

Led by lived experience
Rachael Darling and Zoe Kendall

Advanced Lived Experience KUF Development Leads

Emerge Leeds Complex Emotional Needs Service

- This service is the recently renamed Leeds Personality Disorder Managed Clinical Network.
- Service users don't need (or have to agree with) a diagnosis of 'personality disorder' to access our service.
- We are a city-wide, multi-agency and multidisciplinary service that aims to work effectively with people who are experiencing complex emotional needs and interpersonal difficulties.
- We see people who may, as a result of complex trauma and adverse life experiences, have developed ways of coping and surviving that can cause them harm and distress, and we provide a range of different services to meet the needs of people at different stages of their personal development.
- Our services include care coordination alongside groupwork courses including dialectical behavioural therapy and the Journey programme.

We produced two involvement films to capture the attention of both our service users and our staff

People Participation: Involvement Strategy

2023 - 2026









Key points

- A review of existing involvement followed by a consultation process with service users was led by Rachael and Zoe, beginning in 2021.
- The Strategy was drafted and the platforms and opportunities within it were fine-tuned throughout 2022.
- This involved bringing it to senior leadership forums, gathering involvement case studies and making involvement films, initiating the new peer support group and the people participation panel. The latter provides a governance route for involvement activity as well involving service users in service development, so that the implementation of the strategy is co-produced.

Our goals, from a lived experience perspective

- To challenge organisational culture where it doesn't meaningfully take into account lived experience and reduce barriers to better involvement.
- To gain buy-in of all our practitioners in supporting involvement across the spectrum with their service users because they understand that it is crucial and not an add-on
- To create better platforms for service user voices to be learnt from.
- To facilitate peer support where it enables service users to manage their own wellbeing into the future of their lives.
- To create a sense of community and belonging within Emerge Leeds, and to foster mutual ownership of involvement by all stakeholders.
- To promote a bilateral dialogue that encourages professionals as well as service users to get comfortable with being vulnerable!
- To ensure authentically co-produced care plans and deliver authentically co-produced services.

Key challenges to this strategy

- Staff resource required to embed involvement into service delivery and sustain good communication and timely feedback.
- Acknowledging the limitations of services such as availability of resources and the imperfect nature of people and systems.
- Emphasizing service users and lived experience colleagues as equal partners and allowing an equal steer from every stakeholder.
- Meaningful renumeration that reflects the level of the work, it's value to Emerge Leeds, and
 ensures that involvement partners feel their efforts are worthwhile.
- Non-lived experience stakeholders with conflicting needs to current and ex-service users.
- The risk of pathologizing service user feedback as 'traits' and minimising or dismissing it.
- . Including carer voices as well as wider networks of support (families, friends).
- The stigma surrounding personality disorder / complex emotional needs.
- Being responsive and agile to service user involvement in own care.
- Staff defensiveness and organisational power structures.
- Involving multiagency partners in the work
- Staff buy-In and engagement at all levels of Involvement.
- Organisational and systemic pressures.
- · Use of language, terminology, and acronyms.
- Avoiding idealisations. e.g., 'good service user', 'perfect carer'.



Final Reflection

So far this has been an invigorating, exciting and at times daunting task which required courage from both lived experience leads and other senior managers at Emerge, as well as from our service users and partners, and hasn't always been plain sailing. But we think it's been well worth it and are committed to its delivery.