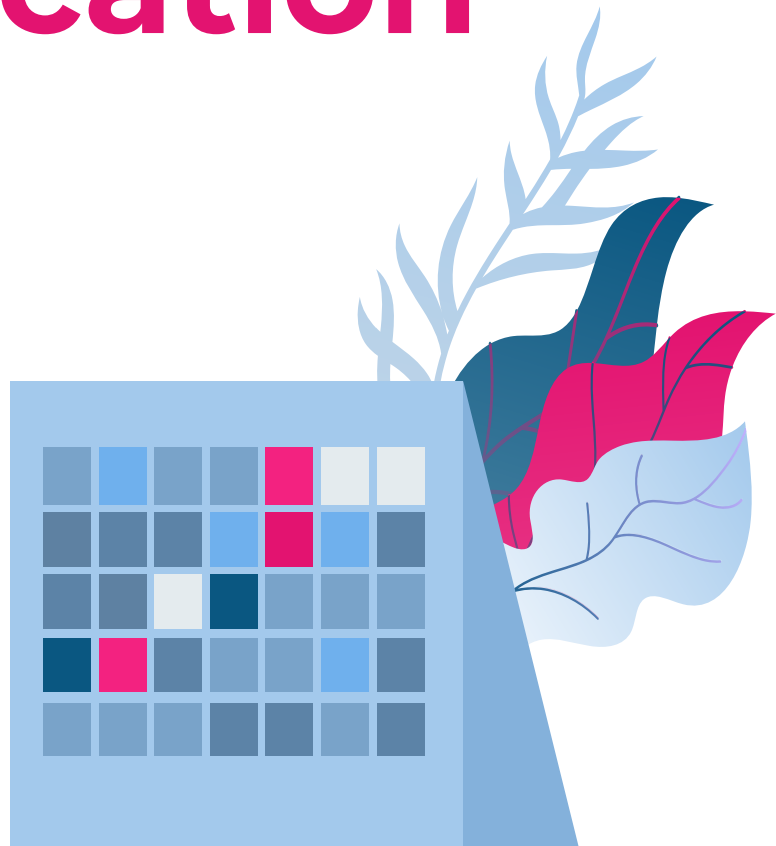
10

What are

Psychiatric Drugs

or

Medication

Psychiatric Drugs or Medication

Psychiatric drugs, often referred to as 'psychiatric medication' are substances capable of affecting the mind, emotions, and behaviour. They can alter the way we think, feel, and see the world. Some people find them beneficial as they can alleviate symptoms of mental health problems. Others do not find they work effectively. Like all medicines, psychiatric drugs can have unintended and undesired (side) effects that impair functioning and can endanger general health.

Mental Health Europe's selected words

Often these substances are referred to as **'psychiatric medication'** particularly in medical circles. At Mental Health Europe we choose to use the word **'drugs'** because there is often no proven direct link between a physical (brain) issue or state and the substance used for treatment.

Also, just like with recreational drugs, the adaptations made by the body to deal with the changes produced by the psychiatric drug can mean that discontinuing the drug produces unpleasant (withdrawal) effects that can sometimes last for a long time. This does not mean that Mental Health Europe discourages or stigmatises people that decide to take psychiatric drugs. What we want is to highlight the importance to make informed decisions and for people to find the right support for their personal case.

Read more about psychiatric drugs, their effects and what to keep in mind when you start or stop taking them in our short guide to psychiatric drugs

11

What is
Coercion
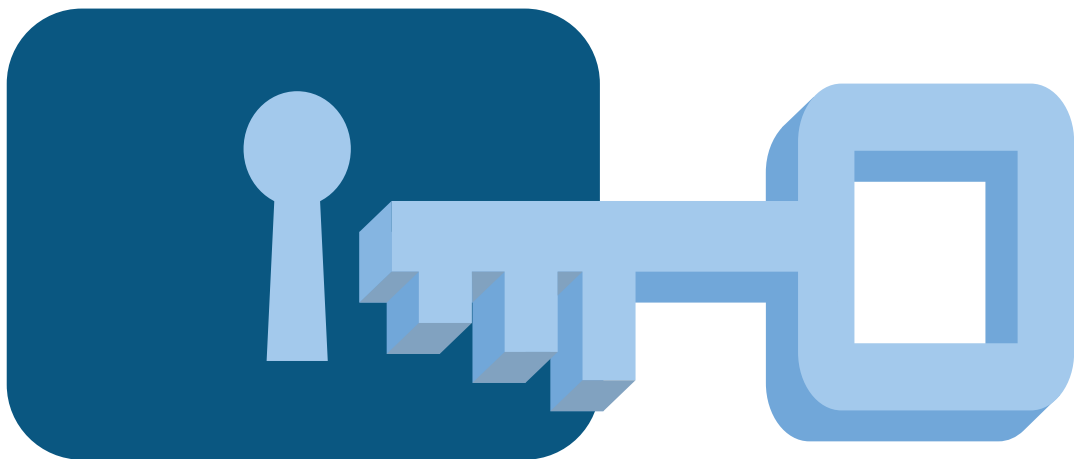
Coercion

Coercion is a term used in the mental health field to describe the use of force or manipulation to persuade someone to do something that they do not want to do, or to restrain them and keep them from doing something that they want to do.

There are different forms and degrees of coercion, and some are more explicit than others. For instance, forced seclusion or physical restraint, forced administration of medication (chemical restraint), and forced treatment all take away someone's freedom and autonomy, and are thus all examples of coercion. But also implied threats or manipulation can make someone comply against their will and are thus coercive.

Experiencing coercion has been recognised to be very distressing and traumatic and does not contribute to recovery. People may also refrain from seeking further support if they have experienced coercion in their care journey. Mental Health Europe is committed to advocating for the reduction and elimination of any form of coercion in mental health, by monitoring the use of coercion until it is prohibited[17], encouraging solutions to eliminate it and recognising the rights of victims. Read our short guide on coercion to learn how you can make your voices and views be heard and (re)take control

---
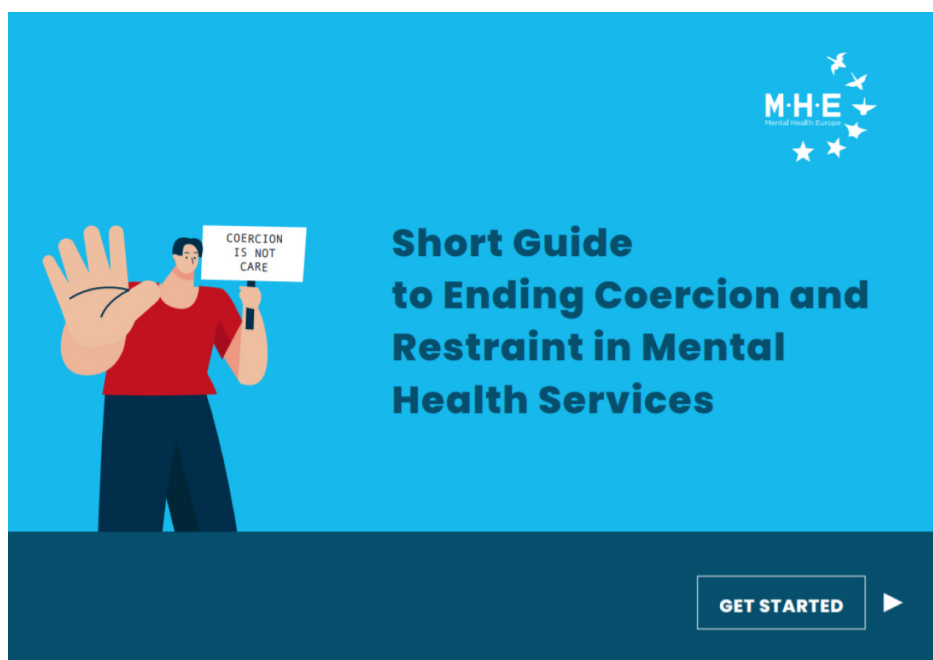
17   Many countries still have legislation that allows forced treatment of people with mental health issues, something that does not apply to physical health issues. See for example the information on the #WithdrawOviedo page and this article.

12

What does
Personal
Recovery
mean
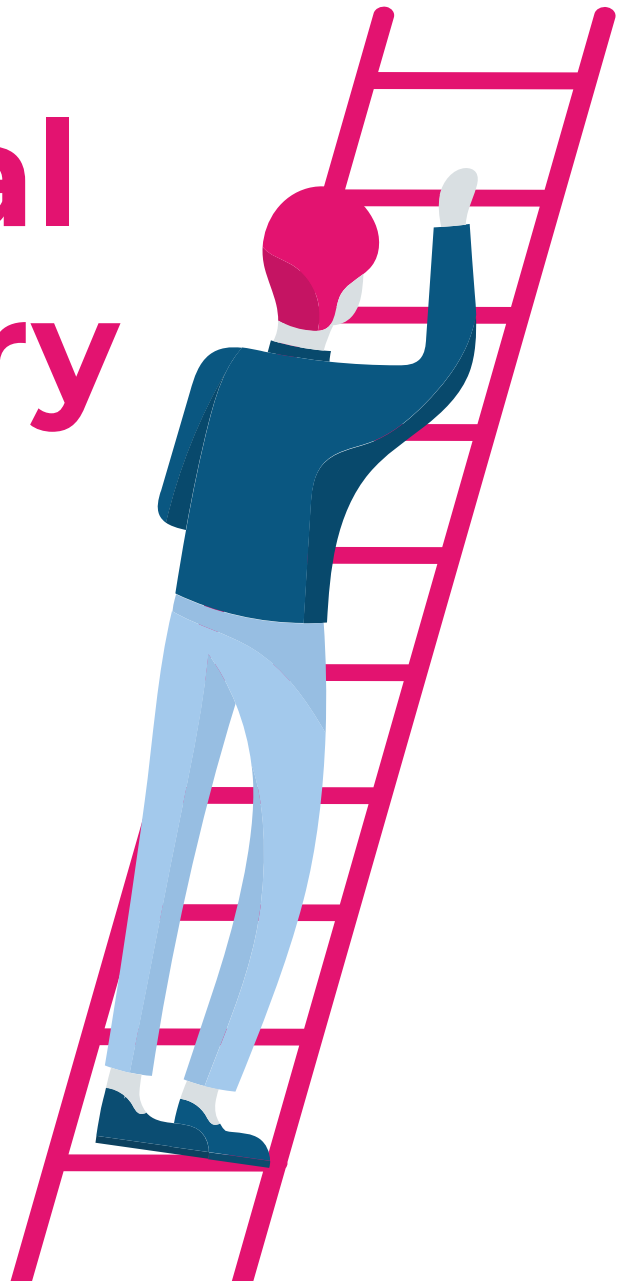
Personal Recovery

Recovery is self-defined. The most powerful definition is the one that you identify for yourself. "There is no single, unifying, definition of recovery but people in recovery describe it as personal and unique to each individual. It's about finding the best way for you to live a life of your choosing even with the challenges of mental health difficulties" (Mental Health Ireland)[18].

Recovery is not necessarily the eradication of the experiences or symptoms accompanying mental health problems, as it would be used in the context of physical health or in the clinical definition of recovery. It can mean living with and managing these experiences, whilst having control over and input into your own life. It means living a satisfying, hopeful life in line with one's values and goals.

Recovery is often described as a journey, or a (re)discovery. It is connected to words like meaning, connectedness, hope, identity and empowerment, and to the value of lived experience.

For more information on the topic, see MENTAL HEALTH EUROPE's short guide on the topic

---

18   https://www.mentalhealthireland.ie/recovery/

13

Community-based
Care

Community-based Care

Community-based care is meant as a type of (mental health) care that enables people to live and receive care in their neighbourhood and families as opposed to in an institution. The thought behind community-based care is that supporting people in their own communities and enabling them to be part of society just like everyone else, helps them recover more sustainably and inclusively and creates more cohesive societies.

The term community-based care describes a wide spectrum of services. Usually, they are designed to comprise an integrated network of services where service users are not isolated from the broader community and/or compelled to live together and where they have control and agency over their lives and over decisions that affect them.
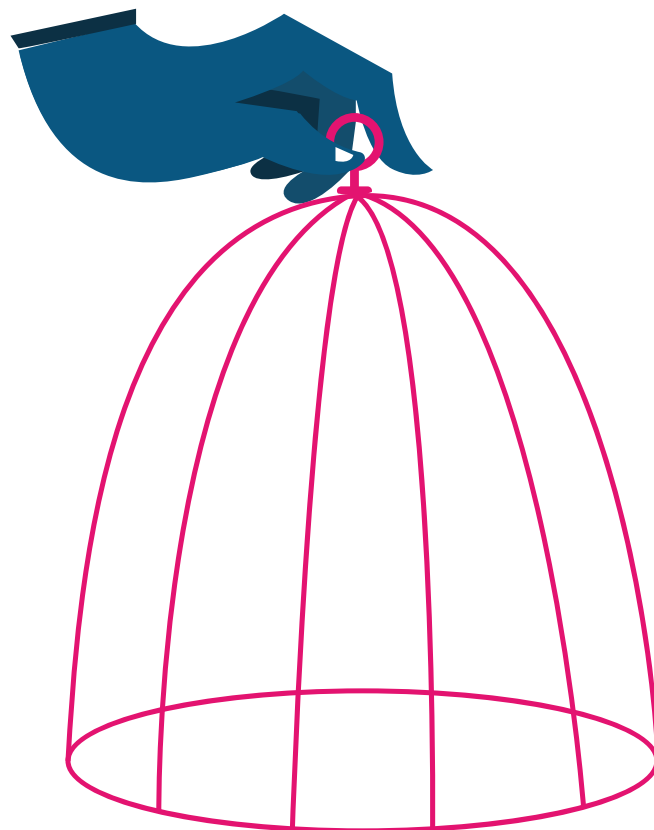
The concept of community-based care is strongly linked to a human rights-based approach, and this is the type of community-based care Mental Health Europe advocates for. A famous example is Trieste, where a system reform in the 1960's towards community-based care strongly emphasised the importance of social inclusion and the need to fight for the rights and freedoms of people with mental health conditions. "Freedom is therapeutic" was one of their slogans.

However, implementation of truly recovery-based community care is still not a reality everywhere. Community-based care requires not only a change of mentalities and policies, but also resources and a monitoring system to avoid replication of institutional care. The transition towards community-based care is part of the broader effort towards deinstitutionalisation in Europe in order to truly provide a wide spectrum of services, respecting the will and preferences of users in their own community.

Institutional Care

As described above, community-based mental health care is the opposite of institutional care, or care in a mental health institution. But what is institutional care? This might seem like an easy question, but it has proven difficult to answer, with many different connotations associated with the words 'institution' and 'institutional'. The European Expert Group on the Transition from Institutional to Community-based Care[19], of which Mental Health Europe is a member, has found agreement in describing 'an institutional culture' as "any residential care where:

- users are isolated from the broader community and/or compelled to live together;

- these users do not have sufficient control over their lives and over decisions which affect them;
-
- The requirement of the organisation itself tend to take precedence over the users' indivudalised needs

14

What is

Co-Creation

Co-Creation

Improving everyone's mental health and care is a joint effort. People experiencing mental health problems, their supporters, health and social care workers, service providers, policymakers, communities and others involved, all have their own role in the process and their own experiences in the system.

To develop policies, programmes, practices and services that optimally meet the needs and wishes of everyone, and above all of the people using them and their supporters, any design process in mental health must involve everyone on an equal basis. This process is called 'co-production' or 'co-creation'.

Co-production/co-creation involves much more than bringing all stakeholders together in a room. It requires careful thought on which actors need to be included and how they can best be reached and involved, ascertaining that all actors have the possibility to contribute to the process, by creating an atmosphere where people value each other's expertise and perspectives. It means involving all actors from the start and being willing to adapt/change the process or aim of the project when they decide that this is necessary.
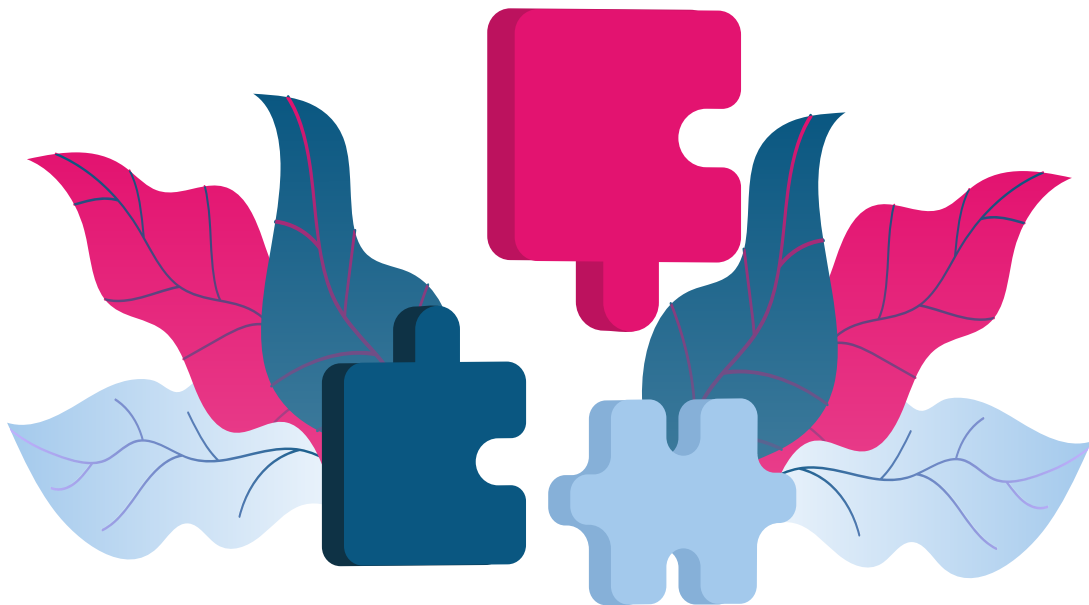
Mental Health Europe's selected words

It is important to be wary of organisations labelling their products or processes as 'co-production' or 'co-creation'. We have seen practices in the past where people with lived experience or their supporters were not fully and equally involved in the process of 'co-production', or even where their involvement was mostly 'tokenistic'. For this reason, at Mental Health Europe we prefer to use the newer term **'co-creation'**. The term co-creation is less associated with practices from the past and gives a chance to set higher standards for what counts as 'co-created'.

At Mental Health Europe we define co-creation as: A collaborative approach involving all key 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. Our definition is underpinned by the principles Inclusivity, Equality, Respect, Reciprocity, Power-Sharing, Accessibility and Transparency.

15

What does empowerment mean to people with mental health issues or psychosocial disabilities?

Empowerment

The term 'empowerment' is not restricted to the mental health sector and can have a variety of meaning for different people. The term as used today originates from an American community of psychology in the 1980's and is rooted in Marxist sociology[20]. It went on to be used in the psychiatric user/survivor liberation movement as well and has become more mainstream in recent years.

Generally, empowerment is described as the power and ability of an individual to have choice and control over their life. The term empowerment can refer both to a person and to a community. In an empowered community, all members can enjoy equal rights, responsibilities, and influence. The term empowerment is also associated with moving away from a 'deficit-oriented' towards a 'strength-based' approach, and from a 'charity'- or medical'- to a 'social'- or 'human rights based' approach[21].

The way the term empowerment is used is important. Sometimes, health professionals or governments believe they are responsible for empowering others. Instead, empowerment should be understood as the person themselves finding the power to gain control over their own life, often thanks to the support and guidance of others around them[22]. Governments, under the CRPD, have a duty to ensure that persons with disabilities have the rights and instruments to find this power and to fully participate on equal terms with others. This also means eliminating and preventing discriminatory actions.

Persons with psychosocial disabilities are often deprived of their basic rights, such as the right to give or withhold consent to treatment and the right to legal capacity. In addition, stigma and discrimination often prevent them from having an equal say and position in society. At Mental Health Europe, we see the empowerment of people with psychosocial disability as the implementation of measures in legislation, policy and practice that provide them with all the necessary tools and possibilities to shape a positive future in which they can enjoy their full autonomy and self-determination.

---

20   Rappaport, Julian. In praise of paradox. A social policy of empowerment over prevention, in: American Journal of Community Psychology, Vol. 9 (1), 1981, 1–25 (13); Burton & Kagan (1996). "Rethinking empowerment: shared action against powerlessness". compsy.org.
21   This is well explained in the 2014 'Convention on the rights of persons with disabilities (CRPD) training guide' (Link)
22   See this helpful guide by the UK government (Link)

16

What is
# Intersectionality

Intersectionality

Intersectionality (a concept first coined by Professor Kimberlé Crenshaw back in 1989) acknowledges that everyone has their own unique experience of oppression. For example, a young black woman from a wealthy background will experience a different type of marginalisation, oppression and discrimination than a middle-aged white woman from a poor background or an older Asian man from a middle-class background.

Many factors form our identity and the way we are socially categorised. Think of gender, race, class, sexual orientation, age, physical ability, mental health, etc. We are all many different things at once.

In order to design fair and inclusive policies, it is necessary to take all these overlapping identities and experiences into account and understand the complexity of prejudices that people face, which is what intersectionality attempts to do.
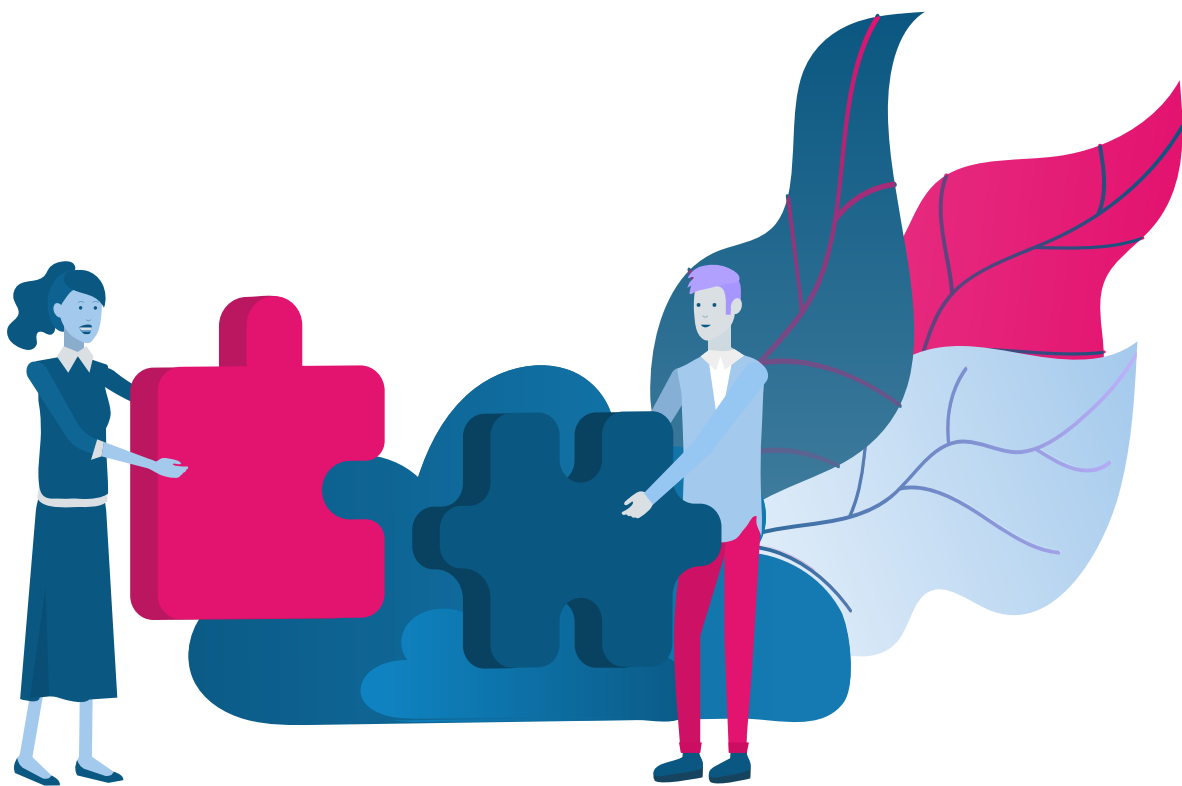
17
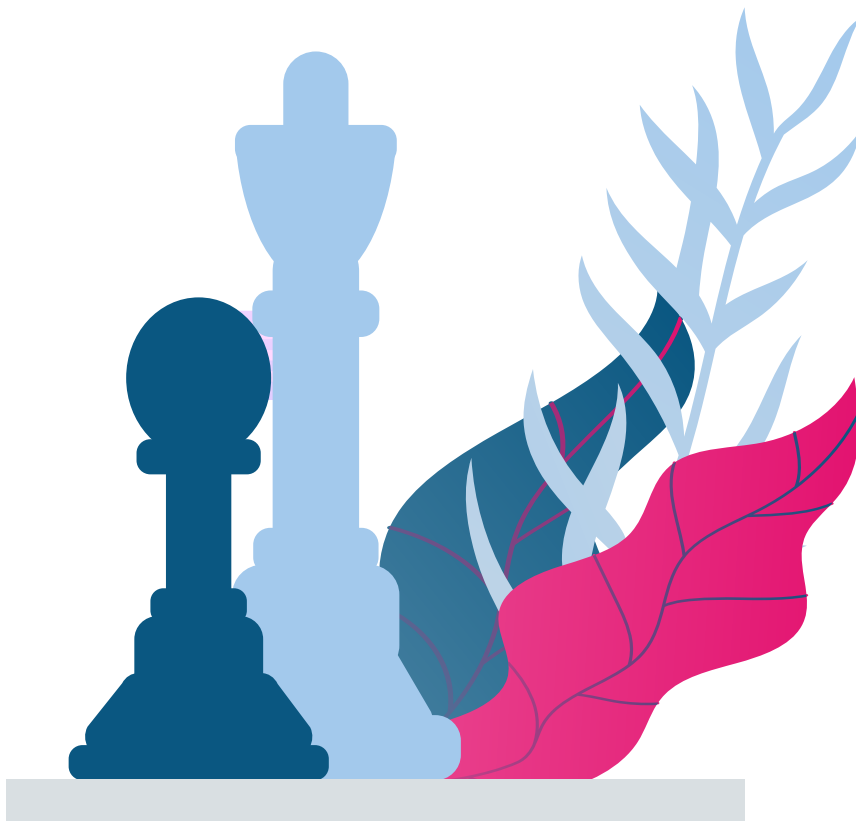
What is
Parity of Esteem

Parity of Esteem

Stigma and discrimination remain prevalent in society when it comes to mental health issues. People do not share their mental health problems easily out of feelings of shame or fear of being treated differently. In addition, mental health is often a lot less visible than physical health, which makes it more difficult to show/see the validity and severity of mental health issues. Consequently, people generally think that mental health is not as serious or as important as physical health. The current context of polycrisis have made people rethink this. Still, the invisibility and under-recognition of mental health issues have an impact on legislative and government policies, and particularly on the quality and accessibility of mental health care, as well as on the allocation of funds to mental health services and research.

Parity of esteem describes the principle that mental health is valued and prioritised equally to physical health. It is one of the key principles of Mental Health Europe's work.

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 vision 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.

Co-funded by the European Union