CAPS
Independent Advocacy

CAPS Independent Advocacy People's Conference

Report 2024

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The People's Conference
& Lothian Voices

The People's Conference is an annual event for people with lived experience of mental health issues in the Lothians to come together and speak about what is important to them. It offers the opportunity to connect with likeminded people, discuss what is affecting them, and think about how they might change things for the better. This year's conference was in November.

Lothian Voices collective advocacy group, supported by CAPS Independent Advocacy, organise the event. Lothian Voices is a collective advocacy group for people with lived experience of mental health issues from the Lothians. The group provides an opportunity for people to bring their lived experience together and have a voice through events, consultations, attending the Scottish Parliament Cross Party Parliamentary Group on Health Inequalities and more.

Picture shows attendees at the table discussions during the People's Conference

Organising the People’s Conference

A key part of the People’s Conference is how it all comes together. It’s not just a platform for people to share their voices on the day of the event, but the entire process, from planning the format to following up afterward, gives everyone a chance to get involved, feel empowered, and have a say. The group chooses the event topic based on what feels most important to them.

Picture shows some of the Lothian voices group who planned the People’s conference.

Lived Experience: Can you hear us?

Lothian Voices decided to focus on the topic of lived experience involvement for this year’s conference. The group engaged in extensive discussions around what involvement feels like, how it can be improved, the challenges involved, and whose voices are being heard. The group felt it would be valuable to invite speakers who could spark conversations on the topic, sharing and reflecting on their own experiences. They wanted to incorporate a visual representation of lived experience involvement, such as the roadmap (P10), and provide an opportunity for attendees to share their personal thoughts through recordings, which would be captured by a member of CAPS staff on the day of the conference.

Format of the day

31 people in total attended the conference. A member of Lothian Voices introduced the day and told everyone about the group and the topic of the conference. Then Alex from Tidal yoga led everyone in a seated breathing activity to prepare us for the day.

Picture shows people taking part in the opening breathing activity with Alex from Tidal Yoga

John Beaton from Spirit Advocacy in the Highlands joined us online as our first guest speaker. He shared insights on meaningful engagement in advocacy and how SPIRIT strives to be a model for involvement. Spirit focuses on co-production, aiming to be positive, purposeful, and productive. John highlighted the importance of lived experience and the desire for more relational, less transactional services. After his talk, we had table discussions to explore everyone's thoughts and experiences.

Picture shows people listening to John Beaton's presentation, from SPIRIT.

Thoughts from table discussions

- People questioned how to navigate the diversity of lived experiences, as each person's needs are different.

- It was seen as common sense to involve people with lived experience in planning, as no one else could fully understand their needs.

- Attendees believed people with lived experience should be involved at all stages of service development, not just in decisions about what services should look like.

- Meaningful inclusion of lived experience helps people feel valued and part of society.
- Co-production was seen as a way to save time and involve more people in lived experience work.
- A barrier to collective advocacy is the need to be physically and mentally well to participate.
- People felt self-advocacy can be demoralizing, especially when nothing changes, and can worsen mental health.
- Advocating for oneself can lead to being seen as "challenging" and stigmatised but using an advocate might be viewed differently.
- People felt the system was inefficient, often prioritising statistics over actual improvements in people's well-being, leading to long waiting lists and alternative help being sought.
- People believed success measures are wrong, with outcomes not being person-centred, and they wanted to be seen as more than just labels.

"We need a system that works for the whole person".

Picture shows attendees at the table discussions during the People's Conference

Lived Experience involvement discussions.

We went on to have a table discussion about people lived experience involvement work.

People told us that they had been involved with CAPS, VOX, in consultations, in training, in panels and in groups with lots of different organisations. Some people had done a lot of lived experience work, and some had done very little.

"It was empowering to understand that I was not alone".

People said there are some barriers to involvement such as a lack of access to information and that information being spread sporadically across different platforms. People felt it would be beneficial to have information in one place, so people would know what choices they have to be involved. People felt venues, transport and their own health could be barriers. Also comfort levels, encouragement and support came up as important. One person said that they felt out of place when going to a meeting in a university building, feeling like they didn't belong there. Another mentioned that it was always quite confusing to find the right room, they found it helpful to go together with someone else.

"You have to see yourself in society in order to feel part of it".

People said that having peer workers could be helpful, due to having lived experience themselves, they would take time to know the person, before supporting them and allocating more time than standard.

"Meet the person where they are at".

Various things that would help lived experience involvement were suggested such as having general funding aimed to showcase the work of the people (creative and otherwise). People felt there should be a diversity of ways to input as one way will be easier for some but a barrier for others. People said that when the lived experience is taken seriously, it feels wonderful and meaningful. People said it makes you feel "less crazy" when you see people talk about an experience you have been through too, and it can be a great way to share information & resources for the rest of life. People felt there is still a big power imbalance between those with lived experience and professionals, that the power still lies in one direction.

Road map of lived experience activity

Next, we moved onto an activity where people were asked to represent their thoughts on lived experience work on a “roadmap of lived experience”: to visually represent the journey that this can be for people. People filled in individual roads with their thoughts then added them onto a large collective road.

Pictures show people filling in their thoughts on the roadmaps of lived experience.

What makes it easier to start the journey or get involved in lived experience work?

“Courage”

“A Safe space”

“Motivation”

“How I am treated”

“Being listened to”.

“Being appreciated”

“Being asked:
Invite me!”

“Available information “

“Understanding of
what may be

“Reputation of the organisation”

“More accessible venues”

“To be considered

“Well advertised”

“Trust from others”

“Strong communication
(what, when, how)”

What are the roadblocks or barriers to lived experience involvement?

“Lack of information”

“Self-doubt”

“Tokenistic”

“Acute or ongoing
medical

“Fear or anxiety”

“Time”

“Money”

“Past experiences”

“Self-worth”

“Energy”

Personal circumstances (e.g. trauma)

“Lack of trust”

No structure

“Stigma”

“Distance or lack
of transport”

“Lack of access
to technology”

How could those left out or marginalised be more involved? How could we hear more from them?

“Improve accessibility (language, non verbal etc)”

“Activism: conversations, get out there & meet people”.

“Better advertising”

“A regular platform/space/body”

“Include diverse viewpoints: Not just those who are articulate”.

Other environments (in the community, on the street)

“To be clearly open to marginalised groups e.g. LGBTQIA+”

“Use of technology”

“Encouragement”

“Awareness & flexibility: People have varying time or energy”.

“Make it easier to try things out without a commitment”.

“Hard to reach means easy to ignore!”

What makes the path smoother or would improve lived experience involvement?

Revised or better policies

Our knowledge is valuable & we deserve financial recognition for sharing it.

Confidentiality

Not to be labelled or pigeonholed, to be seen as a person

Good support from organisation

Diversity

Patience

Safe place

Having feedback and transparency about follow up and contribution

Being seen as a human with experience, equal to anyone else

Being honest, open minded and unbiased

What is the end of the road or ideal destination of lived experience involvement?

Inclusion & Diversity

Feel better about yourself (self-esteem)

Partnership work

Happiness, joy, fulfilment, contentment

Contribute to

To make a difference

Coproduction

Making positive change: services & organisations changing

Power balance

Real life impact

Gained valuable knowledge & experiences.

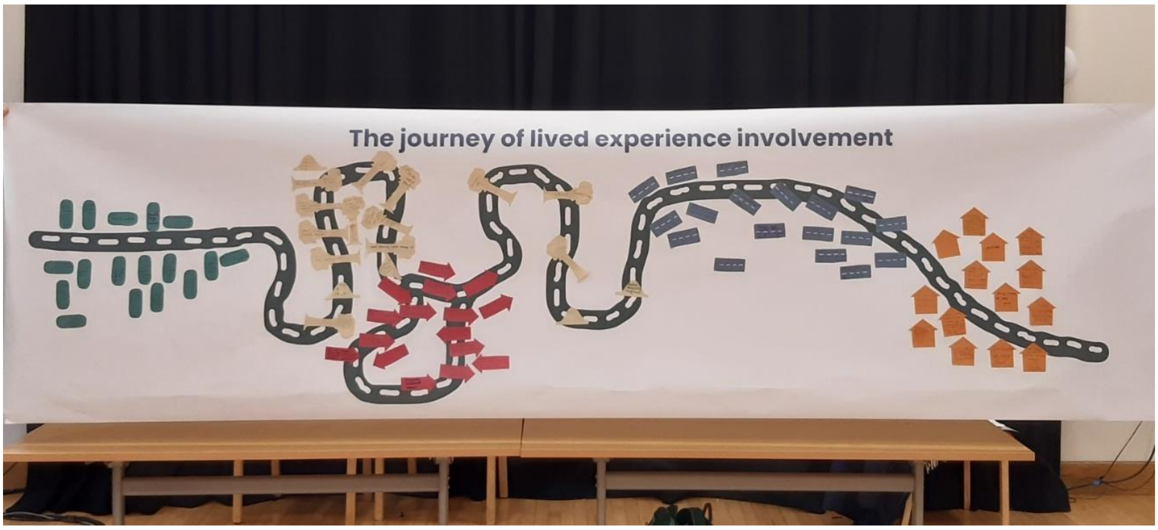
There is no end: this is a constantly evolving process…

To be properly heard

Empowerment

Feedback (hearing what happened)

True involvement from the beginning



Picture shows the finished “journey of lived experience involvement” created collectively.

Recipe for inclusion

We then looked at the “Recipe for inclusion” which was created in 2021’s people’s conference and considered the questions below:

1. **What has changed in lived experience involvement?**

People felt **things have gone backwards** due to covid: meetings have stopped, not everyone is “back in the room” or voices have been diluted due to being online. The **cost-of-living crisis and cuts** mean people have retreated or perhaps feel they don’t want to take away from someone else. People felt there are **human costs** (psychological, nervous system) to lived experience work which need to be addressed.
There is **now more short term than long term funding** and there is limited access to mental health support such as courses. People felt cuts to social care support means people end up hospitalised, but with hospitals under pressure many have to rely on family support, which not everyone has. People said they are funding the wrong thing, and it needs to be more preventative: **prevention is better than cure**.

2. **Is this still what we want from involvement?**

People felt we need to **get services to work together more.** For policy makers and decision makers to come into the community and see; not just to read reports in the comfort of their offices. Also, for people providing the services to put themselves in the shoes of the ‘people’ – open to the possibility that they might at one point be needing support themselves.

There was a consensus amongst people that there needs to be **different forms of inclusion**, finding the way that is right for you to advocate or be included. People said they wanted to be consulted and to be aware of decisions that are being made. To **have a seat at the table** and be made more aware of organisations where lived experience voices are heard on a regular basis and not just a one-off exercise.

People wanted it noted that **mental health problems do not always have to be negative**. There are learnings and strengths to be drawn from these experiences such as resilience, will and self-awareness.

People said there is a **power imbalance** established when one is “accessing a service” – of a ‘professional’ and a ‘patient’. This would need to change to recognise that: **“you are the expert in your own experience”**. One person said that a professional openly stating that they were the expert in their own problem made it easier for them to engage and they were grateful. **Trust**, people said, was important in any relationship, especially so when one is asked to engage through their lived experience. People would like the process to be honest and transparent to establish this trust. People said they need to be **treated as a whole human being** and support needs to be a collaboration, of understanding together who this person is.

3. Has the financial climate (funding) changed anything?

People said: **“yes hugely!”.** In the past they felt people weren’t afraid to ask for help but now there are **more barriers** or may feel “what’s the point?”. Groups and activities that existed before, now don’t (post covid) and people have had to find new drop ins. For example, some said contact point is now closed on Wednesdays, which has a big impact. People felt those with lived experience could be involved in raising awareness of such issues.

4. How can lived experience influence the current funding/savings crisis?

People felt firstly they need to know the decision being made and get information: **people don’t know until they are told**! People want information about big changes (e.g. funding) to be made more **accessible** and **understandable**. Decision makers should look at what’s important to people with lived experience. People don’t want to feel they are being involved in funding decisions if they are actually being asked to collude e.g. if asked what should be cut, so it would appear they are consulted but actually don’t feel they have a real say. People felt lived experience voices should be included sooner and for the entire process.

> **“It’s easier to cut funding from people who don’t complain and make noise: we need to shout about it! The people who can’t shout or have the voice to kick up a fuss are the ones who they take funding**

People felt it is important to do something and **taking direct action**, consistently such as lobbying government but pointed out there is fear about protesting and the possible consequences e.g. media attention, punishment, possible arrest, a criminal record or getting fired from job, that can put people off activism.

People felt gratitude can be weaponised by the government e.g. an attitude of “you could have it worse”. That **lived experience has the potential to humanise systems**, if MPs took this feedback. So that when they are making difficult decisions, they know the reality rather than only the views of people in power, who aren’t directly affected. Lastly people felt there needs to be a **perspective change on what an outcome is**.

Recordings

CAPS staff member, Angharad, took individual recordings throughout the day of peoples lived experience involvement and their views on it.

"The fact that I'm there shows that I'm taking it seriously, I'm engaging, and I want something positive out of it. Me not being there is … well, I can't change anything, I can't influence anything. Yes, part of a change, making a change, making a difference."

Picture shows Angharad preparing to record.

"For me, getting involved in panel discussions or steering groups has been useful, although maybe incredibly slow sometimes. But it feels like I have a seat at a table and that's important."

Guest speakers

Guest speaker, Dr Pamela Jenkins, from NHS healthcare improvement Scotland then joined us in person, to discuss "Amplifying the (many) voices of mental illness".
Pamela spoke about her podcast, "my family, mental illness and me" which focuses on people's childhood experiences of their family member's mental health issues.

Photo shows people listening to Pamela Jenkins

Pamela also spoke about how certain mental health issues are sometimes seen as more publicly acceptable than others and how those with longer term, enduring or more visible symptoms can be stigmatised. She reflected on how not all voices of mental health are heard and how these voices could be amplified.

Robyn Thomas, then joined us to share her written piece, which was published in Asylum magazine, which she wrote about her experiences in hospital and to discuss which narratives of mental health are considered acceptable and which are not.

Robyn is a member of CAPS collective advocacy group experiences of psychosis. She worked as a mental health speaker and is doing a PHD looking at people's experiences of Psychosis.

Picture shows Robyn Thomas answering questions at the People's conference.

Finally, Alex from tidal yoga returned to lead us in a seated breathing and gentle stretching activity to help people gather their thoughts and relax before going home.

Quotes about the day and its planning

"I personally found it worthwhile. The speakers were good too!

"I felt seen. It was supportive to be around those with similar experiences".

"I will take away the fact that CAPS are a really supportive organisation who are compassionate and empathetic in their support of people with mental health challenges".

"I felt inspired, I learned and am feeling braver".

"The planning team grew stronger together and formed a common vision which brought us together".

"I felt it was fantastic, excellent and thought provoking".

Next steps

Lothian voices and CAPS staff will be working on editing the recordings taken about peoples lived experience work and thoughts on this. These recordings will hopefully form a resource that will be useful to organisations who seek lived experience voices to know what people want and need from involvement. The group are deciding whether to put it together as one piece or a series of audio pieces based on themes and whether to add animation to turn it into a film.

CAPS will ensure that this report is distributed to everybody who registered for the event.

CAPS will also publicise this report on our website through our networks and will continue to present it at other relevant forums. We welcome invitations to present these views and are open to conversations about change.

Lothian Voices are continuing to explore other ways of having their voices heard.

Thank you!

Lothian Voices would like to thank everyone who attended and shared their views on the day, CAPS staff who facilitated the event and our guest speakers.

A huge thank you goes out to the Lothian Voices group for organising the event!

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