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What do we mean when we talk about

Recovery?

A guide and practical toolkit to support 'What matters to me?' (2021 – 2026 Recovery Strategy)

Caring, Learning
& Growing Together

Contents

*Glossary Terms (highlighted throughout in ***bold, orange italics***) are explained in plain English at the back of the document

Using this Toolkit

And understanding why it was written the way it's written

This resource has been created to help service users, patients, family, friends, carers health and social care staff, students and volunteers better understand 'Recovery'; what it is, why it's important and how to implement it within your own recovery journeys or in the way you support others with theirs.

Combining the wisdom of lived experience and scientific evidence, this unique toolkit has been directed, designed, written, produced and revised in collaboration between people with both personal and professional experiences of mental health. Based on the discussions surrounding the development of Humber NHS's refreshed Recovery Strategy 2021-2026, ***service users, patients, carers*** and staff within the Humber Teaching NHS Foundation Trust community have driven and coproduced this guiding document through a number of surveys, group workshops, interviews, 1:1 conversations and steering groups. You will see their quotes in ***bold, green text*** and are sure to hear their voices woven throughout this document.

Collaborators felt it important that this resource offered the practical tools needed for service users, carers and staff to better understand and / or implement Recovery. Therefore, it was essential that this be useful and practical, alongside being honest, visual, insightful and accessible.

Colourful diagrams can be printed out and displayed, or used as a teaching resource, easy-to-remember metaphors can help explain and remember guiding principles, and the Glossary at the back of the document can be quickly referred to.

We hope we have succeeded in reflecting the diversity and flexibility of self-defined recovery and that this resource proves to be a helpful guide to all those pursuing Recovery within our shared community.

Introducing the Recovery Approach

An introduction into the philosophy behind this evidence-based, best-practice mental health care model

Living alongside mental health conditions

There is no single definition of the contested term 'Recovery', but within a mental health context the term 'Recovery' is most frequently used to describe the personal lived experiences and healing journeys of 'people with severe and enduring mental health conditions with long term needs' (Deegan, 1998, Anthony, 1993),

Recovery is a **non-linear** process of **rebuilding** after a ***crisis***, taking **responsibility** for personal wellbeing and **learning to live alongside any continued symptoms or impairments** without the pressure to eventually be symptom-free. By focusing on existing and potential **strengths, skills and resources**, an individual can pursue what they consider to be a **satisfying and meaningful life**. Learning from one's **peers**, someone can work towards their own **self-defined goals** at their own pace. This process of rediscovery is often referred to as a '***Recovery Journey'***.

"Recovery does not mean cure. Rather recovery is an attitude, a stance, and a way of approaching the day's challenges. It is not a perfectly linear journey" **(Deegan, 1996)**

Because of a **collaborative, holistic and person-centred approach to care**, people are empowered to lead those who are there to support them.

Sources that informed the content on this page: SAMSHA's 'Components of Recovery'

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What does Recovery mean to me?

As told by our Humber NHS community

Being whole again, OR being on the road to wholeness / wellness, OR having accepted one's limitations.

Difficulties still exist but they're no longer your entire existence – you learn to manage and live with things that have previously been detrimental.

Using my voice.

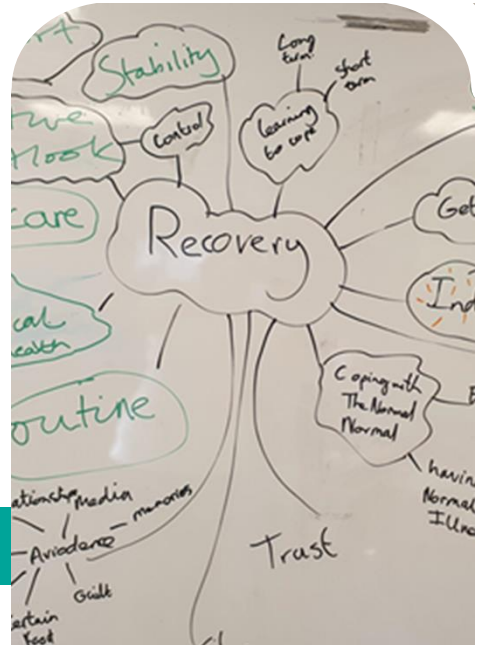
Able to live a full, happy, productive life, within my realistic parameters, at home in the community - with support from services if and when necessary.

Trying to put things back to where they should be.

It's the process of choosing what steps (big and small) you take to move forward - with me or others as support - towards your own understanding and definition of Recovery.

Working on my own self-health with support from professionals (who do not merely dole out pharmaceuticals but KNOW about therapy, prevention, self-care and other strategies) to help keep me well and flourishing.

A movement away from patriarchal, traditional, institutional approaches to mental health. A redistribution of power.



Learning to self-manage mental health symptoms as far as I'm able… but getting person-led help when I need it.

Survival

I think it can be helpful to think about Recovery as a continuum that everyone is on somewhere, some more than others.

To feel safe and largely content with my thoughts and feelings so that it does not have a negative impact on my day.

Caring, Learning & Growing Together

"A meaningful life beyond diagnosis without having to be symptom free."

Meaning and expertise through self-discovery

Making sense of and finding meaning through our unique lived experiences

No, it doesn't mean 'getting better'

When someone says the word 'recovery', most of us think about reaching end goals or experiencing a linear general cessation of symptoms following illness. This idea comes a ***medical model*** of recovery. The word 'recovery' itself suggests 'getting better' - which is part of the reason that lots of people don't really like that word. Many people feel that it doesn't accurately portray what mental health post-crisis is like in reality, and some people with intellectual disabilities or with life limiting illnesses also find the term inappropriate.

Medicalised notions of recovery may be appropriate for some physical conditions (e.g. fractures) but not for mental health and lifelong conditions. This type of recovery, which often evolves and changes over time, focuses more on how we manage and live a meaningful life alongside our experiences, instead of trying to 'get rid of them' with a 'cure'.

This unique process of discovery, or rediscovery, is typically called a ***Recovery Journey.*** And no two journeys are alike.

Hope, Agency and Control

Whilst Recovery is a personal process that is entirely exclusive to the person experiencing it, three concepts are widely considered to be present within meaningful Recovery work. The 'three central pillars of Recovery' are Hope, Agency and Opportunity.

Based on the Hope Agency Opportunity (HAO) measure as developed by University of Southampton and the Southern Health Recovery College

A realistic focus on self-expertise

Recovery is about valuing and learning from personal life experiences to become a better expert in ones self-care. That 'ownership' over ones experiences is the foundation of what enables meaningful change.

An individual can make sense of experiences by rediscovering who they are outside of any mental health diagnosis or situation, learning about the nature of their condition(s) and identifying what works well (and what doesn't). It is a journey of self-discovery and learning which helps a person to develop their own unique, preventative brand of resilience.

This ***self-expertise*** and self-awareness empowers people to make informed decisions for themselves and become more confident in telling others what they need (and what they don't).

It also includes the ability to recognise when extra help is required and give over control of some things when they feel it's needed. In this way, self-expertise does not equate to self-reliance, or independence (which is what many people think it means). Humans are social beings that rely on each other for support. Self-expertise is when people spot manifesting warning signs before it becomes too much of a problem, do things that build resilience, ask for help and say what is needed in difficult times and plan for the future should they experience difficult periods or relapses again. Of course, it's a good idea to learn from the experiences and expertise of others, but an individual's own life experiences are the most valuable thing they could possibly have in their arsenal.

Blending different kinds of knowledge

Good recovery-focused practices tend to result from meaningful three-way conversations between 'me', an Expert in oneself, other ***Experts by Experience*** (e.g. family / friends / ***carers*** and ***Peer Supporters***) and ***Experts by Profession*** (i.e. Health and Social Care professionals). This is similar to the ***Triangle of Care***. It is important to remember that some people may have expertise spanning two or more of these.

Blending these different kinds of expertise can help inform effective yet compassionate routes forward within both personal recovery journeys and in organisational decision making.

The Recovery Approach values and blends both lived and trained expertise, using this diverse spectrum of knowledge to support personal recovery journeys and in organisational decision making. This process of working together as equals is referred to as ***Coproduction***.

What Recovery is (and what it isn't)

Clearing up some of the assumptions and misunderstandings about the Recovery Approach

It can be helpful to remind ourselves what 'Recovery' is *not*, since the concept is very frequently misunderstood, misused and in turn, sometimes abused.

Recovery is …

- ✓ A journey for some, a destination for others
- ✓ Placing the person and their self-defined goals at the centre of their care
- ✓ Having choices and advocacy
- ✓ Valuing personal lived experience and the resulting personal growth
- ✓ Strengths-based learning
- ✓ Coproduction and shared decision making
- ✓ Challenging stigmas and blurring the harmful 'us-them' distinction
- ✓ Building relationships and connecting to others in the community
- ✓ Addressing power imbalances through the disuse of disempowering language and outdated, patronising and/or discriminatory clinical practices

Recovery is <u>not</u> …

- × Something 'extra' I, or others, now need to do
- × 'Just the latest model' that will be replaced with something else before long
- × That others are responsible for my wellbeing
- × Something that doesn't apply to 'my patients' or 'my role'
- × A complete cessation of symptoms achieved as a result of 'making' people independent and 'normal' through 'interventions' and 'treatments'
- × Closing/Replacing existing services
- × That contributing to society can only happen after the person has recovered
- × An excuse to shift all responsibility onto the me
- × About living 'symptom-free'

The CHIME Framework

The values that inform how key Recovery Principles are implemented

Although each individual recovery journey is different, we can use the CHIME framework to help us remember the core Recovery Principles which support meaningful personal recovery. This widely used framework can be used in tandem with other recovery-oriented tools/frameworks when planning personal recovery journeys or when implementing recovery values throughout services.

C – Connectedness

- Peer support
- Social groups
- Relationships
- Support from others
- Community
- Feeling connected to someone, or something

May include connection to: Self, family, friends, places, nature, culture, hobbies, activities, interests and beliefs

H – Hope

- Belief in recovery
- Motivation
- Inspirational relationships
- Positive thinking
- Valuing effort
- Having aspirations
- Hope for the future

I – Identity

- Rebuilding a positive sense of identity and self-esteem
- Challenging stigmas
- Having an identity outside of diagnosis or symptomology

Identity markers may include: beliefs, occupation, hobbies, connections, purpose, relationships, experiences or cultural background

M – Meaning

- Living a good quality life of purpose (as defined by the individual)
- Finding meaning in experiences
- Purposeful life / social roles
- Spirituality

E – Empowerment

- Becoming an expert in ones own self-care
- Personal responsibility
- Focusing upon strengths
- Advocacy
- Having choices
- Doing what you want to do
- Accepting help

Sources that informed the content on this page: Diagram based off Leamy et al. (2011) 'Framework for personal recovery' model

Understanding Recovery Journeys

Lilypads and Relapses

Rebuilding Life

Meaningful mental health recovery is about rebuilding life, making sense of what has happened (or is happening) and finding meaning from it whilst developing a new sense of self and purpose. This may be with or without a continuation of symptoms, whether that means constantly or fluctuating.

> **People still seem to think that a cessation of symptoms is the default, rather than being something the person is probably going to need to learn to live with. I soon found out I had to. People need to manage their expectations.**

This ongoing process of navigating, acknowledging, learning, reflecting and growing following a crisis or difficult period is referred to as a 'Recovery Journey'. It is the process of becoming an expert in one's own self-care, (re)building resilience and (re)discovering who one is… and making the steps that towards what the person finds important.

However, this is not a mechanistic process of getting from A to B, or a rugged, romanticised, individualistic voyage of optimistic self-discovery or self-sufficiency where 'everything is within your reach if you just try hard enough'. This attitude sets people up (especially for those with long-term, psychosocial disabilities) for failure.

Recovery Journeys and Lilypads

Recovery journeys tend to evolve and change over time as we take steps towards where we next want to be. When we reach that goal, or change our minds, we may set our sights on a new goal, or decide that we're happy as things are (and least for a bit).

No matter which route a person's journey travels, it is incredibly important that the individual directs the pace, route and destination of their journey.

Imagine a pond that is full of lilypads, and in the centre is a frog, poised on its own lilypad. It is the choice of the frog about which lilypad it next wants to reach, where it wants to get to, when it

wants to move and how long it wants to stay there before moving on again. It might not be interested in going to certain lilypads, or might want to leap over one lilypad to reach one beyond it. At different times it may want to stay in the pond or rest on the bank. Much in the same way, a person navigating their recovery journey decides what to goals focus on, and when, and how long for.

The person can also decide who they want to bring along with them on their journey, and in what capacity. In this vein, people supporting this person cannot make the 'leaps' for them or wrongly coerce them to be on a 'lilypad' they're not ready or wanting to be on. But supporters can share in the highs and lows, help instil the person with confidence so they can make the next 'leap', share tips on how to navigate the 'pond', spot additional 'lilypads', point out warning signs or maybe even help move some 'lilypads' closer together.

> **Recovery is different for each individual and no amount of predesigned pathways or options will work for everyone – staff need to understand that it's their job to think responsively and flexibly.**

This means that no two journeys are alike. For some people, these journeys have a fixed end point, for others, it's an ever-evolving process of reflection and learning as they visit and revisit a whole array of lilypads.

Personal recovery is uniquely messy

A typical recovery journey is messy. It's often quite painful, especially when expectations (of self or staff) are not managed. It is very easy to 'overshoot' goals, think it's going to be straightforward… and that's without factoring in the curveballs that life throws at us.

> **There's always far too much emphasis on the 'positive' side of Recovery. It's not always plain sailing and it's damaging to be eternally optimistic.**

We can bully ourselves and beat ourselves up when things don't go according to plan. It's very common to stumble, get lost, feel overwhelmed or need a period of rest. We even may find that sometimes things get too much to handle and we ***relapse*** into crisis. Using the lilypad metaphor, this might be when the frog falls

into the pond. It's important to remember that relapses are not steps backwards (or that

we've somehow 'failed') but rather paths we weren't expecting to navigate right now, and that it's probably time to reflect on what's happened, learn from it, maybe change some things and reassess what is going to be the most helpful thing to do moving forwards.

At times like these, we can lean on our supporters for additional help and guidance until we feel more in control again. We can learn from these unexpected detours and be able to recognise potential warning signs in future.

"There are times of rapid gains and disappointing relapses. There are times of just living, just staying quiet, resting and regrouping. Each person's journey of recovery is unique. Each person must find what works for them; the aspiration is to live, work and love in a community in which one makes a significant contribution."

(Deegan, 1996)


Getting active in the local community
Connecting to others
Working on relationships
Taking it easy
Peer Support
(Receiving / Offering)
Developing expertise in self-care
Volunteering / giving back
Education and Training
Employment
Pursuing meaningful activity
Developing meaningful skills / hobbies
Where do I want to go to next?
Navigating inequalities
Developing Living Skills
Managing roles and responsibilities, Citizenship
Tackling housing issues
Handling finances
Therapies
Accessing specialist services
Respite
Medication
Managing addictions
Diet and Exercise
Managing physical health
Reflection
Spiritual Growth
Rebuilding identity and self-esteem
How can I best support you to explore and define your own vision of Recovery?
NHS

Person-led approach: Leading from the front...

… and being reassured that others have "got your back"

"Knowing that I've got that back up makes all the difference"

Recovery is more than just learning about and responding to what someone finds important, it's also about helping someone to feel confident and empowered in making their own choices.

Much like the Captain of a ship, **the it is the role of the individual to set the pace, route and destination,** feeling reassured that they have a diverse team of knowledgeable experts behind them who are able to offer different kinds of support for as long as they need.

If the individual decides that they do want support at this time, their team will include both Experts by Experience and Experts by Training/Profession, and may include people from their existing support network (family, friends and carers) should they choose to include them. Everyone involved has something valuable to offer the individual throughout their Recovery Journey.

On occasions when the person feels unable to make some decisions, or when they're at serious risk to themselves or others, they can trust that their supporting team can work collaboratively to act in their ***best interests*** until they feel ready to take the metaphorical reigns again. It is important to remember that some members of the supporting team may also be simultaneously navigating their own recovery journeys; extend compassion and understanding to any carers, family, friends and colleagues.

Diagram developed by Lauren Saunders in response to coproductive Recovery Strategy workshops (2020-21)

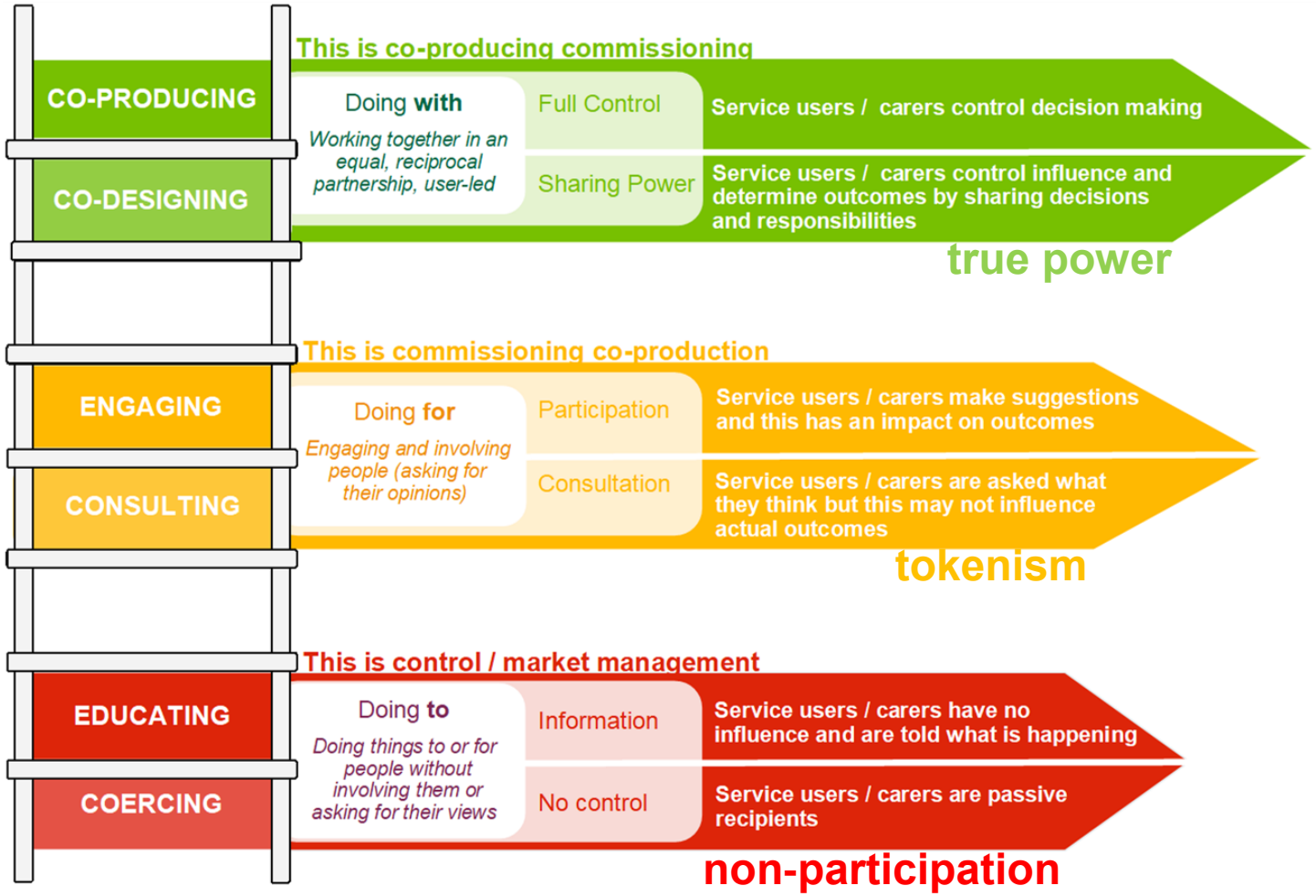
What is Co-Production?

Ladder of Participation

Coproduction must underpin how services, ideas, initiatives and personal plans are led and implemented at all levels of service delivery, from individual care planning to organisational change. This ensures that those accessing services and support have ownership over their care.

Coproduction is more than asking people for their opinions and thoughts. it's about **empowering people to design, create and deliver quality, *user-led initiatives* for themselves.** The role of staff is to offer professional expertise, support and guidance.

We can use the Ladder of Participation (based on Arnstein's 'Ladder of Citizen Participation') to understand and reflect on the distribution of power.



Sources that informed the content on this page: Arnstein's Ladder of Citizen Participation (1969),

Working in equal partnership: A jazzy approach

Co-create. Co-design. Co-deliver. Co-produce.

Coproduction is a back and forth conversation between equals, a space where participants build upon the contributions of others. A good way to think about this is to imagine an ensemble of musicians deciding how they're going to spend their afternoon together.

Traditional, classical schools of musical thought teach that pieces of music (which were often composed a long time ago by 'geniuses') should be played exactly the same, every time they're played, by everyone playing them. It's a rehearsed, one-size-fits-all approach that leaves very little room for individuality or 'heart', much like the traditional approach to healthcare. The musicians are also unlikely to share the same repertoire or possess similar levels of musical ability.

Alternatively, they could take a jazzy, improvisational approach. This is when player begins with whatever feels right, to which the others listen. They respond in a way that matches the key, tone and tempo set. They collaborate, using the strengths of their instruments to coproduce a unique musical score which celebrate their individual and collective musical strength. Nobody needs to know pieces by heart, or have sheet music to hand, and those with less musical experience or confidence can easily contribute. There might be the odd wrong note or missed beat sometimes, but that's expected in jazz; they simply adapt and make it work. They continue to listen, learn and respond to each other the whole way through, careful to give each other an equal share of the spotlight. When the music reaches its natural conclusion, they celebrate and reflect on their improvised and collaborative masterpiece.

Coproduction is like improvisational jazz:
A deliberate, unique, evolving and participatory process of listening, learning and responding towards achieving a meaningful shared outcome.

Top Ten Tips for Coproduction

As advised by ImROC

1. **Gather the right people for the job**

   Identify key stakeholders for an initial meeting to discuss the challenge and use this group to generate a network of peer, family member, personal and professional expertise offering a diverse coproduction group with relevant skills, knowledge and experience. Identify all of the assets in the room (not only those related to their role). Be prepared to invite new individuals and/or ask for advice and contributions from other relevant groups. Allow free movement so that people can choose to join after it has started or choose to leave if they feel it is not for them. Make this an inclusive experience. It's important to avoid the perception of cliques often associated with conventional methods of 'involvement'.

2. **Just get started and build momentum around your shared purpose**

   Don't wait for the perfect moment, or the perfect set of people but build momentum and expertise around your shared purpose and understanding of the process. This will act as an anchor when things get tough.

3. **Spend time agreeing the structure and values of meetings**

   This may involve assigning a leader or facilitator; discussing the rights and responsibilities of members and considering how everyone can both 'give' or contribute to the task as well as 'take' or benefit from their engagement. Ensure that everyone understands what decision making power lies within the group.

4. **Support every member to contribute to their full potential**

   Nurture, support, offer learning opportunities, make necessary adjustments and enable everyone's voice to be heard. Take an even-handed approach across the group, adapting according to need, not label – avoid the temptation to 'other' those who may be less experienced or confident in the setting.

5. **Tackle the challenge in small steps**

   This process will create new ideas, present new challenges, suggest new solutions which require further exploration. Test lots of ideas. Make it safe to fail. It is not possible to work to a predefined set of outcomes in a predetermined time frame.

Sources that informed the content on this page: ImROCs 'Coproduction – Sharing Our Experiences, Reflecting On Our Learning' (2017),

6. Listen, listen, listen

Co-production will only achieve its full potential if every member is prepared to listen and learn, see different perspectives, try new ways of thinking and consider new ideas. It is important for everyone's voices to be heard, so members will need to gauge their input so that those who find it more difficult to speak up have that opportunity. However, the overall 'culture' of the group is one of valuing everyone's contributions and genuinely exploring their utility in the given context.

7. Back up decisions with evidence

One of the concerns about co-production is that any decisions will be based on personal experience rather than 'hard evidence'. The challenge for the co-production group is to back up personal experience with research that demonstrates this goes far beyond one individual. This does not need to be large scale statistical research; accumulated personal narratives, qualitative research and routinely collected data that can be used to demonstrate a level of need or the efficacy of a suggested approach. It is also possible to increase authenticity and credibility by 'sense checking' certain aspects with a wider audience.

8. Beware the comfort zone

Keep a watchful eye to avoid slipping back into old familiar ways, and be mindful of the triggers – such as challenging conversations, differences of opinion, or external pressure to deliver. Be willing to talk openly about this, and regroup around your shared purpose. This is a particular challenge when you increasing the scale of the project – this rarely happens easily or smoothly but needs careful attention

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9. Look to the bigger picture

Consider how your project can influence behaviour, attitudes and outcomes in the wider system. Grasp opportunities to lead others. Even better, create them!

10. Cherish what you create

Co-production comes from the heart. You are building a community like no other. Recognise and embrace its value, strength, wisdom, and potential. Nurture it, celebrate it, love it. It will reciprocate in spades.

Sources that informed the content on this page: ImROCs 'Coproduction – Sharing Our Experiences, Reflecting On Our Learning' (2017)

Collaboration on an individual level

How is it different to group / organisational coproduction?

Coproduction or collaboration?

"I am in control of my own Recovery Journey and so care should be done 'with me' and not done 'to' or 'for' me. I am involved every step of the way. The whole process, from assessment through to review is transparent, clear and in a language I can understand."

Coproduction on an individual level is different to coproduction at a group level. Individual levels of coproduction can be referred to as a 'descriptive' level of coproduction; that is, that at a minimum, there is a 'degree of collaboration in order to achieve an outcome for the person in receipt of the service, and at its most successful, individuals are engaged in an active role or leading their own recovery' (Lewis et al, 2017).

Collaboration and shared decision making is key to any therapeutic relationship, and can be recognised as coproduction in nature, but it is important to distinguish its difference to larger scale, transformative coproduction that challenges and changes the status quo on a wider, organisational level. Although there is difference in the meaning, implementation, scale and impact of the two, many people use the term 'coproduction' to describe both individual and group collaboration / coproduction.

Coproducing person-led care / support planning

An individual can rely on the expertise of their supporters to help them to co-create care that they are in control of. This care reflects their preferences and best supports their personal goals. They might also find it helpful to create a ***Wellness and Recovery Action Plan (WRAP)*** to help document and remember what they find helpful, which they can then share with supporters. Their care includes plans that also detail their wishes for those times they feel unable to make decisions or take the lead. These are commonly referred to as **Advance Statements.** That way, a person is still in control of their care, even when they feel they're not.

Sources that informed the content on this page: ImROCs 'Coproduction – Sharing Our Experiences, Reflecting On Our Learning' (2017)

Coproducing person-led care

"What matters to me?" - what can individuals expect from collaborative care?

Co - assess

- My care and support plan is about the whole of my life and what I find important, not just about assessed health, social or financial needs
- I am encouraged to reflect on my experiences, and I know I am listened to and taken seriously by others when I say what does and doesn't work for me
- When reviewing, I can contribute my honest views to both change my own plan but also improve the system

Co - decide

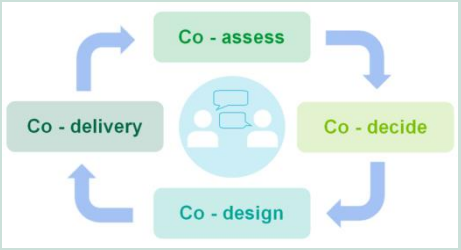
- I feel supported to choose my next steps, based on my own aspirations and goals
- I am able to compare options and make informed, preference-based choices
- I am encouraged and supported to think creatively about ways to achieve my outcomes
- I have all the information I need to plan, when I need it and in an accessible way, including ***signposting*** to what is available locally
- If I need help to plan, I can choose who supports me through the process and to put the plan into practice.

Co - design

- I am trusted to write my own care and support plan - with whatever help I need
- My plan is designed to fit my goals, context and capabilities. Any clinical interventions are designed to minimise the burden of treatment
- People who support me to plan have a flexible, open, honest, positive, solution-focused attitude
- I can involve friends and family if I choose

Co - delivery

- I am supported to contribute to my own care and take responsibility for my wellbeing
- I am supported to take risks, and know it is OK to make mistakes and change my mind
- I know what to expect and when to expect it, because people do what they say they will do



Sources that informed the content on this page: Care and Support Planning Guide, National Co-Production Advisory Group for Think Local Act Personal and Coalition for Collaborative Care.

Reflection Tool: Is what we're doing coproduced and collaborative?

We can use this coproduction table to reflect on where we are

"Not about us, without us!"

Responsibility for the delivery of services	Responsibility for the design of services: Professionals as sole service planner	Professionals and ***service users*** / community as co-planners	No professional input into service planning
Professionals as sole service deliverers	Traditional professional service provision	Professional service provision but users / communities are involved in planning and design	Professionals as sole service deliverers
Professionals and service users / communities as co-deliverers	Service user co-delivery of professionally designed services	**Full co-production**	Service user / community delivery of services with little formal / professional input
Service users / communities as sole deliverers	Service user / community delivery of professionally planned services	Service user / community delivery of co-planned or co-designed services	Self-organised community provision

Sources that informed the content on this page: Carneigie Trust (2006)/Boyle and Harris' (2009) Coproduction Table

Recovery-led Communication

Fear-based relationships are about what's wrong, hope-based relationships are about what's possible

Relationships enrich Recovery

The relationships a person has with those supporting them can make or break a recovery journey. Therefore, it is important to cultivate qualities and demonstrate behaviours that are helpful, respectful and person-centred, and avoid those that are unhelpful, outdated and paternalistic.

"Connection is a bridge built by vulnerability"

The medical model of healthcare makes it very easy to dehumanise or be judgemental of those around us, whether we mean to or not. This might be staff viewing service users as their diagnosis, or people not recognising that the professionals supporting them have a life outside of their job.

We can challenge this harmful, stigmatising mindset by making a personal effort to connect, listen to what others are saying about themselves whilst offering up a little bit about who we are. If you have a relatable personal experience, say as much. You don't have to divulge everything, but showing you really do understand can go a long way to building a meaningful and therapeutic relationship. **"Staff need to understand that their silence is power… not sharing a little about yourself is wielding power over someone else and exploiting that power imbalance."**

Connection	Disconnection
Seek to be more	Seek to be less
Empathetic	Stigmatising
Empowering and Inclusive	Shaming / Blaming
Respectful	Authoritarian
Trust building	Demanding
Person centred	Disapproving
Encouraging	Discriminatory
Clear	Stereotyping
Reassuring	Assumptive
Understanding	Interpreting
Exploring / Inquisitive	(Pre) judgemental
Empowering and Inclusive	Threatening
Collaborative	Agenda – pushing
Culturally competent	Exploitative
Generous	Patronising
Compassionate	Closed off
Aware of your privilege	

Word cloud generated in response to the survey question "What behaviours should staff display to support recovery?"

Why language matters

Making sure the words, phrases and terminology we use support meaningful mental health recovery

Language reflects values

The way we talk and write reflects on what values and beliefs we hold as individuals, as a team and / or as an organisation. Therefore, the words and phrases we use must be consistent but most importantly, support recovery values.

This may mean shifting away from what we are used to and feel comfortable using. Much of the phrasing and terminology around healthcare derives from a ***Medical Model of Health / Disability***, which is an approach of looking at what is 'wrong' with a person rather than what is happening to them, ultimately defining them with a diagnosis or (usually loaded) label.

The word 'patient', for example, comes from the Latin 'pati', which means 'suffering'. It translates as 'the one who suffers'. When referring to someone as a 'patient', we are literally defining and labelling them by that which causes them pain.

Some of the resulting language may be appropriate in *some* physical health settings and situations, but is especially stigmatising and dangerous within the context of mental health.

Why language rooted in 'the medical model' is harmful

The medical model highlights how different someone is from everybody else, identified because someone else uses their medical training to dictate how to be 'normal'. This model enables 'others' to do things to a person through various 'interventions' (such as medications or treatments) because they believe they know more about a person than the actual person does.

People are dehumanised, viewed as an 'illness' or a 'bunch of symptoms' and not as a living, valued human being with needs and desires. This may be especially prevalent if the narrative of the individual doesn't match that of the medical team and the focus moves towards emotionally correcting people; "**it's like emotional and institutional gaslighting**", as one workshop participant said.

Individuals may also be congratulated for "overcoming" mental health challenges/disability. They are often framed as someone without real independence and so therefore require or are deserving of pity, sympathy and/or charity. This attitude contributes to institutionalising someone because it tells the

person that they are not worthy, are a ‘full’ person or otherwise can’t do anything for themselves. It conditions individuals to believe they are ‘lesser than’.

This way of thinking puts people at fault for something they likely have no control over. It also makes it very easy to overlook what a person is actually experiencing and who they are independent of any diagnosis or impairment. It fails to address existing societal barriers which make it more difficult for a person to exercise their rights or lead the life that they want to live (you may want to read about ***Social Model of Health / Disability*** for more context).

> **Health, and therefore Recovery, is entwined with society, economics and politics. We’re lying to ourselves if we think otherwise.**

It is clear that language rooted from a medical model creates low expectations of an individual and strips them of any real independence, choice and control over their own life.

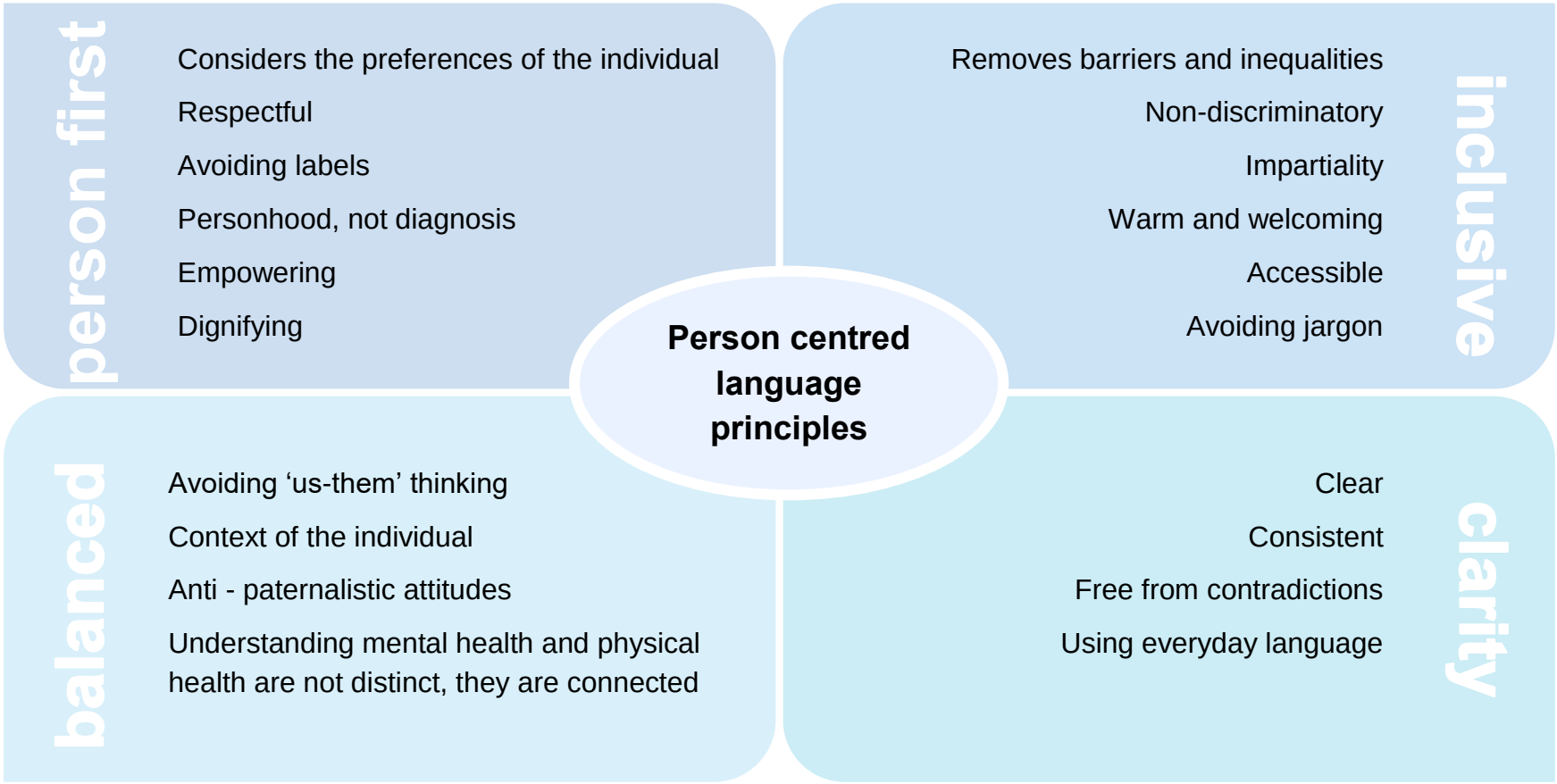
Common words, phrases and outdated language reinforce traditional power imbalances and stigma… to the detriment of the person. Similarly, old language which refers to mental, physical and cognitive disabilities can be just as harmful.

“Use words that empower me, not you”

The words we use when talking to others professionally or behind closed doors, in documentation and in literature, are vitally important and can directly affect the outcome of an individuals recovery journey. The words we use can influence how a person views themselves, or those they support. It may not always be clear-cut, and context is everything, but use words that give power to those the words are about.

Person centred language principles

The values, principles and ideas that guide recovery-focused language



Choosing words to support Recovery

Mind your language!

Here's a brief guide to recovery-focused words and phrases, rooted in person centred language principles:

- Use plain, everyday language when explaining something. Offer non-judgemental explanations for any terminology you use
- Avoid using words/phrases like: 'special', 'housebound', 'can't cope', 'burden', 'unable to make decisions', 'attention seeker' and any other outdated or uncompassionate terminology, even behind closed doors
- Avoid disempowering, time-sensitive or 'doing to' clinical terms like 'interventions', 'discharge' and 'rehabilitation'
.
- Remember, someone isn't a condition, they *have* a condition
- Some terms (i.e. patient, carer) may still be wholly appropriate in some settings (e.g. GP practices, A&E); use words that are appropriate to the setting
- We all slip up. If you make a mistake, correct yourself, apologise if necessary and remember for next time.

Instead of:	Consider:
Patient(s)	The person, individual, people, client, service user(s)
Carer	Family, friends and / or personal assistants, supporters and those who have been in a caring role
Mental patient	Someone accessing mental health services
Mentally ill person	Person living with mental health difficulties
Suffering from...	Experiencing symptoms of… or Person living with...
A victim of mental illness	Has a history of mental distress
Paranoid/'Schizo'	Experiencing paranoid symptoms, Person experiencing psychosis
He is autistic	He has autism
Committed suicide, or made a suicide attempt	Died by suicide, took their own life, made an attempt on his/her/their life
Normal behaviour	Usual, or typical, behaviour
Discharge	Transfer of care

Limitations of and considerations within the concept of 'Recovery'

Recovery as an effective, compassionate and meaningful holistic approach to mental health

'Neorecovery'

'Recovery' emerged from the 'survivor' and ***lived experience*** mental health community in the 1990s in response to the harmful, disempowering, oppressive and abusive practices of the time. Since then, it has been introduced into health and social care policy and has continued to develop into a research-backed approach that is widely championed as a quality, effective and holistic approach to mental health care.

However, this does not mean it is an infallible approach or can escape critique – for example, '***Neorecovery'*** (RiTB, 2019) is a term used to describe the limitations, failures and oversights of the modern approach. On this note, it is not only okay to critique Recovery, but it is healthy to challenge how and why it operates; that's how we learn from it, change how things are done, and grow on both a personal, local and national level. Some of the critiques and observations that came up in conversations that led to this toolkit are as follows…

Recovery research

It is generally felt by people navigating their own journeys that because 'recovery' is experiential and unique; it is also elusive, non-tangible, unquantifiable and therefore eludes true psychiatric, psychological and scientific measurement. This is because experience cannot be boiled neatly down into a book, or a guide, or a manual, or 'dished out' to 'treat deficiencies'; it is something that can only truly be understood by living it.

> **Mental health, and wellbeing in general, is not a commodity that can be boiled down, analysed, packaged up and 'traded.**

With this in mind, it is important to remember that practically all the research surrounding Recovery (and in turn, the research that influences policy and all the relevant guidance and tools) are *led by professionals*. Further funding and legitimacy then tends to go to where the research is, *to the professionals with resources*, and generally not to the everyday people with lived experience who

have long advocated for user-led, democratic and / or collective alternatives.

Despite more recent coproductive efforts from organisations (some of which have been tokenistic), it is worth remembering that our understanding and implementation of Recovery has, over time, been taken away from people using services / initiatives to the professionals leading and working in them, and that this power imbalance is unfortunately ingrained into how Recovery operates and is supported.

Recovery for all?

Recovery is for 'people with severe and enduring mental health conditions with long term needs' (Deegan, 1998, Anthony, 1993), although in recent years (rightly or wrongly) it has been extended to include all people who access mental health services or experience mental distress.

> **There is a difference between 'everyday, human experience' (which is often pathologised) and enduring, acute or lifelong mental health challenges or disabilities.**

Services and research much ensure that they do not sacrifice meeting the needs of those with complex, severe and / or long-term conditions whilst they meet the needs of the majority with mild, moderate and time-limited conditions.

Recovery Tools

Plenty of frameworks and tools, such as ***Recovery Stars, CHIME, CQUINS, WRAPs*** and ***Five Ways to Wellbeing***, have been developed to educate, guide and support the implementation of Recovery-orientated best practice. The Humber Teaching NHS Foundation Trust promote the continued use of these recovery-based resources yet recognise their limitations in practice.

Like much of the Recovery philosophy, the use and implementation of tools does depend on the preferences and situation of the individual at the heart. In DIY, you use different tools in different situations; Recovery tools also cannot be applied in a blanket fashion.

It is essential that any Recovery tools used must fit the needs, preferences, goals and circumstances of the person.

‘Tracking’ Recovery

Within the discussions behind this guidance, for example, it was noted that whereas some people find the ‘tracking’, self-assessed nature of Recovery Stars really motivational and helpful in monitoring their Recovery Journey. Yet other people find them an unhelpful, blunt tool that do not adequately consider the psychosocial or political reality or nuances of their experience, or factor in the things out of their control that perpetuate distress.

People sometimes feel under pressure to live up to the expectations of staff, perform their way through the healthcare system and give the ‘positive’ answers that staff want to hear. If they don’t progress quick enough, or are critical, they are sometimes left to feel as if they are a ‘lost cause’, or are misbehaving, difficult, or otherwise becoming undesirable productivity targets. The pressure to lie and appease undermines Recovery.

It was widely commented that these scoring systems put people and staff under a huge amount of pressure to ‘improve their numbers’, otherwise it demonstrates a ‘failure’ or Recovery or a ‘failure’ of services.

Just because someone can score a number in some banal assessment doesn’t mean they have recovered!

More considerations

Consider, remember and reflect upon these additional experiences, issues, truths and practical advice from those collaborating in producing this guide

- **Check you have a critical understanding of Recovery**: “Lots of people think they know what Recovery is but there is often such a lack of self-awareness that they don’t realise how little they actually know.”

- **Be mindful of your online signposting**. Some people don’t have access to the Internet or have digital / technological tools and resources.

- ***Accessibility*** **is everything**. Some people cannot comfortably afford the bus fare, or are facing mobility difficulties, meaning they cannot easily to get to physical appointments or signposted organisations. Their financial priorities may not be able to extend to their health. Also, a lack of childcare provision, crèches or respite support often act as a barrier to Recovery.

- **People can be different things**. A person can be experiencing severe / enduring mental health conditions (and potentially a service user) in their own right, a carer for someone else and a member of staff supporting others, or a combination of any of the above. People aren't always one or the other.

- **Think *'meaningful activity'*, not just 'work'.** Employment is not the default goal of Recovery and should absolutely not be considered a measurable outcome for 'success'. It reinforces the idea that an individual's worth is judged on their economic value, and pushes people into work when they may not be ready or indeed actually able to. "Work is a meaningful goal for many people, but not everyone has work within their recovery plan".

- **The term 'self-manage' isn't always helpful.** It maintains an unrealistic expectation for those who struggle to be 'self-reliant' (mentally, socially, or otherwise), struggle to consistently engage with services or have complex needs or enduring disabilities. It also ignores the collective, communal support that is needed during times of distress. 'Self-manage' needs to also include the ability to seek help and ask for support when it's needed, yet not overlook the human need people have to be looked after and supported by others.

- **Justified dissent should be encouraged, not squashed.** "Sometimes things 'go wrong' in life. And there's some truth to viewing things from a more positive perspective. But sometimes it feels like I'm always being encouraged to roll over and change how I think about something, rather than develop the tools and skills to take control and advocate for my rights. I'm disempowered through empowerment!" We need a shift in attitude and practice that better promotes and coproductively supports self-advocacy, justified dissent and community activism.

For further discussion, training and learning opportunities, head on over to www.humberrecoverycollege.nhs.uk for courses, workshops and access to our Recovery Hub (pending).

The Recovery Glossary

To check meanings of phrases and words

Accessibility

This term is about the 'ability to access', the ways in which people use, encounter or contribute to something, and the process of making something more accessible / within reasonable reach to someone experiencing additional barriers, obstacles or impairments. This is usually used in reference to making things more accessible to people with physical, mental or learning disabilities, but also includes things like financial accessibility (e.g. being able to afford the bus fare to get somewhere) or caring responsibilities (e.g. childcare or having other caring commitments).

Advance Statements

This is a written statement that sets down your preferences, wishes, beliefs and values regarding your future care. The aim is to provide a guide to anyone who might have to make decisions in your best interest if you have lost the ability to make or communicate decisions. *(NHS Online)*

Best Interests

An act done or a decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made in his or her best interest *(NHS National Framework)*

Carer

This refers to somebody who provides unpaid support or looks after a family member, partner or friend who needs help because of their age, physical or mental impairment, illness or disability. This may also include those who were previously in a caring role.

CHIME

This mnemonic stands for Connectedness, Hope, Identity, Meaning and Empowerment. CHIME is a evidence-based, internationally used framework to help people remember and implement the philosophy and values of Recovery.

Coproduction

A term that refers to the process where people with lived experiences are included in decision-making, from commissioning, to co-design and co-delivery of services and projects, to their care on a personal level. It is about doing *with* (and not for, or to) people all of the time (not just some of the time).

CQUIN

The Commissioning for Quality and Innovation (CQUIN) framework supports improvements in the quality of services and the creation of new, improved patterns of care. *(NHS England)*

Crisis

This is when someone feels at 'breaking point' or needs urgent help. There is no set definition but can be described as any situation in which a persons behaviour puts them at risk of hurting themselves or others, and / or prevents them from being able to care for themselves or function. *(NAMI)*

Experts by Experience

This term refers to someone who has lived experience surrounding a given situation or impairment. Their expertise comes from actually living with or through something. They tend to have practical insights of how to best manage a condition or situation, knowledge which can be of great help and hope to others experiencing something similar.

Experts by Profession / Training

This term refers to clinicians and other professional health and social care staff. They have a more theoretical or scientific understanding regarding a given situation/impairment following study or time working professionally in the field. They can offer evidence-backed advice and support.

Five Ways to Wellbeing

This is an evidence-based framework that suggests

that there are 5 steps you can take to improve your mental health and wellbeing. These five steps are: Connect. Be Active. Take Notice. Keep Learning. Give.

Lived Experience

A term which describes the first-hand accounts and impressions of living as a member of a minority, oppressed group or following challenging experiences. Within health and social care, it often refers to first hand accounts of health conditions, and the first-hand experiences of their carers. The etymological German root of the phrase 'lived experience' suggests a kind of active knowledge that comes from having 'survived' through something (which is different to 'experience, which is more a passive occurance that isn't necessarily processed on a deeper level).

Meaningful activity

This refers to physical, social and leisure activities that mean something to the person in question and are tailored to their needs and preferences. This can range from activities of daily living (dressing, eating and washing), to leisure activities (gardening, arts and crafts, conversation, singing) to work activities (employment, volunteering). It might be structured or spontaneous, in groups or individually, involve loved ones or the wider community, or may provide emotional, creative, intellectual or spiritual simulation. *(**NICE** Guidelines, SCIE).*

Medical Model of Health / Disability

This generally refers to an old-fashioned, systemised and reductionist approach of thinking about health, where a determined set of 'interventions' are 'prescribed to fix or cure a problem'. The issue with the medical model is that it does not apply to the reality of mental health or consider the impact of physical complaints on mental and emotional wellbeing.

Neorecovery

This term is used to describe a type of co-opted form of Recovery (so called because it reflects the current neo-liberal political context of society), typically controlled, designed, delivered, implemented by mental health services, with or without tokenistic 'coproduction'. It emphasizes individualism, 'responsibility', 'dependency' and work as a health outcome. This is different to Recovery as conceived and articulated survivor/ service users, which is democratic, humanistic and based on collective values. *(Recovery in the Bin Collective)*

National Institute for Health and Care Excellence (NICE)

NICE is an independent organisation (set up by the government in 1999 to decide – through their 'NICE Guidelines' – which appropriate drugs and treatments are available on the NHS in England and Wales.

Peer Supporters

This refers to those who are able to offer 'peer support', that is, the help and support that people with lived experience of mental difficulties or a learning disability are able to give one another. It is the process of giving and receiving emotional support, share knowledge, teach skills, offer practical assistance and / or connect people with resources, communities of support, and other people. This may be in an informal setting (such as a friend), through a user-led initiatives (e.g. grassroots self-help groups) or in a more formal capacity (e.g. by employed Peer Support Workers, or within Recovery College settings).

Recovery Journey

This is the ongoing process of navigating, acknowledging, learning, reflecting and growing following a crisis or difficult period, with or without the continuation of consistent / fluctuating symptoms. Recovery Journeys are as unique as the individual navigating them, but they generally are about (re)building life, making sense of what has happened (or is happening) and finding meaning from it whilst developing a new sense of self and purpose.

Recovery Stars

The Recovery Star is a self-assessment tool for supporting and measure recovery-oriented change. It covers ten outcome areas; managing mental health, physical health, living skills, friends and community, use of time, relationships, addictive behaviour, home, identity and self-esteem, and trust and hope.

Relapse

Relapse looks different for different people, but it can be typically described as when a person's symptoms have returned (after having improved) and their functioning has decreased as a result.

They are typical within Recovery Journeys and do not indicate failure or regression. Lots of people don't like the word 'relapse' so may use terms like 'dips' and 'blips' or 'crashes' instead.

Self-expertise

It's the basic concept that through experience and reflection, an individual knows what will help or hinder them in relation to a situation or decision that affects them. It describes the self-aware process of listening to and learning more about yourself and your experiences, to help determine what is best and right for you.

Service users, patients and carers

This defines all individuals who either access mental health or physical health services or care for individuals who access these services, including; adults, babies, carers, children, clients, customers, families, parents, patients, service users and young people. We use the contested term 'patient' to include people who access any number of Humber's physical health services, or prefer to be referred to as such.

Signposting

Signposting is when someone (usually health and social care workers, although it can be from family, friends, carers and other organisations) help people to understand, access and navigate typically community-based or online services that will improve their health and wellbeing, or may otherwise be of help to them.

Social Model of Health / Disability

This model, based on the concept that the body is simultaneously social, psychological and biological, is used to examine all factors which contribute to and are barriers to health and wellbeing. These include social, cultural, political, economical and the environment – rather than just disease and injury (like within the Medical Model). It The focus is often on policies, education and health promotion.

Triangle of Care

This describes an alliance between service user, staff and carer (or sometimes Peer Supporter) that promotes safety, supports recovery and sustains wellbeing. The 'triangle' has been proposed by many carers who wish to be thought of as active partners within the care team.

User-led initiatives (ULOs)

These are groups, projects or initiatives that are run by, and for, the people who use (or are potential users of) care and other support services. ULOs enable groups of people to represent their own needs, lived experiences and solutions to barriers. 'User-led' may be used interchangeably with 'service user led' or 'peer-led'.

Wellness and Recovery Action Plans (WRAP)

WRAPs are a simple, evidence-led, self-management and crisis planning tool designed to increase autonomy and independent decision making. There are many different versions, but they all tend to detail both a preventative / keeping well plan and crisis plan, and outline how an individual would like others to support them at difficult times.

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