



**National Survivor  
User Network**

# The language of the mental health lived experience landscape

**August 2024**





# ABOUT THIS RESOURCE

At NSUN, we are interested in exploring what regularly-used language in mental health means to those with lived experience of mental ill-health, trauma, and distress. In the summer of 2024, we opened an anonymous survey sharing a range of terms selected by the NSUN team, asking people with lived experience to define those terms in the context of mental health.

We are bringing those definitions together into this publication. We hope that this resource, acting as a crowdsourced glossary of terms defined by people with lived experience, can be used and referred to by anyone who would find it helpful.

We also encourage and challenge those working in mental health service provision, research, and policy work to carefully consider the power of the language that they use and the implications that it may have. This resource may serve as a starting point.

People with lived experience are not one uniform group who all share the same opinions and experiences. We aim to acknowledge and celebrate the plurality of language: many words and terms mean very different things to different people.

Within this publication we have included a short summary of the responses we got for each term, as well as a selection of quoted definitions. For some terms, quotations may offer different interpretations and reactions to each other.

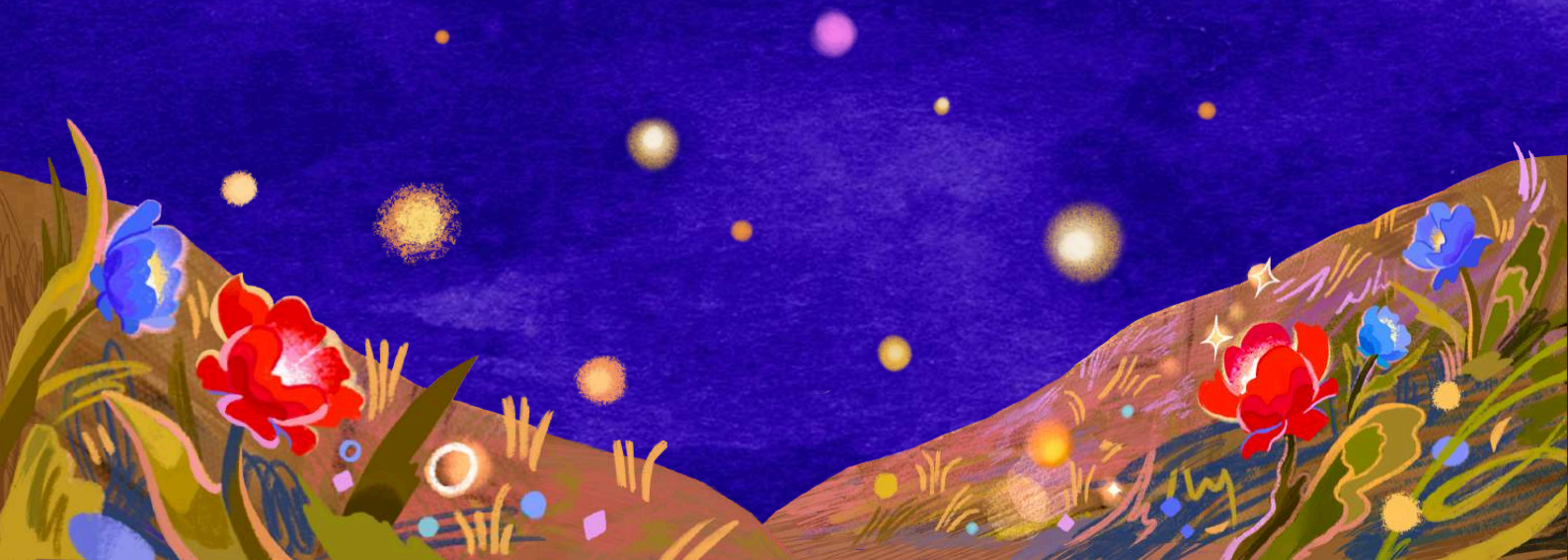




# THE TERMS INCLUDED IN THIS RESOURCE ARE:

Abolition  
Advocacy  
Capacity  
Chronic  
Coercion  
Collective  
Community  
Criminalisation  
Co-production  
Disability  
Discrimination  
Distress  
Grassroots  
Healthcare  
iatrogenic harm  
Identity  
Intersectional  
Injustice  
Justice

Lived experience  
Lived experience leadership  
Mad  
Marginalisation  
Mental health  
Power  
Recovery  
Restrictive  
Representation  
Safeguarding  
Safety  
Service user  
Solidarity  
Survivor  
Trauma  
User-led  
Visibility  
Voice  
Vulnerability





# Abolition

## Summary

Most people said that this was about ending, banning, dismantling, breaking down, or getting rid of something, with some people referring particularly to harmful or oppressive systems and institutions. Some included the building of alternatives in their definitions.

## What people said

“Getting rid of harmful systems and building alternatives”

“Stopping something from happening anymore e.g. "abolition of SIM”

“Bringing down the systems which oppress us”

“Creating a world free of forced institutionalisation, imprisonment and all other forms of being held against your will”

“A loaded term used by lived experience personnel which is meant to be challenging to systems but can be destructive or aggressive against services rather than working with them”

“The dismantling of the current interlocking system(s) of oppression, particularly in relation to (but not limited to) incarceration”

“The dismantling of harmful systems and practices that harm and traumatise us under the guise of 'care', and the building of care centred alternatives”



# Advocacy

## Summary

Lots of people mentioned the act of someone else speaking on your behalf, and in your best interests, to help or support you or to have your voice heard and needs met. Others considered advocacy more broadly (on a collective rather than individual level), referring to the act of fighting for justice and the rights of marginalised people and groups. Either way, the responses implied that advocacy was seen as something representational.

## What people said

“Helping people made powerless by the system to know their rights and navigate things like access to care or benefits or helping us make complaints”

“Someone to fight in your corner when an institution or organisation may not necessarily have your full interests at heart”

“Someone speaking on behalf of someone else. Being on their side”

“Championing, supporting, giving voice to, fighting for what is right, good and true”

“When we speak up for ourselves and others”

“Using knowledge and resources to educate and fight for furthered independence, justice and/or rights of marginalised individuals or groups”

“Representing ourselves and our communities when challenging systems and practices that harm our mental health and sharing solidarity and support to other movements”



# Capacity

## Summary

Lots of people used the word 'ability' in their responses, mostly in the context of an ability to make your own decisions. Some people wrote about how the concept of a lack of capacity can be used to take away someone's agency or power. A couple of people talked about organisational capacity - having enough time and resources to operate or function.

## What people said

"A problematic concept used currently to tell people that they have the capacity to end their lives, absolving responsibility of the state to care for its people"

"A person's ability to make decisions for themselves. Can be a bone of contention [...] unfairly used by staff to make assumptions & restrict power"

"Term used to define someone's ability to weigh up decisions and outcomes, understand and retain information. Capacity does not always mean someone makes good decisions but they make the decision knowing what it means. Someone may have capacity for one thing but not for another. It's complex and a trained professional takes it very seriously to say someone has no capacity means they have decisions made for them in their best interests"

"Ability to understand and make specific decisions about your treatment"

"The extent to which a person can make decisions, exercise their agency, have reserves of energy to expend"

"Resources, time, energy and support to live fully (from a personal perspective) or operate/develop (from an organisational perspective)"



# Chronic

## Summary

Most people used the phrase 'long-term' in the context of experiences of mental ill-health, distress and trauma.

## What people said

"Long-term, ongoing"

"Persistent"

"Severe"

"Long term, reoccurring, flare-ups, I am not going to get 'better'"

"Something long-term, often used in a pejorative or judgemental sense"

"Continuous, unending, constant and unrelenting, haunting"





# Coercion

## Summary

Most responses included the word 'forced', in the context of being made to do something that may be against your wishes. Others used words such as 'manipulated', 'persuaded', and 'tricked'.

## What people said

"Forcing someone to do something they don't want to do or that isn't in their best interests"

"Being forced, having no choice, esp around treatment"

"Being forced or pressured into doing something that you don't want to do. Includes when you aren't informed that other options are possible or where your access and communication needs aren't met to an acceptable level where you feel able to make your own free decision"

"Forced, manipulated, lack of free will, lack of control and power, removal of choice"

"Being encouraged, sometimes by negative means, to do something"

"Being heavily or forcefully influenced to make decisions or agree to things that you may not have otherwise done or agreed with, often due to structural or relational power imbalances"

"Denying freedom or autonomy usually connected with taking control away from another person without their consent"



# Collective

## Summary

Lots of people defined this as a group of people and/or organisations with shared goals, interests, opinions, experiences and/or values coming together. Some specified that the purpose of coming together was to make change, or work towards a shared objective.

## What people said

“Coming together to be more powerful”

“A group that share a common goal/objective”

“Working together”

“As a noun, this might be people forming a semi-formal group with a shared purpose or a group of different organisations coming together with a shared goal to benefit from diverse resources and perspectives”

“A group of people sharing opinions and experiences”

“Support group”

“Working together for the better outcome”

“A group with shared beliefs or feelings about something, shared ideology or collective mood”

“All together, everyone”



# Community

## Summary

Some definitions were similar to those given for 'collective', above, focussing on a group with shared interests, identities, or something else they have in common. Others talked more about the concept of a mutually supportive network. Some focussed on this being something that was local or place-based, while others did not specify that community, to them, was location-specific. Some people defined this in terms of care, as being the opposite to being detained in an institution. A couple of people talked specifically about it being somewhere you feel safe, or feel a sense of belonging.

## What people said

"A group with shared interests that pursues mutual goals and offers peer support"

"Unity"

"Those around you, that can support you, often place based"

"The people who share and understand my experiences"

"Network"

"People, organisation or services within the area I live"

"Either a group of people sharing something in common - living in the same space or enjoying the same thing OR the opposite of being in hospital (being in the community)"



“People actively engaged in building relationships, networks, friendships and connections based on a mutual identity or experience”

“This term can be used in many ways, sometimes helpful to create a shared identity, but sometimes it can lead to divisive practice and 'othering' and can promote tokenism or stereotyping. It can cause exclusion, rather than inclusion when not treated with care. Be careful!”

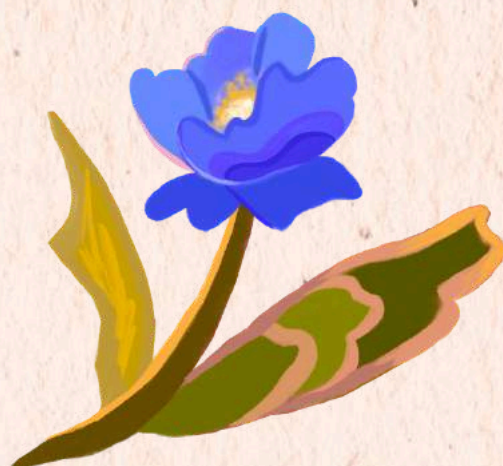
“A place you feel safe, whether it be a place or group of people”

“A group of people to whom one belongs, may be related to place or other interests”

“Group(s) of people who are brought together by similar experiences, beliefs, identities or locations”

“A place or a feeling of belonging within a group of other people”

Interested in the concept of community? Read our report, [\*\*Exploring “community” and the mental health lived experience landscape\*\*](#) (right click and select “open in new tab”).





# Criminalisation

## Summary

Lots of responses to this term referred to the act of making something a crime that was not previously.

## What people said

“Making something that isn’t a crime a crime”

“Being punished for being unwell, pushed into carceral systems like prisons”

“In the context of mental health - taking action to prosecute or punish someone for being mentally unwell”

“Making something a criminal offence or illegal”

“Something becoming illegal, or wrong, or punishable, behaviour being wrongly interpreted and consequences being sought which are not justifiable, lack of justice, harm of wrongful understanding, lack of knowledge and education leading to this”

“The policing of something; attempts to control something or someone through legal means”

“Where people and their actions are framed as inherently dangerous and/or illegal, or decontextualised from the impact of wider systems and structures. They are responded to with punitive measures under the framing that the individual is at fault/inherently 'bad'”



# Co-production

## Summary

This was defined by most people as an equitable partnership between people with lived experience and staff (working in different areas of mental health) on a project or service. Several specified that this should be from the very start, or 'from design to delivery', and mentioned the need for power sharing.

## What people said

"Creating something together from the start, with shared power, values and goals"

"A concept that has been co-opted to do involvement only on the terms of those with the power"

"Power sharing between staff and [lived experience] where all voices are equal and heard from the beginning. Reciprocity"

"Working together in an equal and reciprocal partnership"

"Working WITH not FOR the community who you hope will benefit from the work. An actual meaningful sharing of power, responsibility and decision making, where people with lived experience actually have an equal voice at the table"

"Shared decision making and ownership between people with lived experience and staff working in mental health from design through to delivery of a project/service/resource"

"Rubbish saying, working together, in partnership, big words that are confusing"



# Disability

## Summary

Some responses to this term focused on the idea of disability as an 'impairment', something that makes life more challenging in certain areas, while others highlighted society's disabling role in discriminating against people who have differences to what is considered 'normal' in terms of our bodies or minds.

## What people said

"Anything that impacts your quality of life"

"A condition, impairment or illness that makes elements of life more difficult compared to those without a condition - may or may not be visible - may or may not be life long, could be fluctuating. Not a bad word"

"When people with bodyminds who our society has decided have less value under capitalism are disadvantaged and discriminated against by that society."

"Lack of ability to function within 'normal' parameters, limitations, restrictions on daily life whether through mental health issues, physical issues or anything which has an impact on function. Disability is affecting as a word and suggests one is 'less than', incomplete and less useful. Ableism continues to be a real problem and the 'disabled' really need to be able to feel and truly be 'enabled' within an accepting society"

"Marginalisation due to physical, mental, emotional, social, intellectual or sensory differences to what is constructed as the norm for bodyminds"

"The social model of disability which frames people as disabled by society due to inaccessible, ableist systems and structures"



# Discrimination

## Summary

Many respondents used similar language in their definitions of 'discrimination' as they did with 'disability', defining the term as the experience of being treated differently, while some also included mention of the characteristics protected under the Equality Act. Overall, answers indicated that discrimination involved prejudice or unjust punishment towards someone because of their identity.

## What people said

"Treating certain groups of people differently, in a way that does harm to that group of people"

"To prejudice someone based on factors like race, gender, religion, sexuality etc"

"Treating someone worse because of their identity or lived experience"

"Treating someone/a group of people unfairly because of their identity/protected characteristics"

"Marginalised, treated differently and judged for something. Not enabled. Unable to find the same opportunities as others. Treated as different, wrong, unacceptable somehow"





# Distress

## Summary

Many people chose to respond to this definition with a synonym or other word they felt defined 'distress', such as 'upset' and 'confusion'. Others described distress as a feeling that occurs when you no longer feel in control of your physical or mental health.

## What people said

"Emotional/mental pain and suffering"

"Feel[ing] out of our control and not knowing what to do"

"Extreme anxiety and suffering"

"Having big feelings that you don't feel able to handle"

"Panic, deep seated despair, pain, confusion, overwhelm, crisis, harm, danger"

"Losing control. Trying to make sense of it all at the same time"

"Emotional trauma"

"Overwhelming negative emotion"

"Being in a situation where you are suffering from extreme emotional/psychological pain"



# Grassroots

## Summary

Many people defined grassroots as something that grows from the ground up, collectively across a — often small, local — space. Some people took this definition further in defining the community-based approach of grassroots work, and its often separate identity from more formal structures or organisations, with lived experience at its centre. Others saw the word as defining the beginning of work e.g. the start of growth.

## What people said

“Something that grows from the bottom up, collectively”

“Community-based, outside of formal or official systems and structures”

“Individual people coming together to try and create a better world, outside of the big charity forms of change making”

“Built from the community upwards, usually involving collective holding of power”

“A community of people who want to affect change from the bottom up. To influence positive change encouraging participants, members to take responsibility to become [in]formed and involved”

“The places and people who are at the 'frontline' of experiencing whatever the issues are, and can be the most effective at informing transformation, given good structures to enable this. Genuine lived experience work needs to meet people where they are and for involvement to be organic”



# Healthcare

## Summary

Definitions for 'healthcare' focused on the word 'care' itself and the structures that aim to support it. Both the National Health Service (NHS) and private services were described as having been set up to provide support to individuals' mental and physical health, but many people identified the system's failings and lack of care within current structures in their definitions.

## What people said

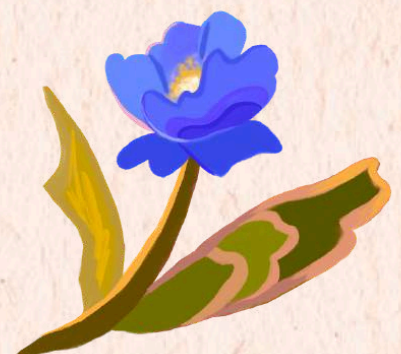
"Care we are all entitled to for our physical or mental health, but a service that neglects us"

"Statutory, private and voluntary organisations providing healthcare"

"Broad! Encompassing so much but it [is] very disjointed and needs to look outwards to holistic care. Should involve prevention of illness and promotion of health, rather than just 'curing' illness"

"Should be exactly as the name suggests, care for health in any way shape or form. Reality is that 'healthcare' often is anything but that"

"Any care which is for the wellbeing of a person"





# Iatrogenic harm

## Summary

Relating to the previous definition, many respondents defined 'iatrogenic harm' as harm caused by the healthcare systems intended to support them. A number of respondents mentioned the potential harms of medication, while others exemplified medical negligence as iatrogenic harm. A few respondents weren't familiar with the term, as it is most often used in academic settings.

## What people said

"Harm caused by the thing that was supposed to alleviate/prevent harm"

"Harm done to us by mental health services, systems, professionals, treatments"

"Medical negligence"

"Harm caused by the healthcare system"

"The outward ripple of negative impact that can come from systems, paradigms, institutions"

"Harm caused by treatment (e.g. mental health services or structures, or interventions like medication or therapy)"

"Bad things that happen in hospitals"



# Identity

## Summary

'Identity' was defined by respondents as something felt and owned by the individual rather than what is assigned to you by society. It was defined as parts of your character which make you unique: your sense of self.

## What people said

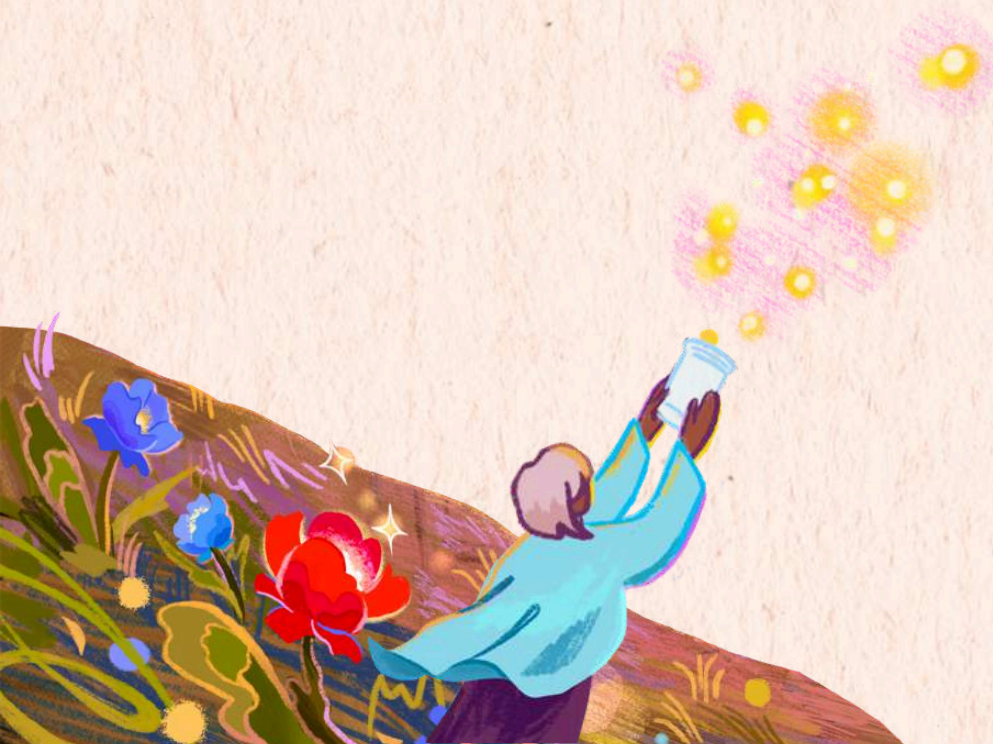
"How you see yourself in the world"

"Someone's concept of self"

"Self, core, ability to know who and what you are, to know your place, to own your space, to know yourself"

"Unique"

"Factors that make up an individual"





# Intersectional

## Summary

The term 'intersectional' was defined as the 'cross cutting' of multiple societal factors or 'issues'. People exemplified multiple identifying factors, such as being both LGBTQIA+ and a woman, in describing the midpoint between these characteristics as intersectional. Respondents also spoke about how intersectionality relates to social justice with regard to the ways in which different forms of discrimination can combine, and in considering how people may work together across communities against discrimination.

## What people said

"Facets of identity/social justice that cross over such as gender + disability + race and the relationship between them"

"The impact of different aspects on one another within a framework, or perhaps the many areas of a person's health which relate and connect, leading to a compounding effect"

"All the different parts of somebody's identity and how they work together"  
"Understanding our experiences in relation to our positionality within society, which is influenced and determined by various factors such as race, gender, socioeconomic background etc"

"Complex way in which multiple forms of discrimination combine or overlap"



# Injustice

## Summary

People described 'injustice' in reference to earlier definitions such as iatrogenic harm, as well as its opposite, 'justice'. Unfair treatment, both on a systemic and personal level, was given as a definition, and the word 'harm' was used multiple times to give an example of injustice.

## What people said

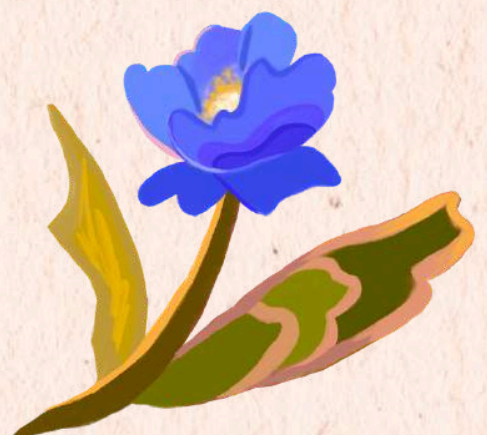
"Treating someone, or a group of people, unfairly. May involve the criminal justice system but often doesn't"

"Experience of things like discrimination and iatrogenic harm, no access to justice"

"Violent acts of oppression and marginalisation, with an understanding that violence can be physical, psychological, institutional, systemic etc"

"Something that is unfair"

"Not being treated fairly, esp in a formal or institutional way, like the law or being detained or not being believed in a complaint"





# Justice

## Summary

In contrast, 'justice' was defined as the fair treatment of people; the state of being free from harm and discrimination. Some people also described justice in its legal sense as something that is received as retribution for a previous harm.

## What people said

"Being heard and recognised for the harm caused"

"Deserved retribution"

"Vindication for a person or community that was done wrong or experienced hardship"

"Fairness, achievement, recognition of something being wrong and being put right as far as it can be, or something changing for the better"

"Being free from harm and discrimination, having equal access, being free from forced treatment"





# Lived experience

## Summary

Respondents defined 'lived experience' both in terms of its direct definition as personal experience of something — often traumatic — and in terms of lived experience's practical application within the world of mental health as personal insight that can be shared with others.

## What people said

“Personal experience of something”

“The stories that make up your experience, especially if they've been traumatic”

“Recognising my experience as expertise other than professional/academic expertise”

“Having lived through something (often MH problems but could be anything)”

“Person who has been through first hand the subject of a topic which is being discussed in discourse for e.g. lived experience of mental ill-health, or lived experience of discrimination”

“Someone's experiences that provide insight, knowledge and understanding from their perspective”

“When someone has experienced something and is using that experience to inform themselves and others”



# Lived experience leadership

## Summary

'Lived experience leadership' was described as the ability for people with personal experience to play a leadership role in the area of work that relates to their experience. People spoke of 'first-hand experience' and the impact of individuals being given power to make change which is influenced by their own experiences.

## What people said

"Organisations being led by those with first-hand experience"

"When people with a certain identity or experience have the position of power, responsibility and decision making"

"The embracing and accepting of those with lived experience, the recognition of the value they have and working effectively with them in all projects and endeavours. Championing them and all their abilities and aspects they have to offer to enable improvements which ultimately helps patients as well as all staff too"

"Where we apply our knowledge gained from lived experience to create, build or lead work that directly responds to the issues and experiences we have lived through"

Interested in the concept of "lived experience leadership"? Read our report, [\*\*Lived experience leadership - mapping the lived experience landscape in mental health\*\*](#) (right click and select "open in new tab").



# Mad

## Summary

This term was met with conflicting definitions but overall defined as a word used to describe people with lived experience of mental ill-health, distress and/or trauma. Some people felt that the word has been reclaimed by individuals with lived experience where once it was a stigmatised word used against this community, while others felt strongly that the word still held negative associations.

## What people said

“Angry, unorthodox, unwell”

“A reclaimed political identity”

“A slur used against those with mental or emotional difficulties or differences from what is constructed as the 'norm'. This term has been reclaimed by many people with 'mental illnesses' or in 'mental health communities', and now often alludes to a more radically left wing social and political viewpoint and/or identity”

“A term we are starting to re-own!”

“Someone who’s brain is pathologised by dominant understandings”

“Not experiencing [society’s] norm of ‘sanity’”

“This can be used in a derogatory way to dismiss, discredit and gaslight people who have been diagnosed with mental illness. However, Mad has also been reclaimed as a sociopolitical identity for people with experiences of mental ill-health, distress and trauma”



# Marginalisation

## Summary

Many people responded to this term with the same definition: 'being treated differently'. Marginalisation was described as removing people's power and pushing them to the fringes of society due — primarily — to an area of their identity or connection to an oppressed community.

## What people said

“Being excluded from society and social goods as a consequence of belonging to a group with little power”

“Being othered and made powerless”

“When someone is treated as lesser than and is excluded from conversations and decision making”

“The targeted systemic oppression of people of certain backgrounds and identities”

“Borders”

“Being pushed to the side and ignored”





# Mental health

## Summary

Respondents highlighted the difference between mental health and mental ill-health in their definitions, emphasising that the former relates more specifically to general wellbeing and is experienced by everyone, but is often confused with mental ill-health. In general it was defined as the state of our mental wellbeing which affects how we feel and think and which operates on a spectrum.

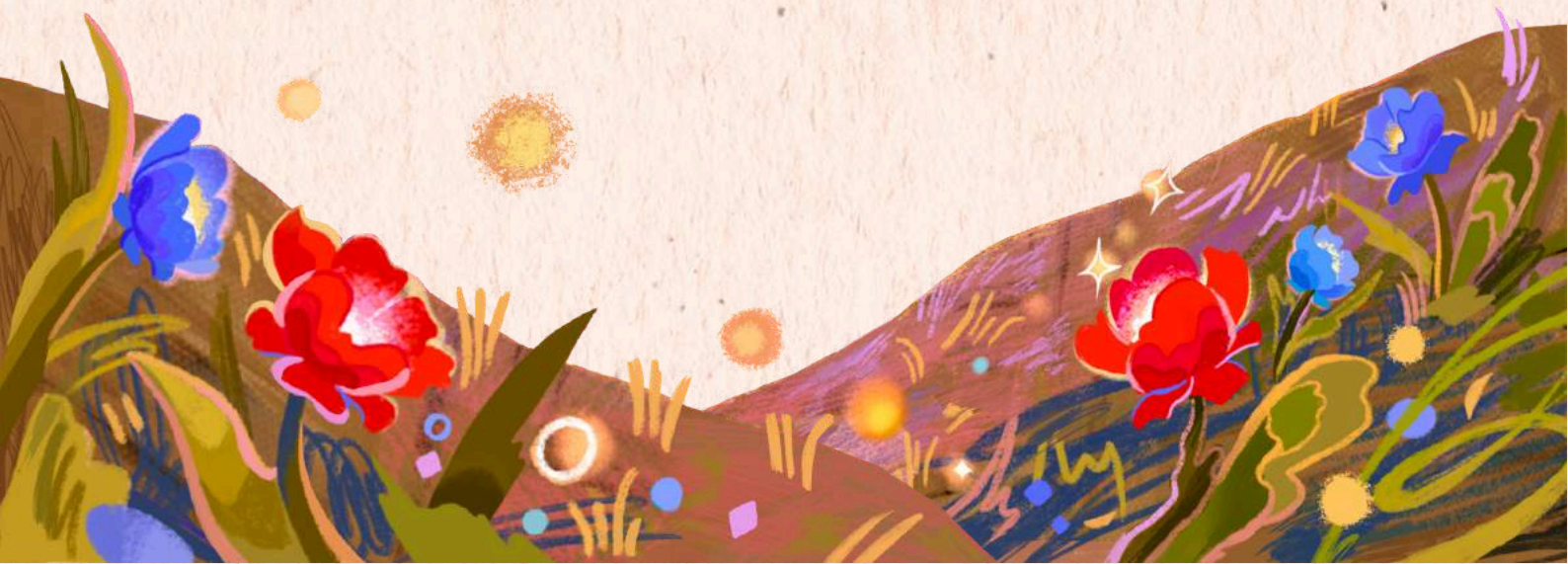
## What people said

“Health related to your mind”

“Overarching umbrella term for mental well being - not to be confused with mental illness as so often it is”

“A spectrum like physical health. We all have it. Some people are very well, and some are very ill and most of us are somewhere between extremes but we can move along this in either direction”

“Part of someone and how they feel, think and behave”





# Power

## Summary

People defined 'power' in relation to control and who has or does not have it. Power was defined as the ability to influence and make change and which has both positive and negative impacts depending on how it is used and by whom. It was also highlighted that power can be difficult to recognise, and within the context of mental health is often weaponised through access to resources and knowledge.

## What people said

"Being able to control people and things to ensure personal advantage."

"Influence to make change"

"When someone holds more power than you, in mental health services there is a power imbalance where treatment providers hold all the power"

"Power is often weaponised. The trouble with fighting for power is that in a tug of war, even the winners fall over. Instead of trying to gain power, let's all let it go, and seek to serve as a leadership model"

"Something that is held and withheld and can be hard to recognise, define, share or grasp"

"Access to resources, knowledge, and the ability to make impactful decisions"

"Often within MH settings, the power balance is skewed in favour of the worker not the patient/service user."



# Recovery

## Summary

The term 'recovery' meant something different for each respondent. While some people felt that it defined a process of returning to the life that was lived before the onset of mental ill-health or getting 'better', others described it as adapting to live well in your new state or identity. Finally, some people defined recovery as a process rather than a final state, or rejected the term completely.

## What people said

"Something that is not possible for me and something that mental health services want me to do for good stats"

"Nonlinear process of finding oneself after a period of illness which may never be cured. Adapting, accepting and living with your condition as well as you can"

"Individual, often co-opted based on societal norms e.g. having a job or coming off benefits"

"A journey not a destination"

"The ability to recuperate, learn from distress and ill health and recognise how to manage one's mental wellbeing on a daily basis. Being aware of triggers and stressor and knowing how to manage oneself or seek support to do so if necessary"

"Getting a bit better over time. A difficult term for those for whom it is not possible or for whom staying stable is considered a challenging enough aim. I think it puts pressure on people to get better which is not always helpful"



# Restrictive

## Summary

Many respondents defined the word 'restrictive' in reference to human rights and the removal of them in enforcing treatment or taking away freedoms. Some described it as the taking away of choice or control in relation to mental health treatment, and the feeling of being trapped and limited by an institution, medicine or individual.

## What people said

“Stripping away of human rights”

“Being blocked from doing this, losing freedom, for example on a ward, or being told your freedom is conditional on you do[ing] something”

“Having your personal freedoms curtailed due to perceived mental ill health, distress or trauma”

“Putting barriers in place that control someone. This could be through direct physical constraint or indirectly through social or legal barriers”

“Practices and environments that limit a person's autonomy”





# Representation

## Summary

Respondents described 'representation' as being seen, both in terms of seeing a member from your own community speak on your behalf, and seeing people who share your identity or experiences in a position of power or authority. Some definitions were similar to what was said for 'advocacy'. However, people spoke to the limits of 'representation' and the dangers of expecting one person to represent an entire, diverse community.

## What people said

"Being seen by a society through a nominated individual"

"Where your opinions may be raised by others with a seat at the table. true representation is a myth as we are all unique"

"Seeing people like you in important places that makes you also feel seen and valued such as in leadership positions, in the media"

"Usually a person involved to present the voices of a particular 'group' of people. Can be tokenistic or limited. e.g. I cannot represent all disabled people"

"Societal recognition of someone; being able to see people like yourself in society"

"The visibility of people from different backgrounds, cultures, identities and experiences"



# Safeguarding

## Summary

The words 'vulnerable' and 'harm' were shared multiple times in respondent's definitions of 'safeguarding'. Safeguarding was defined as the act of protecting people against harm, abuse, neglect or injury through policy and procedure, though multiple people highlighted systematic issues present within safeguarding which often fail those it aims to serve, or put them in the path of other forms of harm.

## What people said

"Looking out for those who are vulnerable to manipulation, harm, bullying, coercion etc."

"Supposedly something that's meant to keep us free from harm but can actually deliver us into the hands of people who will e.g. section us "for our best interests" but maybe against our will because there are no alternatives"

"Keeping people safe from harm, procedures etc."

"Practices and/or policies put in place in order to keep people safe within systems. Often conversely used to protect systems from legal or social ramifications, rather than the people within the system"

"Practices and systems put in place to monitor and ensure safety. However, these practices and systems can often fail to ensure safety due to being carceral in nature or failing to respond appropriately or sufficiently"



# Safety

## Summary

The word 'safety' was defined as a feeling of freedom from harm, describing an emotional or physical space where you are able to be yourself without any risk or threat.

## What people said

"Being physically or psychologically free from harm"

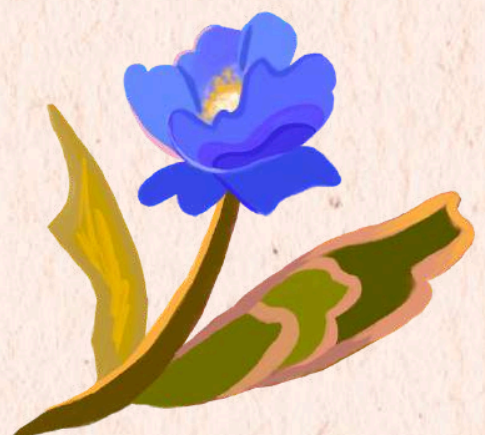
"Finding place, finding space where you are not going to be harmed in any way"

"Care"

"Feeling that you can exist and be your authentic self without retribution or harm"

"When we are not at risk of interpersonal, institutional or systemic harm"

"Looking after yourself or others"





# Service user

## Summary

While the majority of people defined 'service user' in its literal sense: an individual who uses a particular service, and in this context, most often a mental health service, some respondents highlighted the ways in which the term is transactional, stigmatising, and strips the individual of their identity.

## What people said

"Someone who is or has been a user of a particular kind of service (usually mental health)"

"A term that reduces people only to their 'use' of mental health services"

"Usually a patient but can also encompass carers. Often also used for lived experience personnel even if they are no longer using services!"

"Awful term, someone who uses an organisations services"

"A person who uses a service, or who wants to use a service but is somehow prevented from doing so through the services' practices"

"Someone who accesses health and other services, sometimes called patient, best word would be person!"



# Solidarity

## Summary

Multiple respondents defined 'solidarity' as standing together, or standing as one, to describe the act of working alongside a group towards a shared goal, or simply expressing empathy and togetherness with a specific community or individual.

## What people said

“Standing with others to fight for a cause”

“Powerful empathy”

“Doing something to forward the rights or aims of others, even if you aren't directly affected by the same system(s) of oppression”

“Acknowledging that we are all impacted by the same systems of oppression and building collective power to resist this across a diverse range of experiences and movements”

“Mutual connection and support with others with shared experiences, helping each other”





# Survivor

## Summary

In this context, 'survivor' was defined as someone who has lived through either an experience within the mental health system, or an instance of trauma and/or mental ill-health. Some respondents went further in defining a survivor as someone who uses their traumatic experience to empower others.

## What people said

"Someone who has survived mental health services and/or iatrogenic harm"

"Someone who has survived something harmful, whatever it is, or is continuously striving to survive the ongoing harm they may experience, no matter what the cause or circumstance"

"Someone who has lived through something very difficult. In the context of mental health, this term is often used for people who have been through mental health systems, especially if they have been incarcerated due to their mental health"

"Having got through trauma and forced treatment"

"Someone who thrives or empowers after they have lived through a life changing event"



# Trauma

## Summary

'Trauma' was defined by respondents as an event or series of events that had a negative or distressing impact on the mental health of the person affected. Some people defined trauma as a specifically long-term impact, while others defined it as any event in the past which had any kind of negative impact.

## What people said

"An event (or series of events) that caused distress"

"Result of emotional conflict, harm or abuse"

"The terrible and potentially lasting impact of awful experiences, whether past, present or ongoing"

"Anything that leaves a mark on someone"

"bad things that happen to someone and is very subjective - trauma is always valid to the person who experienced it but not always understood by others"

"Harm from system and environment"





# User-led

## Summary

People linked the definition of 'user-led' to the previous definitions of both 'service user' and 'lived experience' in defining the term as something explicitly created and led by a service user or a person with lived experience. Whether a sole activity or whole organisation, user-led was described as a process implemented by people with first-hand experience of its subject.

## What people said

"Being run by and for people with similar experiences"

"A movement led by the service-users"

"Activity or organisation which is led by people with direct lived experience of the issue at hand"

"Led by a person or people who have used a service. This does not necessarily mean that they have designed the system or thing that they are leading, or been consulted on its creation"

Interested in user-led groups and their needs? Read our report, [\*\*What do user-led groups need\*\*](#) (right click and select "open in new tab").



# Visibility

## Summary

In the literal sense, 'visibility' was defined as being seen and heard, but respondents developed on this by describing the significance of witnessing people with similar experiences or identities in places of power.

## What people said

"Being seen, being heard"

"How much people who are from underrepresented communities are part of and seen in the wider picture of an organisation"

"How accessible information is"

"Someone being seen and understood for who they are and choose to be"





# Voice

## Summary

People defined 'voice' as the ability to be heard and listened to when speaking, rather than the act of speaking itself. Voice is not only the words or signs themselves, but access to the ways in which they can be communicated effectively and impactfully.

## What people said

"Being able to make choices and have my opinions and experiences heard and acted upon"

"To be able to speak up and express views and opinions"

"To be heard, to have something to say, to matter, to contribute meaningfully"

"Our ability to tell our own stories and experiences"

"Enabling the issues of people who feel unheard to have a voice so that their narrative can be useful to validate not only their own experience but to be of use to others"

"Being heard and understood"

"Personal experience, representation and/or views communicated. This is not limited to vocal communication, and could refer to communication via text, sign language, etc."



# Vulnerability

## Summary

'Vulnerability' was defined both as the conscious act of opening yourself up to the world by showing your true emotions without fear of harm, and as an unconscious or assigned characteristic of a person who may be, or may be perceived to be, less able to protect themselves from harm.

## What people said

"A paternalistic and patronising concept assigned to us"

"Being open to experience all emotions"

"Susceptible to further harm and trauma"

"We all have vulnerabilities, but they come alongside strengths"

"Either passive in the sense of being a person with less structural power due to illness or other disadvantage, or chosen, in terms of offering your 'vulnerable' self in order to communicate authentic experience or to enable others to feel safe to do so also"

"How exposed a person is to harm. Can often be used in a paternalistic way to dismiss the knowledge and power held by people and communities, framing them as inherently 'at risk' rather than systems and institutions as inherently oppressive"





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