Lived Experience Workforce Lounge Report

This report would not have been possible without each and every person who attended the session.

Thank you for sharing your time, experiences and thinking. We hope for this report to be useful in developing NICICLE further, for you, your work and our lived experience community.



Introduction

Welcome! to the report of The Lived Experience Workforce Lounge, which happened on 11th June 2024, 10am-12am (with an optional 12-1pm peer space to chat afterwards) on Zoom. It brought together a range of people from and representing the children and young people's mental health, lived experience workforce. The session was developed by people with lived experience and supported by the Children and Young People's Mental Health Coalition (couldn't have happened without you, thank you!). 64 people signed up and 51 people attended on the day to share experiences throughout the session. The overall aim was to have a conversation together exploring experiences in the children and young people's mental health lived experience workforce. With information from the event contributing to the potential development of NICICLE (National Independent Cooperative in Children and Young People's Mental Health.

This report will first outline the session and then be a compilation of the breakout spaces and following discussions, including notes taken from conversation and from the chat. It will be split into two sections representing the two break out spaces 'Lived experience workforce roles,' and 'Professional role supporting lived experience.' But first shall outline the session.

The Session

A detailed agenda for the session was emailed out in advance (titled 'Detailed agenda 11th June Lived Experience Workforce Event' see Appendix 1) but for reference and for those who may not have seen this document, a summary has been included here.

- Hello welcome and getting comfy!
- · Stories from the field
- Nicicle
- Why this matters to us
- Break time
- Lounges for a game of snakes and ladders
- Sharing from the lounge
- What happens next and how was it for you?
- Chat & reflect







Hello welcome and getting comfy!

The session started with a welcome and getting comfy, this was around setting the ethos for the session to help everyone feel safe to contribute, here is the slide we used.



Stories from the field

Everyone who attended the event had a story from the field of lived experience working. The facilitators shared a little of their story and why this work is important. Attendees where then invited to share a bit of their own in the chat.

The stories that were shared were really powerful and representative of so many different experiences and organisations. They really set the scene that we are here for a shared goal.



Nicicle (National Independent Cooperative in Children and Young People's Mental Health Lived Experience)

Wendy and Leanne talked through their experience of lived experience working, the conversations they have had with over 50 people interested in this area of work and the development of Nicicle. See Appendix 2 for slides.

Feedback on the day was in support of the idea, that it was really hopeful and needed but also that people needed more time to take in and reflect on what was shared.





For me LE [lived experience] work gave me a community and a voice when in the world there wasn't anyone who got it.

Key themes that came up during Nicicle discussion were;

- Lived experience working burnout and the need for support of the workforce
- In support of Nicicle being needed
- A desire to get involved and learn more
- Support for supervision standards and a governing body
- Exploring the different challenges for different people and roles
- Adjustments and supports needing to be unique rather than fitting into existing systems
- Consideration around traumatic experiences and how lived experience working can retrigger trauma
- Joined up working, big organisations with smaller ones
- Starting and looking after the heart

This feels very hopeful! We are seen as a 'go to' organisation in our area, especially for others who want to grow and develop their lived experience workforce or add voices into their work. Somewhere we could signpost them to would be incredible.

Why this Matters to Us - Children and Young People's Mental Health Coalition (CYPMHC)

Charlotte shared how important lived experience working is to the CYPMHC, how they are on a learning journey and the importance of ensuring the voice of babies, children, young people, parents and carers have a role in their work.







- At the heart of our strategy is the promise to champion the voices of children, young people and parent-carers.
- This mean we want to push ourselves harder to ensure that the voices of babies, children, young people and parent-carers play a meaningful role in our work.
- We want to see a mental health system that includes and partners with those with lived experience.
- We are on a learning journey.







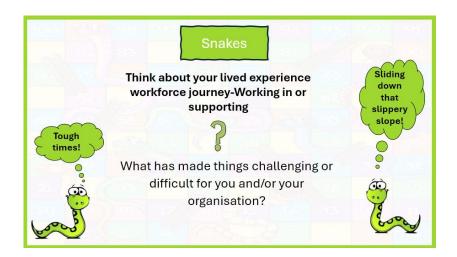
Lounges

After the break the room split into two breakout spaces, with attendees choosing which one to join out of 'Lived Experience Workforce Roles,' and 'Professional Role Supporting Lived Experience.' Both spaces had the same set of slides and questions to aid discussions, based on a Snakes and Ladders theme.



Snakes

This section used the metaphor of the 'snake' in the game Snakes and Ladders to explore what can feel like the 'slippery slope,' when things are tough in lived experience working. It asked the questions, what has made things challenging or difficult for you and/or your organisation? The feedback has been grouped into bullet point themes.



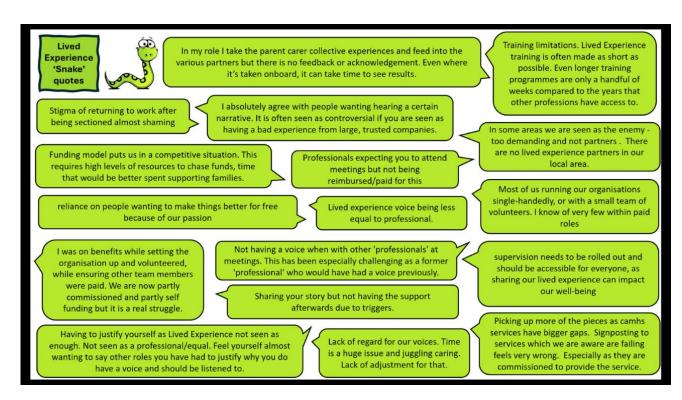
Lived Experience Workforce Roles breakout room feedback

- Doing a **new role** and trying to carve a path as to what the role looks like- doing roles that haven't been done before. / Setting up services with no idea what doing- just knowing that there is a need out there.
- Postcode lottery with access to services- knowing that support isn't available to everyone
 when doing lived experience work in a different areas. / Limited opportunities in certain
 areas e.g Wales.
- Not being recognised for the roles done in professional services.





- **Funding-** personal impact when you know how much something is needed but might not be able to survive, lack of funding opportunities. / How to manage financial side of things, requirements of funders and commissioners. / Reliance on people wanting to make things better for free because of our passion.
- CAMHS to acknowledge what you're doing.
- Working with young people with similar childhood stories can be hard.
- **Difficulty being heard** on the same level as a professional. / Being overlooked. / Taken less seriously. / Not being treated equally to other professionals and not being given the same
- Stigma around talking about lived experience amongst professionals. / Fear of lived experience as something unsafe- assumed incompetence and incapability of young people. / Not being able to share experience because of the role. / Lived experience hasn't been fully accepted authentically in many circles- we can do this but we have to respect the professionals (trade off). / Views seen as radical when they're not- just views that people that haven't had lived experience may just not ever consider. / Judgements made by professionals when saying you are coming from a lived experience perspective.
- NHS tied to old fashioned medical approaches- limits the way lived experience works
- **Not enough spaces** to listen to individuals who are marginalised or harmed by these systems- certain groups that are listened to more than others- you have to be nice, white, able-bodied. / Professionals just wanting to listen to a certain narrative from certain people.
- Setting **boundaries** with other organisations: pushback from other organisations when saying there needs to be boundaries for lived experience professionals (e.g payment, always expected to share experience without consideration about difficulties with sharing).
- Personal challenges around switching off and always wanting to keep going.
- **Balance** on knowing when to share and the support you'll be able to access or how people will be react if you don't have a specific lived experience role but your role is related.
- **Needs must** if the doing of it isn't done it won't get done.





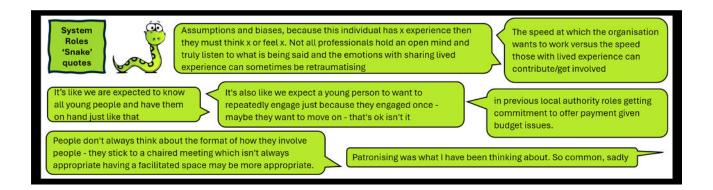


Professional System Roles breakout room feedback

- When lived experience join meetings, it's challenging to get the professionals to take account
 of this and change their language. People with lived experience are asked to join meetings
 with no adaptations made.
- **System is not set up to support people** in these challenging roles we need to think how we accommodate them
- Funding is a big barrier... intention is to do good quality work but people don't recognise the work behind it but without paying for time then that can cause damage to young people. Systems don't budget that in. / Financial limitations example of partly commissioned and partly self-funded and it being a real struggle. / In previous local authority roles getting commitment to offer payment given budget issues. / Commitment to get payment due to budget. / Having funding to give to young people is really hard. / Co-production work and the funding that people come with to do this work organisation having to turn away work.
 People don't value the background work that goes into co-production people don't budget this when wanting to do co-production.
- Assumptions and biases, because this individual has x experience then they must think x or feel x. Not all professionals hold an open mind and truly listen to what is being said and the emotions with sharing lived experience can sometimes be retraumatising.
- Lack of regard for our voices. Time is a huge issue and juggling caring. Lack of adjustment for that.
- **Judgments** made by some professionals when you say you are coming from a lived experience perspective, not being valued as much as professional experience.
- The **speed** at which the organisation wants to work versus the speed those with lived experience can contribute/get involved.
- Separating personal feelings, particularly when have own lived experience of the system. How to manage the two hats of own lived experience and being a professional
- Managing participation team feels like everyone in organisation 'wants a piece' of the young person and no structures in place to make sure they are safe and protected.
- Managing someone with lived experience and when they were triggered by the role they
 were in, had to go through local authority systems of support ended up being re-deployed
 but the system and journey to get there was really difficult. 'Person wanted to be at work but
 work did not want them to be at work.'
- Hard when working with young people to keep consistency having to work project by project. Not having a consistent pool of young people to work with – real challenge when participation lead.
- Pressure as participation lead to know everything
- As an organisation working with young people, found that not always communicated who the organisation are and setting the context.
- Challenging when facilitating meetings with young people when have own lived experience
 of mental health difficulties and having to be the supportive person to young person when
 not feeling they can be.
- Fear of patronizing young people. / Fear of overstepping boundaries.







Ladders

This section used the metaphor of 'ladders' from the game Snakes and Ladders to discuss the positive steps that have made a difference when things have felt good in lived experience working. It asked the questions, what was happening and what helped to make things feel good for you and or your organisation?

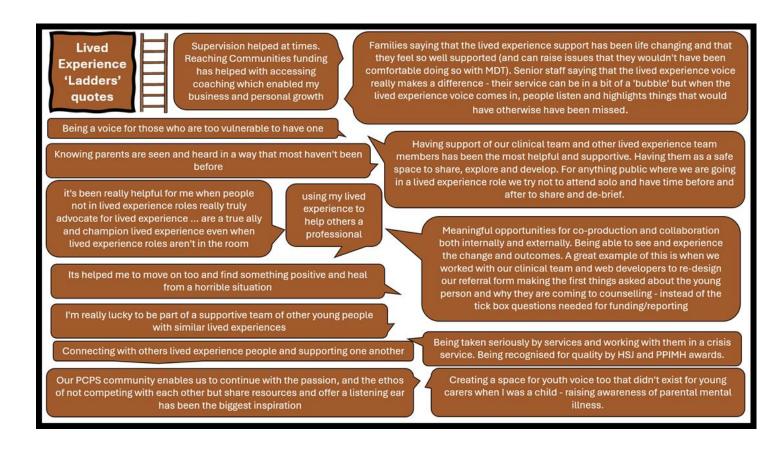


Lived Experience Workforce Roles- Breakout room feedback

- Realisation there is a need for lived experience roles even if it can be tokenistic at times.
- Lived experience **community** similar and overlapping experiences. / Meeting with other people with lived experience.
- Making a difference to so many families. / Making a difference and changing the system for others.
- It is **inspiring** listening to other people's experiences.
- **Being a voice** and support for the vulnerable who are not able to voice things themselveshelp people to represent themselves and be a voice for them. / Knowing parents are seen and heard in a way that they haven't been able to before- have voices heard.
- Helping people to **not feel alone.** / Safe space- can't fix the journey but can walk together and get through it.
- Helping parents to feel heard and listened to..
- Working in the role with someone else and mentors- provide that support for you







Professional System Roles Breakout room feedback

- **Right space** for the participants to feel comfortable and safe; right audience to affect change (so young people don't have to repeat themselves and so its meaningful; the right voices (are they representative etc) and the influence (feedback loop and impact). All these things are equally important.
- You need to **really trust people** we have done some work where the people with lived experience were so passionate that they wanted to work on things when the professionals were not available. The work that they did was amazing.
- Having a really clear framework and participation strategy linked to Lundy model has
 helped everyone in the organisations have clear guidelines. / Clear procedure for including
 those with lived experience to allow all the preparations to take place. / Clear guidelines
 about what is expected from someone in a lived experience role in terms of sharing.
- Speaking with other professionals to offload, share experiences. Being able to share some of
 my authentic self to show that I am human too. Being realistic about what you are able to do
 and not able to do. Building psychological safety and environmental safety. Letting young
 people know that they are able to share as much or as little as they like when THEY feel
 comfortable.
- Lived experience volunteers and staff feel supported, heard and empowered.
- Have chaired meeting with young people involved what worked was the amount of
 preparation that was done with young people. Worked with young people to put the agenda
 together. Putting energy in as Chair to make it work in the meeting. Key was having a chair
 who was committed to lived experience and lots of planning. Had a whiteboard with the
 jargon.
- Using policies and guidelines when having challenging times.







Winners

This section continued with the board game metaphor theme and used 'Winners' to imagine you have won the lived experience game and everything is in place to help you feel like a winner every day. It asked the questions, what is happening in the workplace? What is in place for lived experience staff, volunteers and the people who support them?



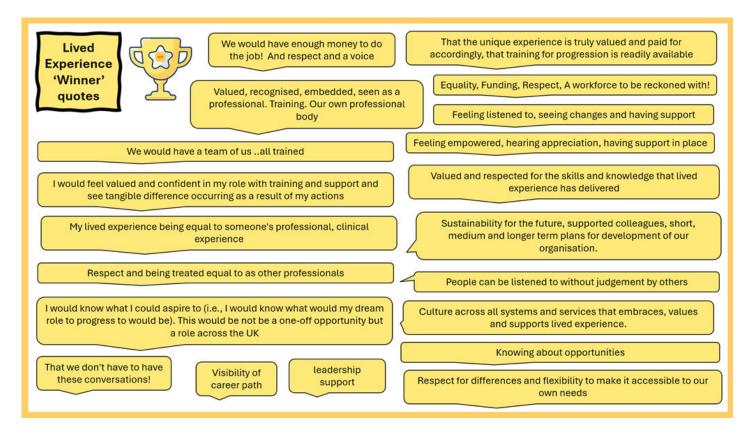
Lived Experience Workforce Roles breakout room feedback

- Having **enough money** to do the job, having respect and a voice.
- Feeling listened to seeing changes and having support.
- Having support from non-lived experience roles and people championing lived experience.
- Feeling empowered, hearing appreciation, having support in place.
- Team of us all trained.
- Feel valued and confidence in the role with training and support and tangible differences.
- Lived experience being **equal** to someone's professional, clinical experience. / Respect and being treated equal to other professionals.





- That the unique experience is truly valued and paid for accordingly, that training for progression is readily available.
- Equality, Funding, Respect, A workforce to be reckoned with!
- Valued, recognised, embedded, seen as a professional. Training. Our own professional body.
 / Valued and respected for the skills and knowledge that lived experience has delivered
- **Sustainability** for the future, supported colleagues, short, medium and longer term plans for development of our organisation.
- People can be listened to without judgement by others.
- Visibility of career path. / I would know what I could aspire to (i.e., I would know what would my dream role to progress to would be). This would be not be a one-off opportunity but a role across the UK
- Leadership support.
- Respect for differences and flexibility to make it accessible to own needs.
- Don't have to have these conversations.
- Culture across all systems and services that embraces, values and supports lived experience.
- Knowing about opportunities.
- More practitioners to support more young people.



Professional System Roles breakout room feedback

- Not second guessing if what I am doing is right or good. Not having the fear.
- Not just listening, but acting on what has been expressed. And not being afraid to ask
 questions. Also, witnessing the power lived experience voices have how they connect, how
 they change people's prejudice/assumptions and perspective.





- Properly funded work where children and young people are engaged from the start of
 conception have the option to engage in a range of ways and where what is produced is
 actually used and how it's used is evaluated by the CYP. / Protected funding in budgets for
 participation always the first thing to get cut as seen as nice to have. Success would be
 participation as core to work. / Not having challenging conversations with colleagues and
 funders everyone being aware of participation of how it works.
- Clear accountability.
- Young people have their voices heard and seen and it makes an impact on their lives and also impacts others- sustainable system change. Empowering other young people/ professionals. Being able to ask questions and not feel like you are expected to know everything.
- When you see smiles on the faces of lived experience people who have got involved in something you've facilitated.
- Measurable and tangible outcomes. Things changing!
- Human Resource (HR) systems etc are flexible enough to be properly supportive of these kind of roles.
- **People become more than their lived experience** and we see and value people and all their skill and knowledge and what we all give to the group/process.
- When young people are able to use experiences from co-production to add to their educational and professional lives to access opportunities.
- More co-production, peer researcher roles for lived experienced workforce in research, rather than just advisory roles.
- When we see changes that children and young people want.
- Meaningful involvement, with real change, rather than just a tick box exercise.
- Collaborative working in order to make whole system change across various organisations (so that young people are not repeating themselves).
- Youth-led rather than 'top-down' more often than not.
- **System change** and seeing that young people have got something out of participation (i.e., confidence, learning) young people get what they want out of it.
- When young people have been **supported to independence** but **feel safe** with the relationship that has been built, so feel ok to check back in with professionals from time to time if they do later want to share some news or get some help or bounce ideas off you.
- **More career-paths** for lived experience roles otherwise they get to the end of their contract and what then
- Having supervision to think of my mental health and wellbeing and not just Key Performance Indicators (KPI's).
- Not to be judged to be treated as an individual.
- Research to be driven by the young people young people in funding bodies choosing what gets funded. Young people being higher priority.





System Roles 'Winner' quotes



Not just listening but acting on what has been expressed. And not being afraid to ask questions. Also, witnessing the power LE voices have - how they connect, how they change people's prejudice/assumptions and perspective

Properly funded work where CYP are engaged from the start of conception - have the option to engage in a range of ways and where what is produced is actually used and how it's used is evaluated by the CYP

it HAS to be about relationships, belonging and community

young people have their voices heard and seen and it makes an impact on their lives and also impacts others- sustainable system change. Empowering other young people/ professionals. Being able to ask questions and not feel like you are expected to know everything

Lived experience volunteers and staff feel supported, heard and empowered

Clear guidelines about what is expected from someone in an LE role in terms of sharing

HR systems etc are flexible enough to be properly supportive of these kind of roles

When you see smiles on the faces of L.E. people who have got involved in something you've facilitated

having a clear framework and procedure for including those with lived experience to allow all the preparations to take place

Having supervision to think of my mental health and wellbeing and not just kpi's

collaborative working in order to make whole system change across various organisations (so that yp are not repeating themselves) youth-led rather than 'top-down' more often than not

measurable and tangible outcomes. Things changing!

More co-production, peer researcher roles for LE workforce in research, rather than just advisory roles Meaningful involvement, with real change, rather than just a tick box exercise

People become more than their lived experience and we see and value people and all their skill and knowledge and what we all give to the group/process

I think there should be more career-paths for lived experience roles - otherwise they get to the end of their contract and what then...

clear accountability

When young people are able to use experiences from coproduction to add to their educational and professional lives to access opportunities

Closing Thoughts

Great session - I'm very keen to be involved moving forward, thank you! It's been brilliant. Amazing start to what I'm sure will be something huge!

Thank you for a great session! It's been refreshing and engaging

It was really informative to hear others' experiences and the Nicicle working group is much needed, thank you and excited to see how it progresses

Felt a really safe space to share

Really appreciated having the questions in advance allowing time to think ahead - not feeling rushed and also doing it at a time that was right for me

Would love to stay involved

Closing thoughts

Thank you for a really interesting session!

Thank you for a really helpful, thought-provoking session.

> Really exciting to see how this goes forward. It has been a really good session, and I have loved hearing

Excited to seeing how this develops and interested in being involved

Thank you so much, been really great and a relief to have space to think about this

Lovely to be part of some great

conversations with Heart 9

What a safe space this has felt. Thank other people's experiences and ideas. Thank you!

> Having the agenda so detailed in advance was great, and felt like a great space to share. Thank you

you

Good to see people coming together to discuss this

Really helpful session - enjoyed the breakout rooms and having smaller groups to discuss. Would like more on those who span both groups. Would be great to hear more about Nicicle

Thankful for this space and would love to continue the conversation.







Children & Young People's Mental Health Coalition





Chat GPT insight

We uploaded the report to Chat GPT and asked the questions which are shown in blue. We have made some minor changes but otherwise left it as it appears.

Our question: Can you give conclusions from the Lived Experience Workforce Lounge Report?

Chat GPT response

Importance of Lived Experience Roles

Recognition and Respect: The report highlights the necessity for lived experience roles to be
recognised and respected within professional settings. These roles bring unique perspectives
that can significantly enhance mental health services, especially for children and young
people.

Systemic and Organisational Challenges

- **Need for Systemic Change:** Traditional medical approaches and systemic biases often limit the effectiveness and integration of lived experience roles. There is a need for systemic change to create inclusive practices and frameworks that support these roles.
- **Financial Instability:** A common challenge is the lack of consistent funding, which affects the sustainability of lived experience projects and roles. Financial support is crucial for the stability and growth of these initiatives.

Support and Supervision

- **Emotional and Professional Support:** Lived experience workers face significant emotional and professional challenges. There is a critical need for support mechanisms, supervision standards, and trauma-informed practices to ensure their well-being and effectiveness.
- **Training and Career Development:** Providing opportunities for training and career advancement is essential for the personal and professional growth of lived experience workers.

Collaboration and Inclusivity

- Building Trust and Collaboration: Successful integration of lived experience roles requires building trust and fostering equal partnerships between lived experience workers and traditional professionals. Collaboration leads to innovative solutions and improved service delivery.
- Valuing Diversity: Embracing diverse perspectives and breaking down biases are vital for creating an inclusive environment that respects and values lived experience contributions.

Impact on Service Delivery

• **Enhanced Services:** The inclusion of lived experience perspectives leads to better outcomes for service users, increased satisfaction, and engagement. Lived experience roles contribute to tangible improvements in organisational culture and practice.





Frameworks and Policies

• Implementation of Supportive Policies: Developing and implementing supportive policies and frameworks is necessary to guide the integration and sustainability of lived experience roles. Standards and guidelines help ensure these roles are effectively supported and valued.

Key Themes for Future Development

- **Burnout and Support Needs:** Addressing burnout and providing adequate support are critical for the well-being of lived experience workers.
- **Supervision and Standards:** Establishing supervision standards and a governing body to oversee the implementation and support of lived experience roles.
- **Trauma-Informed Practices:** Recognising and addressing potential trauma triggers is essential for the effectiveness of lived experience work.
- **Collaborative Efforts:** Promoting joined-up working between large and small organisations to support lived experience roles.
- **Customised Support:** Tailoring support mechanisms to fit the unique needs of lived experience roles, rather than trying to fit them into existing systems.

Final Reflections

The report underscores the transformative potential of lived experience roles in the mental health sector. By addressing systemic challenges, providing necessary support, and fostering a culture of inclusivity and respect, organisations can significantly enhance their service delivery and create meaningful, sustainable roles for lived experience workers. The insights and feedback from the event participants highlight the urgent need for systemic change and the implementation of robust support frameworks to realise the full potential of lived experience contributions.

Our question: What are some key actions from the lived experience report?

Chat GPT response

The Lived Experience Workforce Lounge Report outlines several key actions and recommendations from the discussions. Here are the main actions identified in the report:

Key Actions and Recommendations

1. Support and Address Burnout:

- Provide comprehensive support for the lived experience workforce to prevent burnout.
- o Implement supervision standards and establish a governing body.

2. Inclusivity and Representation:

- Ensure adjustments and supports are unique and tailored rather than fitting into existing systems.
- Address the challenges faced by different roles and individuals in the lived experience workforce.

3. Trauma-Informed Approaches:





 Be mindful of traumatic experiences and avoid re-triggering trauma in lived experience work.

4. Collaboration and Integration:

- o Foster joined-up working between teams, organisations and the wider system.
- o Promote collaboration to enhance the impact of the lived experience workforce.

5. Funding and Financial Support:

- Secure sufficient funding to support the roles and ensure sustainability.
- Recognise and budget for the work behind co-production and lived experience contributions.

6. Professional Recognition and Equality:

- Acknowledge the lived experience workforce on par with professional workforce.
- Promote equality and respect for lived experience roles within professional settings.

7. Training and Development:

- Provide training and support to provide opportunities for further learning to enhance the confidence and skills of the lived experience workforce.
- o Create visibility of career paths and opportunities for progression.

8. Organisational Culture and Flexibility:

- Cultivate a culture that embraces, values, and supports lived experience.
- Implement flexible HR systems to support the unique needs of lived experience roles.

9. Meaningful Involvement and Impact:

- o Ensure lived experience voices are not only heard but also acted upon.
- Focus on sustainable system changes and measure the impact of lived experience contributions.

10. Children, young people and family-Led Initiatives:

- o Promote children, young people and family-led rather than top-down approaches.
- Support children, young people and families to use their lived experiences to access educational and professional opportunities.

11. Supervision and Wellbeing:

- Provide supervision that addresses mental health and wellbeing, not just performance indicators.
- Ensure that those in lived experience roles feel supported and not judged.

12. Communication and Adaptation:





- Adapt professional language and meeting structures to be inclusive of those with lived experience.
- Provide clear guidelines and frameworks for involving lived experience in organisational processes.

These actions aim to enhance the effectiveness and sustainability of the lived experience workforce, ensuring they are valued, supported, and able to contribute meaningfully to the mental health sector.

Our question: What are the three biggest takeaways?

Chat GPT response

The three biggest takeaways from the Lived Experience Workforce Lounge Report are:

1. Need for Comprehensive Support and Recognition:

 There is a significant need to provide comprehensive support to the lived experience workforce to prevent burnout and ensure their wellbeing. This includes implementing supervision standards, establishing a governing body, and acknowledging the lived experience workforce as equal to professional services. Addressing these issues can help in retaining and empowering the workforce, ensuring they can contribute effectively and sustainably.

2. Inclusivity, Representation, and Trauma-Informed Approaches:

The report highlights the importance of ensuring that the supports and adjustments for the lived experience workforce are unique and tailored to individual needs. It also underscores the necessity of adopting trauma-informed approaches to avoid retriggering trauma. Inclusivity and proper representation in the workforce are essential to address the varied challenges faced by different roles and individuals, promoting a culture that truly values lived experiences.

3. Sustainable Funding and Career Development:

 Securing sufficient and sustainable funding is crucial to support the roles within the lived experience workforce. The report emphasises the need for financial recognition and budgeting for the work behind co-production and lived experience contributions. Additionally, creating visibility of career paths and opportunities for progression can help in professionalising the workforce and ensuring long-term sustainability.

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