

The Price of Recovery

The People's Conference 2022



CAPS



Lothian Voices

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The People's Conference and Lothian Voices

The People's Conference is an annual event for people with mental health issues to come together and discuss things that are important to them. It offers opportunities to connect with likeminded people, discuss what is affecting them in their lives, 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 is an opportunity for people to bring their lived experiences together and have a voice through events, consultations, attending the Scottish Government Cross Party Parliamentary Group on Mental Health and more.



Picture showing attendees at the People's Conference around two tables discussing what uses up their energy. One person is holding up a green sheet of paper showing the notes the group have made.

Organising the People's Conference

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 group decides what the event is going to discuss based on what feels important for them.



Picture showing attendees at the People's Conference around a table in discussion. One person is looking directly at the camera.

The Price of Recovery

This year Lothian Voices chose the topic of "The Price of Recovery". Discussions started out around the financial cost of helpful services not offered on the NHS – such as yoga or swimming. Things that are helpful in recovery often cost money. The cost of living crisis, as well as affecting people's finances, was also using up a lot of people's energy. This lack of energy was another barrier in accessing helpful services. Given the time, energy, and financial cost people have to put into their recovery, we ask: *What is the price of recovery?*

Key Questions

- What are services doing to help those with their own experience of mental health issues during the cost of living crisis? What more needs to be done?
- How is the cost of living crisis affecting people's mental health recovery?
- What uses up our energy? What can be done by ourselves or services to increase our energy?

On the day: Panel Discussion

Lothian Voices wanted to find out what services were doing to help those with mental health issues during the cost of living crisis, and identify what more needed to be done by services. The group decided to try something new – they invited a panel of people to come and speak about what their organisations were doing to help people with lived experience of mental health issues in the cost of living crisis.

The panel consisted of MSP Maggie Chapman, as well as representatives from Home Energy Scotland, Changeworks, Nourish, and Edinburgh Coalition Against Poverty.

CAPS were able to facilitate this portion of the day as a hybrid event so that people could choose to join online or in-person.

23 people attended in total.



Picture showing the panel. From left to right we can see Charlotte from Lothian Voices, then Maggie Chapman, Alan from Changeworks, Mark from Home Energy Scotland, Diana from Nourish Scotland and Mike and Gordon from Edinburgh Coalition Against Poverty.

A member of Lothian Voices collective advocacy group introduced the panel, and Maggie Chapman was the first panel speaker.

Maggie talked about the creation of the cost of living crisis, improvements but also areas in need of improving within the benefits system and the universal basic income.

"Scottish Greens have long talked about the universal basic income – something that gives everybody dignity and respect and doesn't measure an individual's worth by how much they contribute to the economy. So there is so much more to do." Maggie (Green MSP)

Alan from Changeworks gave lots of tips of things that people could do to save money on bills.

"So, there are lots of different things where you can save small amounts of money and hopefully over the long term you can save more money if you do a lot of them" Alan (Changeworks)

Mark from Home Energy Scotland added to what Changeworks had said by explaining help that people could get to upgrade their home energy systems.

"Our core mission is to help people stay warm at home, help people to spend less on their energy bills and to reduce carbon." Mark (Home Energy Scotland)

Diana from Nourish Scotland's Dignity in Practice project explained the work that this project is doing to help people have dignity and control over their food systems.

"We make sure that everyone can access food that is affordable, nutritious, sustainable, culturally appropriate, and most importantly food of your choice, so food that you want to eat."
Diana (Nourish Scotland)

Mike and Gordon from the Edinburgh Coalition Against Poverty (ECAP) talked about the way that their organisation works and how they are bringing people in poverty together to create change.

"We bring together people on benefits and low wages to support each other and resist austerity and we organise to combat poverty through solidarity and self-activity"
Mike (ECAP)

"One of the most important things we do is, in terms of solidarity, we will accompany people if they have appointments at a job centre or need to go to a health assessment, we will be there for them."
Gordon (ECAP)



Picture showing some of the panel members: Diana from Nourish Scotland and Mike and Gordon from Edinburgh Coalition Against Poverty.

Questions

After we had heard from the panel members, we had a question and answer section. Some of the questions are summarised below:

How closely do your services work with benefits services or other statutory services?

Changeworks said they inter-work with services by referring people on. ECAP said they work with the ordinary workers at the DWP and with organisations like Living Rent. Nourish Scotland have been doing some training with local authorities around food.

How have LGBTQIA+ people been affected since Covid in your organisations?

Maggie answered that LGBTQIA+ people were more negatively affected by welfare cuts. Nourish Scotland said they try and create an atmosphere where people feel they are creating something together rather than creating barriers through labels.

How are your organisations reaching out to the most marginalised people?

Home Energy Scotland said that NHS can offer financial help with bills if you need medical equipment at home and explained that they work with other organisations that reach out to marginalised communities. ECAP do outreach through stalls outside of job centres to speak to people there.

How can someone get help if they don't have computer access?

Home Energy Scotland said they were largely accessed through the telephone, and they also work with organisations that are directly speaking to people in communities. Maggie highlighted that libraries have computers that can be freely used.

If you are interested in hearing all the questions asked you can contact us for a recording of the panel from the day.

On the day: Spoon Theory

After lunch and some informal chat with the panel members, everybody learned about the 'spoon theory'. In spoon theory, spoons represent units of energy. Molly and Ele gave a short demonstration showing that everybody has different levels of energy, so they start their day with different amounts of spoons. Your mental and physical health effects how many spoons you have. People with long term health conditions generally have less spoons than people who are mentally and physically healthy. Different things take a different amount of energy for each person, so while socialising for some people might lose them 2 spoons of energy, for another person it might reenergise them (gain spoons).

Attendees then split into smaller groups to think about what used up their energy the most. The most draining activities mentioned were written onto cardboard boxes at the front of the room. These were:

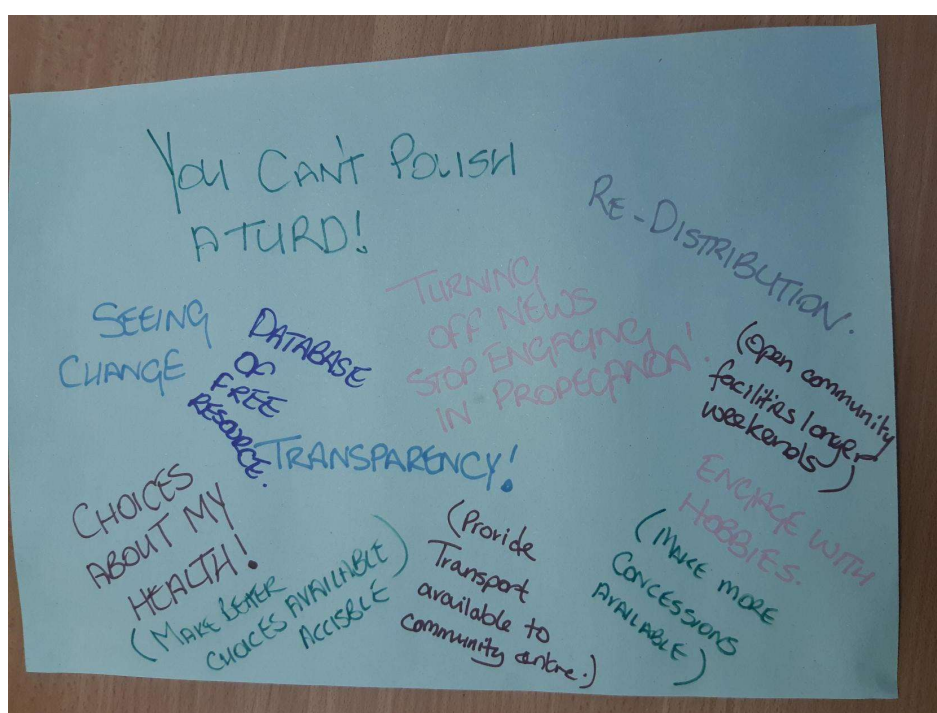
1. Travel
2. Disjointed services
3. Planning days
4. Negative interactions
5. Justifying yourself (explaining)
6. Budgeting (prioritising)
7. Waiting lists for appointments
8. Family and dependants (including pets and children)
9. Services and utilities
10. Debt (the financial and emotional implications).



Picture showing attendees at the People's Conference deciding which boxes they would put their spoons in.

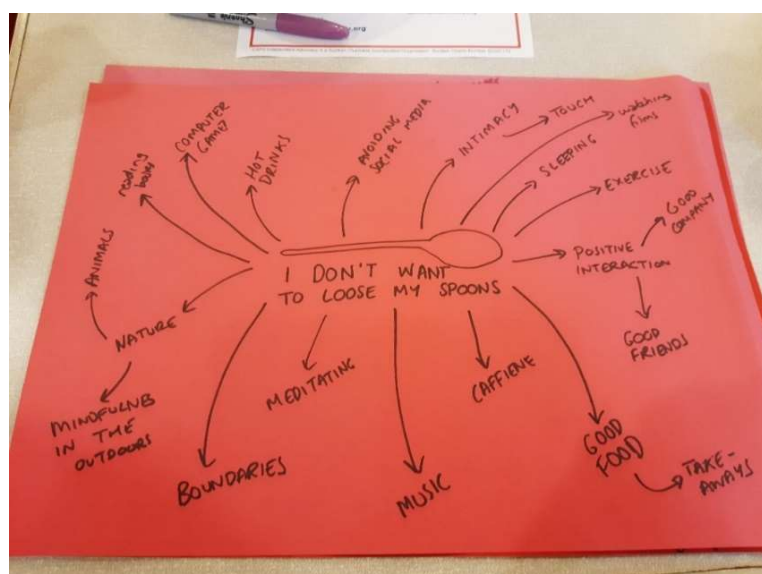
We followed this with a bit of a fun activity to get everyone moving about! Everyone was given 10 spoons each to place in the boxes of the activities they felt used up most of their energy. Travel was the top "spoons stealer" with 20 spoons. Planning days, having to justify yourself, and budgeting followed closely behind as big "spoon stealers".

Over tea and coffee, we discussed how either we could increase our own energy levels (gain spoons) or what we think services could do to reduce the number of spoons we lose in dealing with them.



The picture on the left shows some ideas people came up with. Ideas include having choice in your own health, having transport provided to community centres and engaging with hobbies.

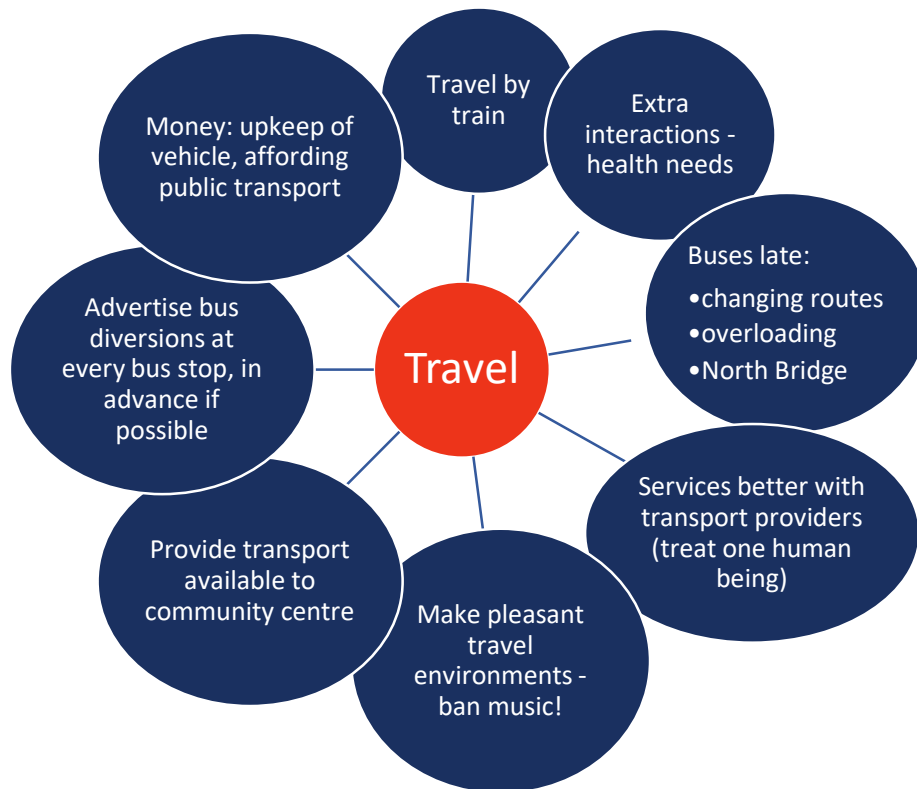
This picture on the right shows some ways that people on the day said they could increase their own spoons (energy levels) including setting boundaries, spending time in nature and sleeping.



Key Themes

Travel was a key theme at the People's Conference, as well as using up people's mental and physical energy there were also discussions about the time and financial cost of getting around.

You can see below the notes that people made on the day around the topic of travel:



Another key theme was having **choice and options**, particularly when it came to choices about people's care or treatments. Some examples of where people felt they should be given options of how to interact with a service were:

- Having longer opening hours;
- Removing limits on the number of sessions you have access to;
- Having options of how to contact a service e.g. phone or in-person
- Allowing people to miss appointments without this affecting their future care;
- More offers of prescriptions for things such as art, music or exercise – and more choice of programmes at each;
- And having the option of online or in-person appointments.

Inclusiveness was another area of focus within the discussions on the day. Conversations around how people had been let down by a lack of trans-inclusiveness and understanding of neurodiversity when trying to access healthcare were discussed.

Some ideas raised on the day for how services can be more inclusive for different minority groups is below:



Through discussions about how mental health services can improve, the topic of how there should be **more mental health support for mental health staff** developed. People felt that mental health staff could only help others if they had enough emotional energy themselves.

Suggestions for mental health support for staff included:

- Flexible working, including a 4-day week;
- Space for staff to reflect;
- Better pay;
- And hiring more staff to reduce individual caseloads.



Picture (left) shows Alan from Changeworks speaking.

Other really important key themes that arose from the day were:

- The energy used and potential for re-traumatisation by having to justify and explain yourself to disjointed mental health services. It was noted that repeatedly having to justify why you need help can prevent you from being able to get better;
- The importance of people's hobbies (e.g. reading books or being in nature) in helping people gain and maintain energy levels;
- The role of supportive people in your life and how they can help you when your energy levels are low;
- Long healthcare waiting lists as frustrating and draining.



Picture above showing attendees at the People's Conference listening to the panel speakers at the start of the day.

Next Steps

Lothian Voices has already presented information from the day at the *Thrive Edinburgh Conference: Think, Talk, Act* in December 2022. At this conference, group members shared the discussions on the day, taught everyone about spoon theory, and ended by asking people to write down examples of good practice within mental health services to share with others.

Post-it notes collected from the audience about good practice included:

"Actively listen + be solution focussed"

"Providing the opportunity for service users to feedback on services & influence how they are run"

"Work together to increase capacity and share resources. Remove admin barriers. Demand more long-term funding that allows for flexibility and growth. Use less spoons -> meet service users where they are (-> local services in the community)"

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 also exploring other ways of having their voices heard, including planning to create a short play from a lived experience perspective.



Picture above shows attendees at the People's Conference listening to the panel discussion.

Thank you!

Lothian Voices would like to thank all of the speakers on the panel: MSP Maggie Chapman, Mark from Home Energy Scotland, Alan from Changeworks, Diana from Nourish Scotland, and Mike and Gordon from Edinburgh Coalition Against Poverty.

We would also like to thank everyone who attended on the day, and the CAPS staff who facilitated the event.

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



Picture (left) showing boxes ready to be named and filled with spoons.

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