



CAPS

**Meaningful Involvement?
then MEAN to involve us!**

**CAPS People's
Conference 2021**

**Meaningful Engagement and
Involvement of lived experience**

Lothian Voices and The People's Conference

The People's Conference is an event for people with lived experience of mental health issues. It is planned by the Lothian Voices steering group, a collective advocacy group of people with lived experience of mental health issues, supported by CAPS Independent Advocacy.

The Steering Group

A key part of the People's Conference is how it happens. As well as being a platform for people to have their voice heard on the date of the conference, the process of planning the format of the event and the follow up are all ways in themselves for people to be involved, empowered and have a voice.

The Conference 2021

This year's conference was planned and attended online for the second year.

When the group were discussing the theme for this year's conference there were several topics that people felt were particularly relevant. However, a consistent idea that ran through these was involvement, and more importantly, *meaningful* involvement, of people with lived experience in how decisions are made, services are designed and delivered.

Key Discussions

- Lived experience involvement stories
- What does meaningful involvement MEAN?
- How do we achieve meaningful involvement?
- Trauma Informed Involvement

On the day

24 people attended the conference on the day. We started the conference with a lovely rendition of 'Smile' sung by Tony, which put everyone in a very cheerful mood to start the event!

The first session of the conference included examples of involvement from volunteers in the steering group and an open discussion thinking about what meaningful inclusion and involvement means to people.

There were two workshops that ran across the event that everyone was invited to have the opportunity to attend.

One of these was looking at how to achieve Meaningful Involvement and was facilitated by the Scottish Recovery Network who joined us on the day.

The other was facilitated by CAPS and looked at how meaningful involvement can be Trauma Informed.

After a well-earned lunch break we re-joined the event with the obligatory ice breaker to bring our energy back up!

An interactive game of 'inclusion' spot the difference proved to be great fun!

Throughout the planning for the event the idea that meaningful involvement resembled the idea of baking a cake was a common analogy!

Bringing together ingredients that complemented each other and spending time working on how these fit together; the way it was done and the time it took to get it right, all seemed to be necessary to ensure that meaningful involvement of people with lived experience could be achieved.

The final session of the event concentrated on how we could design a 'Recipe for Inclusion'.



How can we make involvement meaningful?

SRN (Scottish Recovery Network) facilitated two workshops throughout the day asking:

“What makes involvement meaningful to us?”



The groups on the day brought lots of points on what the difference between ‘involvement’ and ‘meaningful involvement’ meant to them.

Being seen as a whole person, a distinct identity within any shared space, and finding ways to incorporate this as a collective, was important to people.

Having joint clear intentions is vital for meaningful involvement. People told us that they often feel as though, even if they are listened to, it is without intent. These goals should be agreed and shared at the start of any process.

“The main thing is it has to be *humane*. How can we make it humane involvement?”

“Deeply listened to and understood”

Being truly ‘listened’ to and having choice in how they are heard was raised several times.

“Stated shared objectives of what the group wants to do/achieve up front. A ‘problems statement’ can be useful.”

“Choice in how we are heard, listened to and being able to change our minds and different perspectives as we progress”

“What creates a space for meaningful involvement?”



Being **accessible for all** was at the top of the list for creating a space for meaningful involvement. And extending this to be accessible in different ways - physical, emotional, and cognitive accessibility were equally as important.

[Involvement].....feels genuine when people consider things folk need e.g. travel expenses, access, extra chairs for people, doesn’t just feel like box ticking.”

Compassionate space was highlighted. People spoke about the importance of creating a welcoming space, whilst noting that creating spaces of equality can be challenging. People agree it is most rewarding when time is taken to reach **common goals**.

“Space needs a foundation, need time to develop relationships, reflect and actively listen.”

Communication was another key to meaningful spaces – knowing the structures within any process – who to speak to and being responded to was important to create meaningful spaces.

“We own our stories up to a certain point...Helpful to be able to edit things/pull back if necessary.....”

Along with this was the idea of value. To believe that a space has been designed to encourage meaningful involvement. It is important that people can see **evidence that their contributions** are valued. Also, that they have the same power to edit, change or add to notes and minutes from meetings.

“Language affects how people respond to us”.

“You can have all the resources in the world and all the learning opportunities in the world, but if you don't feel valuable, why would you contribute?”

“How will we know our involvement made a difference?”



The groups considered the question:

What would success look like?

There was an acknowledgement that an ‘all at once’ approach was not helpful and a coming together with dialogue was the way change happened.

Creating spaces was discussed and how this could contribute towards positive change. Allowing for spaces to be **created BY people with lived experience** was highlighted as an important way to encourage equality. Genuine collaborative work would support ‘blurring the boundaries’ of ‘them and us’ that people recognised as one way to feel a sense of belonging.

“... we have so much to share-we can shout and scream but won't be listened to so how do we get heard?”

One of the things that people identified as being most important when considering what success might look like was the notion of **acknowledgement**. To feel appreciation for contributions and be kept informed of the outcome of people's inputs was identified as paramount to a sense of meaningful inclusion.

Trauma Informed Involvement

What would you expect if you went to a 'trauma informed' service?

During sessions on trauma informed involvement, we encouraged people to think about what they would expect if they accessed a service that advertised as 'trauma informed'.

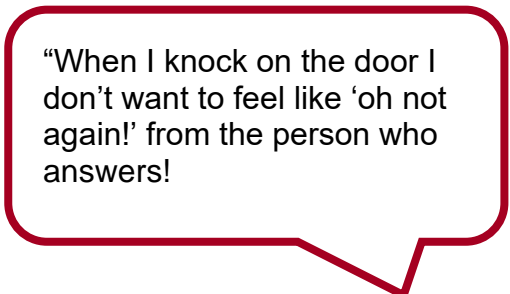
The discussions covered many elements of what a service might feel like or should offer that would connect with being trauma informed for people.

The most common theme was around the interactions with people in a service:

- **Not being asked too much** – people told us that being bombarded by too many questions was often difficult to deal with when first accessing a service.
- Feeling that there was **no pre-conceived ideas** or judgement was important to people.
- A commitment from services to take time to **understand a person's point of view**.
- **Patience and kindness** in their manner and their approach to conversations and interactions was essential.
- Good **listening skills** – don't just respond – consider.
- An attitude of **compassion and respect** for everybody in equal measure was also noted as a way to embody a trauma informed environment.
- How to **access** the service, the **gender of the person you dealt with**, the time that you accessed the service etc.
- **Recognising and valuing people's strengths** was very important to people. Being aware that people are whole individuals and not only the issue that they are accessing a service for

Elements of a service that people considered essential to provide a genuinely trauma informed environment:

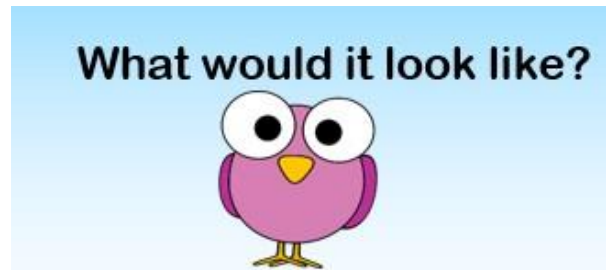
- **Confidentiality**
- **Transparency**
- **Boundaries**
- **Equality**



"When I knock on the door I don't want to feel like 'oh not again!' from the person who answers!"

What does this mean for involvement?

Given what people had identified about what 'trauma informed' meant to them, the second part of the workshop asked – “how could this influence what trauma informed involvement would look, sound and feel like – before, during and after involvement.”



Before:

- Having sufficient **relevant information** about meetings/events.
- Being **greeted in person** on arrival by a person, not left confused at reception!
- Understanding WHY people are involved, that the **purpose of involvement** has been discussed and agreed by all parties.
- That an invitation has been made about how a person wishes to be introduced and that this is respected.

During:

- Recognition from everybody that **not everything may be achievable** in the way they want it to be.
- That there is **not a separation** – professionals vs people with lived experience. That private conversations do not happen during meetings.
- That there are **equal chances for everybody to contribute** during interactions.

After:

- That there is a **check-in with people** - how did they find the involvement? Is there anything that would improve their experience?
- That people are **notified of the impact** of their involvement.
- **Included** in any additional communications about the interaction, i.e. meeting notes, future plans etc.

What would it sound like?



Before:

- **Accessible language** in communications.
- Using **plain English** and not using acronyms that people may not know.
- **Consideration of choice** when communicating, by phone, by email etc.

During:

- That conversation is **relevant**, does not stray into topics that people attending are not aware of and cannot contribute to.
- That tone is **polite and calm**. It is important that everyone in the meeting is introduced to make people feel **comfortable**, know who they are speaking to and to feel **included and welcome**.

After:

- That **feedback is welcomed** from people.

What would it feel like?



Before:

- Invitations extended feel **genuine**.
- That the information given is **transparent**. That people are receiving the same information as all other participants.
- That questions and requests for adjustments are welcomed and encouraged.

During:

- That participation is voluntary and that it is fine to leave if needed.
- That people are not under a microscope and being interrogated.
- That the **environment is safe to speak** in and that confidentiality is respected.

After:

- That contributions were included in a **genuine way and that they were valued!**

A RECIPE FOR INCLUSION

Serves: Everyone

Preparation Time: As long as it takes!

Ingredients:

Attitude:

- Patience
- Kindness
- Respect
- Trust
- Empathy
- Reciprocity
- Sincerity

Processes:

- Democratic intent
- Acknowledgement
- Universally agreed language
- Collaboration
- Trauma informed environment
- Clarity and Transparency
- Flexibility and Fluidity
- Time
- Open to criticism/comment/complaint
- Reflection and Accountable feedback

Must Include:

- Diversity & Volume of Voices
- Human Rights Approach
- Commitment

METHOD:

- Acknowledge and embrace **patience** as a two way street.
- Ensure there is a clear **understanding** of WHY involvement is happening – not tokenistic.
- Find ways to highlight and **promote involvement**. Make it not only worthwhile to the issue at hand but desirable, valued in a way that is recognised – ‘The price we pay’ (people give their time) and the ‘price you owe’ (recognise and value contributions.)
- Let people know outcomes, achievements and developments from involvement.
- Ensure **equal share of decisions** – ‘Where, when, how?’ Agenda setting, report writing, implementation.
- Provide **options for voices** to be gathered and options to contribute – attend meetings, complete surveys, phone consultations, case studies, build up volumes of lived experience from all ages/genders/experiences etc
- Agree **vocabulary of inclusion** – ‘members of group’ not professionals and lived experience.
- **Listen with intent** to contributions, consider how these fit with goals and aims.
- Ensure that spaces **recognise ‘person/individual’**.
- Engage people as capable, whole human beings with skills, capacity, sincerity and patience – not threatening.
- **Take time! Prepare, explore**, provide options, listen to needs, give choices and ensure that agreed actions are taken. Consider the Before, the During and the After of inclusion.
- Ensure engagement starts at inception, continues through design, is included in implementation and delivery.
- **Recognise and verbalise power dynamics**, make communication genuine.
- Be **aware and considerate** of comfort, body language, room layout etc.
- Make interactions **purposeful**.
- Include time with every involvement for **reflection** – ‘How can we make it better?’
- Be open and active to change –create opportunities to grow
- **it’s a process, it takes time!**

Next Steps

Our steering group hope to get involved with events over the next year looking at meaningful involvement. They also want to consider how they can create an environment for services to discuss how they use our 'Recipe for Inclusion' in their planning and structure.

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

CAPS will publicise this report on our website through our networks and will continue to present it at other relevant forums.



Acknowledgements

CAPS would like to thank everyone in the Lothian Voices steering group who was involved in the planning, collaboration and delivery of this year's, People's Conference!

For all those who participated in the conference CAPS would like to thank you for your time. It was great to see so many people attending and joining in with all our virtual activities.

Thank you to the Scottish Recovery Network for their input in the preparation, involvement on the day, and for the huge enthusiasm they brought to the event!

And a special thanks to Tony for opening the day with a 'Smile'!

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