Empowering us through lived experience

Continue to embed involvement throughout the organisation

Ensure Involvement is meaningful and rewarding and that we are creating a community with a sense of purpose and belonging

Involvement
Strategy
2024 to 2029

Ensure Lived Experience has strategic influence

Develop more diverse representation

Use Lived Experience to inform our campaigning









mind in Berkshire Involvement Strategy 2024-2029

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Executive Summary

Oxfordshire Mind's second Involvement Strategy has been developed taking a coproductive approach, meaning that how we have taken stock, reviewed our progress against our first Involvement Strategy, and chosen the priorities to guide us over the next five years have all been decisions taken with and involving people who explicitly bring Lived Experience of mental health challenges to our organisation.

This strategy is a culmination of many conversations, thoughts, opinions and findings gathered over the period September 2023 to September 2024. It is framed around five goals.

- 1, Continue to embed involvement throughout the organisation
- 2, Ensure Lived Experience has strategic influence
- 3, Ensure Involvement is meaningful and rewarding and that we are creating a community with a sense of purpose and belonging.
- 4, Develop more diverse representation
- 5, Use Lived Experience to inform our campaigning

This strategy reflects our core values. We recognise and respect that our Experts by Experience and all the people involved with us are more than their diagnoses and experiences - they are unique individuals with skills, interests and aspirations that stretch beyond their mental health challenges. We are all people.

"We should aim to be unashamed about our mental health problems. I think doing this kind of work, people see us and some of them might say oh, OK, you're quite capable, that's nice to see. Because you know lots of things, let's say the benefits system for example, they want to focus on the way that you're incapable. And that makes life difficult. I'm not ashamed of my mental health problems, but I am still capable and have lots of other skills." EbE





Embracing the principle of "nothing about us without us," Oxfordshire Mind recognises the importance of working with lived experiences of mental health challenges to shape our development as a mental health charity.

This strategy was co-designed with staff, service users and Experts by Experience; it is a collaboration of all our voices.

Our overarching mission is:

We won't give up until everyone experiencing a mental health issue gets both support and respect.

We demonstrate our commitment to this by engaging in dialogue and working in partnership with communities to grasp their unique requirements. Our approach aims to ensure that we are meeting the needs of all our communities and have high levels of collaboration and participation. We will honour and appreciate and respect the thoughts and opinions of those we aim to serve.

As members of the Mind Federation, our commitment to having lived experience lead and guide our work is assessed every three years as part of our Mind Quality Mark re-accreditation. This is the process led by National Mind to ensure that all parts of the Federation, including a Local Mind like ours, are well run and meet expected standards.

In 2023, the review team noted,

"It is clear that lived experience is valued and used by Oxfordshire Mind."

Whilst we are proud to have met this standard consistently, our primary motivation for Involvement work is our ethos that we see people as people and not just their diagnosis, and acknowledge that the insights, expertise, and evidence coming from lived experience empowers us to design services and support to better meet people's needs and preferences. We often work in partnership with statutory bodies subject to legal duties to involve people who use their services, e.g. the NHS and local authorities. Our commitment to involvement places us in a strong position to support these partners to meet their own involvement duties.





Benefits to our services, our staff and the individuals involved with us

There is a strong body of research showing that lived experience involvement can lead to people being both more likely to engage with services and more likely to be satisfied with those services. When individuals feel actively involved in their care and decision-making processes, they are more likely to feel empowered and motivated along their journey of mental health recovery. These journeys are rarely linear, but involvement has been shown to lead to improved outcomes and reduced rates of relapse.

Lived experience involvement offers numerous benefits to staff members, including improved communication and strengthened ability to build supportive relationships with service users. Feeling empowered to make a meaningful impact can foster a sense of community amongst people who draw on their own lived experience, knowing that they are part of a collaborative effort to improve mental health outcomes and giving a sense of fulfilment and purpose in their work.

As an organisation we want any involvement work to be of benefit to the individuals involved with us. The work should always be recovery focused, financially compensated and meet the goals of the individual, whether this is to enhance their CV, learn new skills, or be a valued member of our group.

An important benefit to us as an organisation is that lived experience involvement makes us better at meeting the needs of a community, so we're not putting effort into creating services or materials that aren't effective.

Barriers to involvement

Lived experience involvement in mental health services can require addressing several barriers which we need to be mindful of, so as not to hinder the realisation of the full potential of involvement.

- Stigma surrounding mental illness can discourage service users from openly engaging with mental health services or participating in involvement initiatives.
- Fear of judgment or discrimination may prevent individuals from sharing their experiences or seeking support, thereby limiting their involvement in shaping services.
- Limited resources, including funding, time, and staffing, can pose significant barriers to meaningful involvement.





- Communication barriers, such as language barriers or limited access to technology, and, additionally, physical accessibility issues, such as transportation barriers or inaccessible facilities, may further hinder participation, particularly for individuals with disabilities.
- In some cases, involvement initiatives may be implemented tokenistically, where the involvement of lived experience is merely symbolic and lacks genuine influence on decision-making processes. This can lead to disillusionment and undermine trust in our organisation.
- Resistance to a culture of involvement or a lack of understanding within an
 organisation or among staff members can impede efforts to promote
 involvement. Oxfordshire Mind addresses this within our recruitment,
 induction and ongoing staff development plans, recognising that some staff
 may be reluctant to relinquish control or may perceive involvement as a
 threat to their expertise or authority.
- Mental health issues are often complex and multifaceted, making it challenging to effectively involve people. Balancing diverse perspectives and needs within involvement initiatives requires careful consideration and resources.
- Mental Health issues are often closely intertwined with physical health disorders; the physical health disorders can frequently overshadow the mental health problems and therefore minimise their importance.

Addressing these barriers requires a concerted effort across Oxfordshire Mind to promote cultural shifts within mental health systems, prioritise the voices and experiences of our community, and allocate resources to support meaningful involvement initiatives. We also need to foster open communication, promote antistigma efforts, and actively involve the community in decision-making processes.

Definitions

In this strategy we use the following key words:

Lived experience – is the knowledge and understanding which comes from having personally experienced mental health challenges.

Service user – Is anyone who has accessed any mental health services. To ensure a broad range of involvement this is not limited to users of Oxfordshire Mind Services only.

Carer –Is anyone, including children and adults, who looks after a family member, partner or friend who needs help because of their health problems.





Lived Experience Interviewer (LEI) —Is a person with lived experience of mental health problems who has been trained to sit on our interview panels as an active member of the recruitment process.

Expert by Experience (EbE) – Is a person who has experience of living with mental health problems, who works with us to influence the planning, development, delivery, and evaluation of Oxfordshire Mind's services.

Involvement - The term 'involvement' is an activity that supports people with experience of using mental health services to have an active influence on actions and decisions at all levels within the organisation.

Co-production –This refers to a way of working where those planning and providing services, and those who user services, work together towards a shared goal in a fair and equal partnership. It is a particular form of involvement.

Levels of involvement

We commit to involving people with Lived Experience of mental health challenges throughout our work. This will take different forms in different situations, and we will be clear about what can be influenced through involvement work and how.

Sharing information with people is the starting point of involving them. Listening to people's opinions is the next stage. Communication and engagement are important elements of involvement – but there is another dimension, which is how power is shared in the decision-making process. We aim to co-produce plans with those who bring lived experience to the discussion, meaning we work side-by-side to agree priorities and approaches, acknowledging that true co-production is not always possible.

The diagram below is based on Arnstein's Ladder of Participation but simplified to offer more accessible guidance.





LEVELS OF INVOLVEMENT





Telling

We value and respect people with lived experience and want to keep you informed of our decisions

Notify- Informing the community about planned or completed changes. There is no opportunity for community input on the decision. Communication methods can include newsletters, flyers, websites, and social media.



Listening

We respect the views and opinions of people with lived experience. We will listen and discuss your views and will incorproate your preferences into our plans, but we make the decisions.

Surveying & Conferring –
Collecting opinions on
specific questions via
surveys or hosting forums
Other methods include
online polls, discussion
groups, suggestion boxes,
and research interviews.
These are spaces where the
community can discuss
ideas and plans presented
by our organisation.



Co-production

We value and respect people with lived experience and will work in partnership to co-create where the power and decision making is equally shared.

Co-production – power is equally shared with the community and the organisation. We work together from the outset to agree the goal and how to get there

Communication Engagement
Building blocks of involvement





We have developed a Toolkit for Meaningful Involvement which provides more guidance on how to choose and use different involvement techniques.

Strategic aims

Building on our past achievements, our goal is to grow our culture of involvement within our organisation. We aim to create a collaborative community that values lived experience and continues to exemplify how listening to these voices leads to improved mental health support.

We can do this by having a layered approach to involvement so that we are listening and working with lived experience throughout Oxfordshire Mind. We will engage with communities – including but extending beyond those who have used our services - to build trust and relationships, allowing us to better understand people's needs. We will treat each service user as a unique individual and recognise that care must be tailored rather than one-size-fits-all. We will work with those with lived experience on service design and delivery and, we will incorporate lived experience involvement at a strategic level.

Our strategic aims are:

- 1, Continue to embed involvement throughout the organisation
- 2, Ensure Lived Experience has strategic influence
- 3, Ensure Involvement is meaningful and rewarding and that we are creating a community with a sense of purpose and belonging.
- 4, Develop more diverse representation
- 5, Use Lived Experience to inform our campaigning

1, Embed involvement throughout the organisation

To become an organisation that genuinely collaborates with the community we serve through involvement, including co-production, it's imperative to integrate involvement throughout the entire organisation. We aim always to expand our use of co-production methodology, but use other involvement approaches where appropriate.





Involvement should not be treated as a distinct workstream but rather should be prioritised within every service or project, and recognised in how staff resources are allocated. When involvement is compartmentalised, there's a risk of it being tokenistic, merely a checkbox to tick. For instance, adding a lived experience perspective to a project halfway through makes it an afterthought. Demonstrating true value and inclusion means making lived experience involvement a primary consideration from the outset, not an afterthought.

To ensure our strategy is known, understood, and followed by our staff, trustees and other volunteers, and also helps us to grow our Experts by Experience pool, it will be communicated in a variety of formats. We will also promote and continue to evolve our Meaningful Involvement Toolkit, and grow our bank of involvement stories and case studies.

2, Ensure Lived Experience has strategic influence

We want the voice of lived experience to resonate throughout our entire organisation. To influence meaningful change in mental health provision, it's essential to integrate lived experience involvement at a strategic level within Oxfordshire Mind.

Within our organisation, we're fortunate to have a wealth of lived experience represented on the Board of Trustees and amongst our staff. We deeply appreciate the insights and wisdom this brings to Oxfordshire Mind. However, creating roles for those whose primary purpose for being part of conversations is sharing their external lived experience perspective offers a fresh insight, akin to that of an outsider looking in. Staff and Trustees with Lived Experience 'wear several hats' whereas a Lived Experience Expert (advisor) can focus on bringing an external voice to challenge organisational perspectives, question our assumptions and highlight issues that we may overlook due to familiarity.

We will create new Expert by Experience advisor roles whose primary aim is to raise the profile of lived experience, challenging senior management and trustee perspectives and collaborating with us to envision new objectives. We will develop role descriptions and training to support impactful involvement of our Expert by Experience advisors.





3, Ensure Involvement is meaningful and rewarding and that we are creating a community that has a sense of purpose and belonging.

Involvement should be reciprocal and not a one-way street. For the people with Lived Experience who are involved with us it is important that they feel valued, respected and are gaining new skills and experiences by being involved with us.

We are incredibly fortunate that individuals with lived experience opt to collaborate with us, sharing their insights and stories. Beyond the personal rewards and professional growth opportunities, working alongside these remarkable individuals should foster a sense of belonging within our community. It's our aim for people with lived experience to feel deeply valued and respected, recognising that we are all in this together.

We commit to listening attentively and remaining open to ideas brought forth by the community that we are privileged to serve. Staff, trustees and other volunteers often bring lived experience of mental health challenges, and we aim to foster a culture where everyone feels able to be open about their mental health challenges where appropriate to break down stigma, and as a counter to the EbE feeling like the lone voice of mental health challenges in the room.

The Meaningful Involvement Toolkit includes a checklist to remind staff to plan involvement opportunities to identify benefits from the Lived Experience perspective as well as the organisational perspective. Our aim is to develop a range of involvement opportunities that are meaningful and rewarding for the EbEs and the organisation and thereby create a community of involvement that is caring, enriching and fun to be a part of.

We will promote a clear EbE pathway for those considering involvement; continue to work closely with our EbEs to note their goals and motivations behind getting involved; connect EbEs with a range of involvement opportunities internally and externally; and ensure EbEs receive feedback on the impact of their involvement.

4, Develop more diverse representation

The 'inverse care law' describes how the people who most need health care are least likely to receive it. We need to be proactively finding and listening to all the





voices within our community to promote equality of access to mental health support.

Whilst it is true to say that individuals with lived experience can only truly speak for themselves and not an entire community, it is vital for us to ensure representation from all the diverse communities across our geography (Oxfordshire, West Berkshire, Reading and Wokingham) so that we can better understand the experiences both common and unique to each of our communities.

When we are speaking about ensuring diversity of involvement we will proactively consider the grounds on which some people have historically been under-represented within organisations - race, ethnicity, gender, sexual orientation, age, physical abilities and disabilities, cultural background, socioeconomic status, religious and other beliefs.

Each of us is a unique individual, often belonging to multiple communities and having diverse life experiences. We recognise that the intersection of these identities shapes how we navigate life and the discrimination and inequalities we encounter.

Our involvement training will incorporate bias awareness. We will monitor the diversity of our EbE group by reference to local populations, and actively recruit lived experience voices from under-represented communities.

5, Use Lived Experience to inform our campaigning

Many of our EbEs have chosen to engage with us because they are eager to share their experiences and advocate for real change across the mental health care system and wider society, rather than solely assisting in the development of services and support for our organisation.

We have the opportunity to amplify the voices of our community of EbEs and offer them our unwavering support; we stand united. As an organisation, we possess a platform and a duty to confront outdated and erroneous assumptions about mental health, advocating for improved rights.

Any campaigns will be developed in partnership with the Oxfordshire Mind Communications Team and in line with Oxfordshire Mind's Marketing Communication and Campaigning Strategy, and will include political campaigning only in the context of supporting our charitable purposes, as permitted by the Charities Commission. We will campaign on issues which align with our vision and values.





Work with lived experience to develop Oxfordshire Mind's role as a campaigning organisation. In selecting campaign topics, we will consider: policy advocacy; mental health awareness and education; and addressing mental health risk and support factors.

What next?

We will share this strategy in various formats to ensure all staff, service users and partners understand our Involvement vision. We will maintain transparency by making the strategy accessible on our website for inquiries.

The Involvement Strategy is supported by an Action Plan, which will be reviewed at least annually.

Our involvement work is intended to support our organisational mission, and so improve the support and respect given to anyone experiencing a mental health issue. In order to track our progress, we need to be able to gauge how well our involvement work is supporting this. We will work across teams and with our EbE community to catalogue our involvement activity and its impact, considering: the quantity and range of involvement projects, the breadth of participation, the influence on staff, the effects on services, and the impact on EbEs.

As well as holding ourselves to account against the commitments specific to the Involvement Strategy, we recognise the need to maintain the alignment between this and related strategies. The Oxfordshire Mind Involvement Strategy supports the 2022-25 organisational strategy, which has *Our People* as one of its four strategic priorities. Delivery against this is developed through the Involvement Strategy which aligns with our Equity Diversity Inclusion and Equality Strategy, and is also supported by the work led by our Human Resources and our Volunteering and Peer Support teams.