

The People's Conference Report

People with lived experience of mental health issues coming together to look at the Lothian Mental Health Strategy
'A Sense of Belonging'

What people said...

June 2014



This word cloud shows what people said they got from the conference. A bigger word means more people said it.

*To see a short version of this report or for more information, please contact
Lili at CAPS Independent Advocacy on 0131 273 5116, or
lili@capsadvocacy.or*

Contents

What is <i>CAPS</i>?	Page 3
What is <i>The People's Conference</i>?	Page 4
What happened at <i>The People's Conference</i>?	Page 5
What was said at <i>The People's Conference</i>?	
Presentations from Local groups and projects	Page 6
How people feel about recovery	Page 11
Tackling Health Inequalities	Page 15
Building Social Capital and Wellbeing	Page 20
Improving Services	Page 28
Setting Priorities	Page 33
Next steps	Page 35
Acknowledgements	Page 35
Contact details and copyright information	Page 36



What is CAPS?

CAPS is an **independent advocacy organisation** for people who **use or have used mental health services**.

CAPS **works with people who use or have used mental health services** as individuals or as members of a group to **set their own agenda**, to find a **stronger voice**, to **get their point across**, and **influence decisions** which affect their lives.

CAPS provides individual and collective advocacy in **Midlothian and East Lothian**. CAPS also has several **Lothian-wide** experience-led projects.

Individual Advocacy is about working **alongside a person** to help them **express their views** and have more **influence** over **decisions** being made about their lives.

Collective Advocacy is about **groups** of individuals with a **common cause** who come together to **raise awareness**, **campaign** and **influence** service planning and provision.

CAPS is an **Independent Advocacy** organisation.
This means that it:

- Puts the people who use advocacy first
- Is accountable
- Is as free as it can be from conflicts of interest
- Is accessible

These things mean that CAPS can work effectively to get:

A stronger voice for
people with mental
health issues

CAPS is a Scottish Charity, Number SC021772

CAPS is funded by East Lothian and Midlothian Councils, NHS Lothian, and East Lothian Community Health Partnership.

What is *The People's Conference*?

The People's Conference was an event for people with lived experience of mental health issues. It was a space for people to give their views on NHS Lothian's Mental Health and Wellbeing Strategy 'A Sense of Belonging'. It also gave people the opportunity to meet others and learn about different projects and groups in Lothian related to mental health and wellbeing.



Why was the People's Conference held?

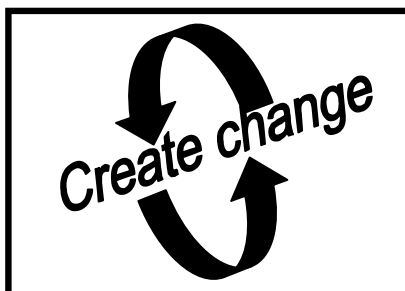
Every year there is a stakeholder event about the NHS Lothian Mental Health and Wellbeing strategy. This event is called 'Taking Stock' and is organised by NHS Lothian. Anyone who has an interest in mental health services in Lothian can go to Taking Stock. The aim of Taking Stock is to look at what work has been done over the year and what still needs to be done.

CAPS organised The People's Conference because people who have lived experience of mental health issues told us that they would like more opportunities to give their views on NHS Lothian's Mental Health and Wellbeing Strategy. It was in response to this request that CAPS held the first People's Conference in April 2014 at Queen Margaret University. A total of 22 people came to the conference and gave their views.



An additional 13 people fed into the topics from a workshop held at Redhall Walled Garden, and one more person via email, giving a total of 36 people's viewpoints included in this report.

What is happening to the information collected at the People's Conference?



What was said at The People's Conference was presented at the Taking Stock event by people that had gone to the People's Conference. What was said is also being used to write this report, and to be presented at other relevant meetings, for example NHS Lothian's Strategic Planning Board.

What happened at *The People's Conference*?

1. Talks by local groups

First, 5 local groups gave presentations about what they do. The groups were:

**Lesbian, Gay, Bisexual, Transgender (LGBT)
Health and Wellbeing**



Pink Ladies 1st



UNITed Eating Disorder Peer Support Group



**Edinburgh Community Voices/
Self-Carers**



Haddington Community Hub

2. Giving views on the strategy

After the talks, there were 4 creative activities that gave people a chance to give their views. The themes of the 4 activities were based around the 4 areas of NHS Lothian's Mental Health Strategy. These are:

1. Tackling Health Inequalities
2. Embedding Recovery
3. Building Social Capital and Wellbeing
4. Improving Services for People

What was said at *The People's Conference*: Presentations from local groups and projects

LGBT Health and Wellbeing - Demonstration Project



Alison Wren from LGBT Health and Wellbeing talked about the Mental Health Demonstration project. This project collected information about the effects of stigma and discrimination on LGBT+ communities in Edinburgh and the Lothians in addition to looking at how a range of different types of support helped LGBT+ people to improve their mental wellbeing. 'LGBT' means lesbian, gay, bisexual and transgender, with the '+' (plus) indicating that it also includes other people with related identities such as queer, intersex, asexual and those questioning their sexual orientation or gender identity.

Alison gave us general information about the mental health experiences of people from LGBT+ communities. For example, compared to the general population, people who identify as LGBT+ are three times more likely to experience violence, and three times more likely to attempt suicide. The largest piece of research in the UK about transgender people's mental health found 1 in 3 people had made a suicide attempt and but despite these high rates of distress, more than 25% of people were unlikely to access mental health services for support due to previous negative experiences. Stigma and discrimination are major factors in the ongoing lives of people in LGBT+ communities.

Alison then showed us some of the specific findings from the Mental Health Demonstration Project:

- Isolation is a negative factor throughout the LGBT+ community
- People benefit through contact with groups in the LGBT+ community
- People are more likely to access other services once they felt comfortable and supported through LGBT+ groups
- Suicidal thoughts were reduced among those people who were part of an LGBT+ group

The Project also asked questions of service providers. 53% of professionals who responded said that they didn't know whether or not their service was welcoming to individuals from LGBT+ communities: this indicates that they were not aware of important access issues to their services for members of the LGBT+ community

The findings of the survey led the Demonstration Project to produce a self-audit tool for services to use to help them work effectively with LGBT+ people. At the time of the conference, the project was coming to the end of its original funding; however, the mental health and wellbeing programme,

Headspace, continues to deliver services with support from NHS Lothian and The Robertson Trust.

The project will continue with this type of work to help others to understand why people in the LGBT+ community experience the level of isolation that they do, and where possible help improve services that promote good mental health for members of the LGBT+ community.

Pink Ladies First

Three speakers from *Pink Ladies First* in Midlothian spoke about their project around women's mental health.

They aim to counter the stress, anxiety and depression that are often a part of women's mental ill-health. Pink Ladies offers self-management courses and can also provide "one to one" coaching and peer support.



The atmosphere in the Pink Ladies First project is kept informal. Use of humour and working towards confidence building are major features of their groups. Women that use the service aim their self-development towards awareness, acceptance and adaptability.

One of the women spoke about her personal experiences of working in the Pink Ladies Group, and how it had been an invaluable step on the road to her recovery. The service has helped her to work out what direction to go in and to explore what possibilities were there for her.

At the time of the conference, Pink Ladies First had a waiting list of around 30 women. As the organisation looks to the future, Pink Ladies wants to strengthen the project so that Pink Ladies First is available when women who are likely to need this kind of help get in touch.

The individual women who use the service are discovering talents and strength that they can also feed back in to Pink Ladies' work.

Financial issues are an area of big concern for the project. The service is free, and the funding they receive is mainly short term. The group is currently considering whether or not to charge organisations that refer women to their service. Self Directed Support may also be a way to provide resources to Pink Ladies without a direct loss to the women that use their service.

UNITed and Seen but not Heard

Our next speaker spoke about two eating disorder projects they were involved in- *UNITed* and *Seen but not Heard*.

In 2013 CAPS did a survey looking at the experiences of people with eating disorders. There were 56 responses to the survey which shows a good level of interest. The survey found that services for people with eating

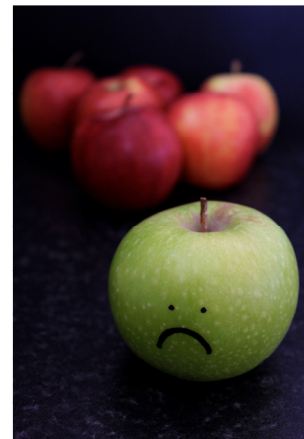


disorders are very limited. One priority from the survey was to make a film explaining what it is like to have and to experience eating disorders. The survey also showed that many who have/have had these experiences want to meet and be supported by other people who know firsthand what the issues of eating disorders are like.

UNITed is the peer support group for people with eating disorders set up on the back of this survey. It was set up by people with lived experience, with support from CAPS, and funded by the *Butterfly Bursary*. The group is going well. The members meet once every two weeks to support one another and to discuss any issues that have arisen. It gives all involved a safe space to talk about whatever issues they want to discuss.

People with lived experience also made a film about their experiences called *Seen but not Heard*. This was also funded by the *Butterfly Bursary*. The film has raised a huge amount of interest and the group are keen to show the film in as many places as possible in the community.

At the time of the conference, the people involved in *Seen but not Heard* were looking for more funding to continue to build on the work they have done so far. They plan to develop a toolkit for professionals as their next step.



Since the conference, the group has successfully won funding from the *Butterfly Bursary* and *See Me*. The *Butterfly Bursary* funding has enabled the project to employ one of the people involved as a development worker to facilitate the project. The *See Me* funding will be used to develop the toolkit for professionals.

Community Voices - Self Carers

Community Voices is the community collective advocacy group in Edinburgh. People with lived experience of mental health issues came together in the beginning of 2013. They were all living on their own without the support of family or friends. The group addresses the unique problems that arise from living totally on your own and from having experience of mental health issues, and use the phrase self-carers to refer to themselves.



The group identified that self carers find themselves isolated and their problems intensify as they become unwell mentally. They feel as if there is nowhere to turn especially for practical help. Neighbours, for example, don't want to become involved. The stigma around being someone with mental ill health complicates being on your own and they identify that it feels like you are falling through the net.

They shared an example where a person was asked to go and see a community dietician for help with losing weight. Unfortunately the dietician appeared to have no knowledge about psychiatric issues and the side effects of medication. This example shows that training about mental health issues and experience should be required for a great range of service providers. With more awareness and training of professionals, interventions are more likely to be effective in helping people who experience mental health issues.

The group have made a number of contacts, including VOX, MSPs, the Human Rights Commission, the Mental Welfare Commission and Community Psychiatric Nurses. The group have also approached NHS Lothian for the resources that this group needs.

The group of self-carers are determined to research the need and gather necessary evidence. At a Rapid Improvement Event they recorded stories from people who are on their own that illustrate the range of issues which are important to self carers. The group have outlined their next steps:

- Get recognition of the category "Self Carers"
- Get acknowledgment of all the issues identified
- Develop a Assessment System (which is holistic in its approach) with one central coordinator

Haddington Community Hub

Veronica Forrest spoke about the Haddington Community Hub. This is a group of people who support each other and meet in the Annex of Tyne Park in Haddington. She described the effects of a decision by the local authority to close the building that their group used as a drop-in meeting space. No alternative was offered.

Group members are very disillusioned. They want their meeting space to be replaced. They feel that no one is listening to what the members have to say about the effects of this loss.

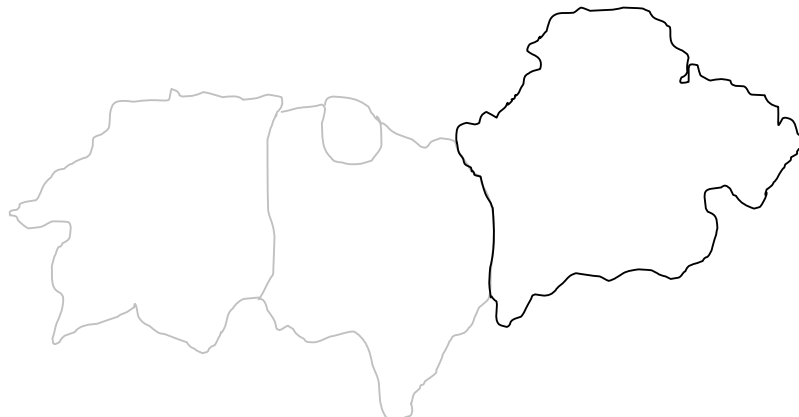
The group know about how valued the Orchard Centre is for the people of Midlothian. They view the Orchard Centre as an example of a good drop-in service. It is funded quite well and the value of the service seems to be appreciated by Midlothian Council.

The picture in East Lothian is completely different. The Tyne Park group had its funding removed. The group was paying rent for the drop-in venue and it no longer has the funds to do that.

This lack of support for what the drop-in meant to the group is disheartening. From the group's point of view the value of the centre was proved specifically at times when one of their members was becoming unwell and the group drew in round the person and helped to encourage the person to take up services and get the help that they needed.

The group noted that there was a low rate of referrals from local services prior to the closure of their centre. The group have wondered whether the low referral rate was also a way of professionals distancing themselves from the kind of support that can be given by a drop-in service.

They now feel that they are in unbearable isolation and it feels like hope is slipping away.



What was said at *The People's Conference*: How people feel about Recovery

What is recovery?

Recovery is defined as being about living a satisfying, hopeful and contributing life even with limitations. It means different things to different people.

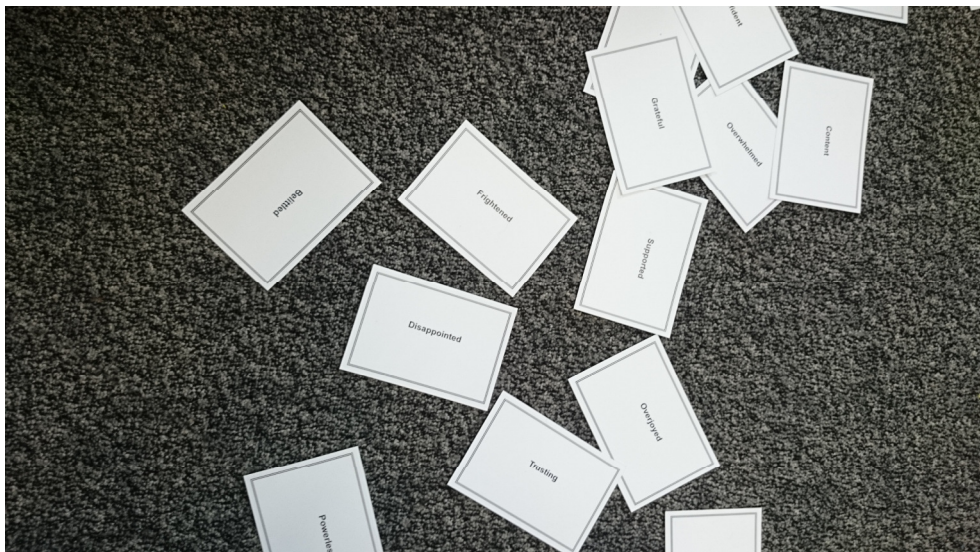
A Sense of Belonging wants to make sure that recovery is being embedded in services, promoted by services and that professionals are working with people to achieve the recovery they want

What was the activity?

We wanted to find out how people feel about the concept of recovery and the way that services promote recovery.

First, we said what recovery means using the definition above. Then we asked people to split into small groups. We put cards on the floor that had words for different feelings written on them. We asked people to pick up a card that described how they feel about recovery. They spoke about the card they had chosen and why they felt like that. A facilitator recorded what was said in each group.

So, by the end of the activity, we had a list of words that people said related to how they felt about recovery, and a record of what people said was why they felt like that.



Below we've written the main themes of what was said. At the end of this section there is a word cloud which shows the words that people chose to show how they feel about recovery. The bigger the word in the word cloud, the more often it was said by people.

Recovery is imposed from the top down. It is defined and led by professionals and politicians. Some people feel it is undermining and belittling.

Many people felt that recovery is in the power of professionals and politicians. People are feeling pressured by services to get well and are often patronised, belittled and undermined. Some people said they were forced to make a WRAP (Wellness Recovery Action Plan) and feel like services are ticking boxes rather than really listening to what people need.

Recovery is held up & we need and are expected to aspire to the health board's definition of what recovery is.

There is too much blame and pressure on the individual. There is an assumption that there is something wrong with you.

Intervention can be about being taught to cope with what is unacceptable in society.

wrong with society.

People felt that recovery moves the emphasis to the individual with the implication that there is something 'wrong' with them. It does not look at collectively trying to change a hostile environment or working to identify what is

People want to be accepted and valued for who they are and not to aspire to be someone they are not. People feel overwhelmed with the expectations and pressure to recover, there is too much at once and things are not taken at their pace.

Why do we have to recover from our personalities?

The word recovery has various definitions and is becoming meaningless. It's individual but recovery is often limited and generalised. Some people feel misunderstood and frustrated.

Recovery is personal but it is in policy and therefore generalised.

Recovery has become a buzz word and is losing its meaning for many people. People feel that it is now the language of professionals and politicians.

Recovery was a word that people used – people with mental health issues have to invent a new word that's theirs and captures what's real

One of the things that people identified is that recovery is personal, and the concept of recovery works for some people but not others. The fact that recovery is in policy means that the definition is more generalised and the general definition does not fit everyone.

Some believe that recovery needs to be reinvented and reclaimed by people with lived experience of mental health issues.

Some people are not getting the help they need and treatment is based on medication.

They just give medication. Expect me to recover without the support, it makes me more depressed.

There were many people who are not getting the help they say they need and are only getting medication. People said they have not experienced this concept of recovery from the NHS and are frustrated by the overuse of drugs to treat mental health conditions.

Peer support is very important in recovery.

People said that one of the most important things in their recovery was peer support and being around people who understand where you've been. People said there are not enough opportunities to get peer support in the community.

A number of people commented on their feelings about their own recovery.

People said that they felt overwhelmed because there was so much out there, anxious that it wouldn't go well, insecure because of the lack of support, depressed due to relapse and having to cover old ground, and hopeless because they feel they've been prevented by a psychiatrist from getting a job and studying which would have been helpful.

Some people feel grateful, supported, hopeful, inspired and respected

Some people feel grateful and supported by services. People who said this said they feel respected by support staff and Occupational Therapists and are hopeful about recovery. People also feel that they are involved as an equal partner. Some people also said that they feel inspired by hearing what recovery means to other people.

I felt involved as an equal partner. People looked at me as a person who needs help

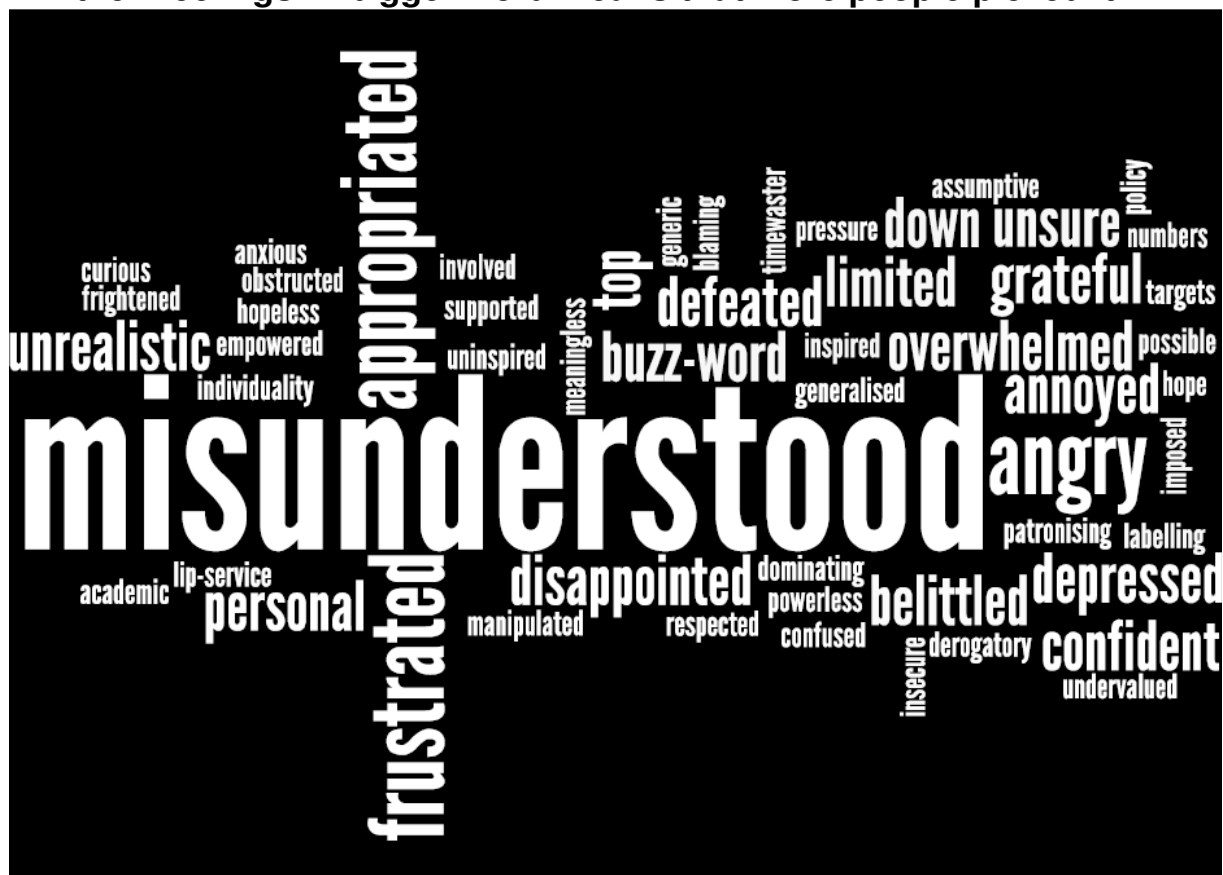
Advocacy can help

There were a few people who said that working to change things and having a voice was helpful in their recovery. There is still work to be done around the stigma and discrimination surrounding mental ill health.

Recovery has become too academic

You can get certificates and go on courses around recovery: some people feel it has become too academic.

This word clouds shows the words that people picked to represent their feelings. A bigger word means that more people picked it



What was said at *The People's Conference: Tackling Health Inequalities*

What are health inequalities?

Health inequalities describe the way that certain groups may experience more things that have a negative impact on their health. For example, you might have a long-term health condition in addition to experiencing mental health issues, and you might feel that this makes you unequal as services don't work to address the way these two things interact, therefore making your mental health worse.

Tackling health inequalities is about finding solutions to remove these health inequalities.

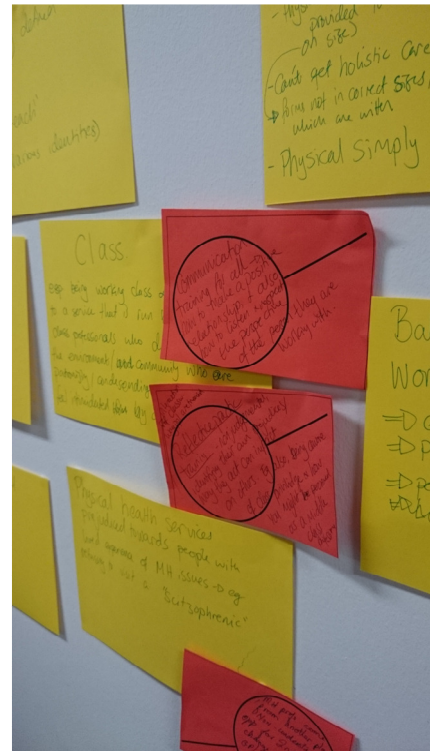
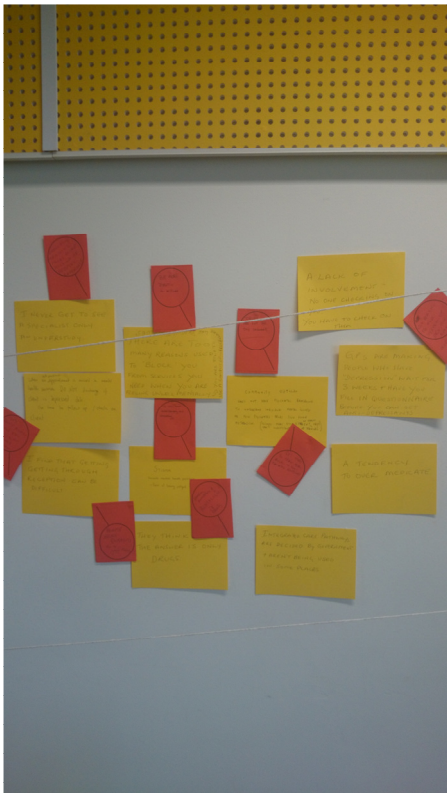
What was the activity?

We asked people to think about whether they feel that they- or others- experience disadvantage in society, in what ways that this might be, and potential solutions.

In small groups, we asked people to write on paper bricks the things that make them

unequal. Each group then built a wall of inequalities with the bricks. After this they were asked to write on pieces of paper shaped as wrecking balls the things that could address this inequality and break down the wall. Below is a summary of what was said.

Barriers with similar themes have been grouped together. Solutions have been grouped by type, for example all suggestions for training going together.



Barriers to health equality

Having mental health and physical problems

Mental health and physical health are dealt with separately and holistic care is hard to come by:

- Physical symptoms are often treated as being a result of mental health issues
- Mental health issues are often neglected when you are being treated for physical health issues
- People experience prejudice from physical health services as they have a mental health diagnosis
- There is a lack of understanding about medication side effects
- Often it's hard to get access needs met by services- e.g. documents in the right size font
- People have been refused access to psychological therapies due to a physical health issue

Being over 60

People said that being over 60 meant they experienced inequalities:

- There is a lack of services for people over 60 (especially for people living in Midlothian and people who identify as lesbian, gay, bisexual or transgender)
- There is ageism in services.

Having an eating disorder

People said that they were disadvantaged if they had an eating disorder:

- Mental health services don't deal with eating disorders
- GPs are not educated on eating disorders
- It is particularly difficult if you are a man with an eating disorder.

Identifying as LGBT+ (see page 6 for a definition)

People said identifying as LGBT+ made them experience inequalities:

- Transgender people still experience negative attitudes
- People still experience assumptions being made about their gender
- LGBT+ people experience exclusion and discrimination
- Hospitals and old people's homes don't cater for people who identify as LGBT+.
- People said they weren't aware of a service for over 60s

Trying to access services if you are feeling unwell, but don't quite meet eligibility criteria

- People said that there are too many reasons used to 'block' you from services you need when you are feeling unwell
- For many there is no support unless you are really suffering or in a

crisis.

- People are discharged if they miss appointments and no-one checks up if they are ok

Religion, culture, race and ethnicity

Having various identities (for example different home language, cultural backgrounds, mixed cultural relationships, different family set ups, different experiences, other minorities) leads to people experiencing inequalities in services:

- People are defined as 'hard to reach' because of their identities
- Some identity groups have specific services, others don't

Class

People felt they experienced inequality because they were working class, or because they had different levels of education:

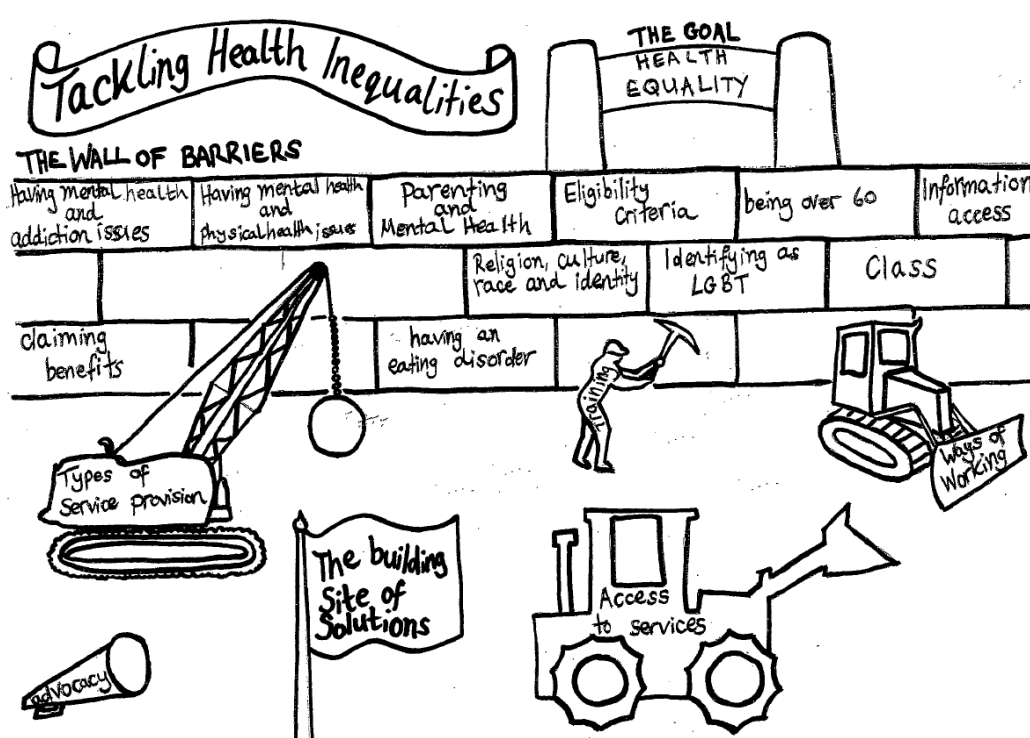
- Middle class professionals don't understand the environment or community you come from and are patronising and condescending

Parenting and mental health

People said that they experienced prejudice and discrimination especially as a parent- it is assumed that you will be unfit to look after your kids. There is a fear of being judged.

Other health inequalities people identified:

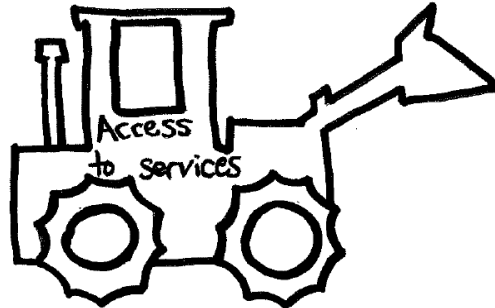
- Having mental health and addiction issues
- Not being able to find out information in a way that they can access- e.g. there is more of a reliance on being able to use the internet
- Claiming benefits- e.g. GPs don't know about the effects of welfare reform on mental health and now they won't write letters



Ways to tackle health inequalities

Access to services:

- People would like to be able to get a second opinion or change psychiatrist; GP or Community Psychiatric Nurse if they are not happy
- No age limit on services
- Better information about eligibility
- Make services self referral
- If someone has missed an appointment don't discharge them, use the time to check and follow up on them
- Make sure you don't have to start from scratch if you have been discharged
- Provision of interpreters
- Provide help to fill in forms and help with self referral



Ways of working

- Non-judgemental
- Listening
- Respect the perspective of the person you are working with
- Don't make assumptions
- Show understanding and empathy (e.g. if people miss appointments)
- Show sensitivity to identities
- Positive in attitude
- Encourage reflective practice, including identifying your own prejudices and how the way you act can impact on others.
- Encourage staff to have an awareness of class privilege and how they might be perceived as a middle class professional
- Ask about literacy sensitively
- Collaboration between professionals and people using the service
- Take action on discrimination
- Have better communication between community and health care services



Training

- Include mental health training in general medical/ nursing training
- Have more experience-led training for professionals
- Make sure that medical training takes more account of people's experience
- Make sure GPs are educated in eating disorders
- Training on equality and diversity, including LGBT+ training, training about not making assumptions about gender, and training about a variety of identities
- Communication training for all
- Promote awareness of mental health and diversity



Types of service provision

- Have condition-specific mental health peer support in GP surgeries
- Make sure there is eating disorder self-help available for all genders
- Have more early intervention services
- Have mental health staff that you can see at the GP surgery instead of the GP
- Use the old system of doctors on call not NHS 24
- Conduct a survey to ask people who are called 'hard to reach' what they want/need/would help them access services

Advocacy

- Have voices of lived experience at a strategic level



What was said at *The People's Conference*: Building social capital and wellbeing

What is social capital?

Social capital is about feeling connected to your community and feeling like you belong.

Building social capital is then about increasing these links and bonds in a community.

A Sense of Belonging says that building social capital is one way to deal with things like social isolation, low levels of support and low self-confidence. This can make people's mental health better.

What was the activity?

We wanted to find out what people thought would enable them to take part in things that help build social capital. To do this, we made bunting.

So, we asked people to talk about the types of things that would help them:

- Have more confidence;
- Feel connected to their communities;
- Feel like they belong;
- Bring about changes in their lives.

We looked at 7 areas that can help with building social capital. These were taken from *A Sense of Belonging*, with Collective Advocacy added.

- Creative arts
- Volunteering
- Education
- Spirituality
- Greenspaces
- Employment
- Peer support/ socialising
- Collective Advocacy

Each activity was pegged to a string, with another string for 'anything else', in case there were activities that people were interested in that we hadn't listed.

We asked people to writing on a bunting flag the type of thing that would empower them to take part in the activities that interested them. These were then pegged to the string for that activity.

So, by the end of the session, we had 8 strings of bunting. This means we now have a list of things that people say will help them have more *confidence*; feel *connected* to their communities; feel like they *belong*; and bring about *changes* in their lives.



Volunteering

People said that things that would enable them to become involved in volunteering are:

- For volunteering to be taken as seriously and considered as important as a 'real job'
- For no assumptions to be made that because someone is fit to do voluntary work they are 'fit for work'

- To not be penalised for doing small amounts of work that help them with their condition
- For organisations to be empathetic and understanding to mental health related things
- That a drop-in centre can be a way for people to get involved with volunteering

I'm afraid the Department of Work and Pensions/ JobCentrePlus will think that the small amounts of volunteering work I do means I can do a normal job

I get a HUGE amount of support to do the volunteering work I do and it's all mental health activism related so there's empathy and understanding

Employment

People said that things that would enable them to become involved in employment are:

- A drop-in centre as a route to employment
- A self-employment co-op or a Non Government Organisation to provide employment support
- Training towards employment
- The chance to try employment out on a trial basis to work out coping skills
- For work to be meaningful and secure
- To get paid a living wage
- For employers/ organisations to have more training and understanding about mental health issues; to adapt policies to make it easier for people with lived experience of mental health issues to feel able to work; to not discriminate against people with any type of illness

Pay me – Don't use me!

Peer support/Socialising

People said that things that would enable them to get more involved in peer support or socialising would be:

A range of types of activities in a variety of locations:

- To have more activities for older people not discos or bookies and public houses
- LGBT+ support groups in other areas in the Lothians
- Book clubs
- Chess clubs
- Bullying prevention groups for children
- Eating disorders meet-ups
- Peer support on either a self-carer basis or group like-minded basis.
- More help with access if there are no groups in the area.
- Places like Redhall Walled Garden. A Supportive work environment

More services:

- To have a drop-in centre
- To have more places like the Orchard Centre to help people with mental or physical illnesses.
- To have more support from the government to help fund drop-in centres
- Re-open the drop-ins
- “recovery” hubs
- Keep the gym at the Royal Edinburgh Hospital open to outpatients

Support to set up peer-led groups:

- To have help, support and advice to set up and run a Borderline Personality Disorder peer support group. At the moment none of us in the “group” wishing to access it are well enough to co-ordinate this by ourselves due to the fluctuating nature of our conditions.
- More funding for peer led support groups
- Paid peer support workers

Creative Arts

People said that things that would enable them to become involved in creative arts are:

- More access to art/ music therapy
- Help with accessing creative arts
- That a drop-in centre would help people get involved in creative arts activity

Spirituality

People said that things that would enable them to become involved in spirituality are:

A range of types of spiritual activities in a variety of locations:

- To protect and improve Chaplaincy services- a number of people have said that they have been refused access to chaplaincy services when they were an inpatient in a mental health hospital
- To have groups for people who don't follow a particular religion
- To have secular groups
- For drop-in centres to have gardens

To make sure that things are accessible:

- For services and venues to be accessible
- To have someone to go with
- To have a computer

Green Spaces

People said that things that would enable them to become involved in green spaces are:

Support to make sure that green spaces are accessible:

- A buddy to go and get involved with green spaces with
- Supported groups for walking
- To have support to go out (of hospital)
- For more access for people with lived experience of mental health issues/patients to use the countryside for walks etc.

More services:

- More labyrinths to wander round
- A drop-in centre

Education

People said that things that would enable them to become involved in education are:

Increased access to education in general:

- The provision of drop-in centres provide a place to signpost to education
- More help with access to education
- More access to college & university for people with lived experience

Provision of specific skills training:

- Computer courses for people with mental health issues
- Reading, writing and maths courses
- Have mental health nurses in schools for young people to talk to

Getting involved in delivering education:

- Training/education courses for people who have been recently diagnosed with a condition (e.g. Borderline Personality Disorder) which will be run by people with lived experience and facilitators (if required) to help people understand/come to terms with their diagnosis. This would include information on coping strategies, treatments, support, how to access welfare advice and basic reading, writing and maths skills.
- Getting involved in delivering education and training to the general population (see ideas of what below)

People also used this section to talk about the ways in which education can have a positive impact on the lives of people with lived experience of mental health issues:

Training and education for the general population:

- Ensure that people have more education about mental health issues
- Start education about mental illness early
- More education about how stigma can negatively impact on someone's mental health
- More awareness and openness from an early age would create more understanding
- Education should result in meaningful empowerment and critical consciousness

Training and education for people with lived experience of mental health issues, related to mental health issues:

- Education for people with lived experience of mental health issues to learn more about their illnesses, funded by NHS, could help alleviate their symptoms & could allow opportunities to teach others.
- Training/education courses for people who have been recently diagnosed with a condition which will be run by people with lived experience and facilitators (if required)

Collective Advocacy

People said that things that would enable them to become involved in collective advocacy are:

To make sure that things are accessible:

- Someone to push wheelchair
- Other support to make sure that the things going on are accessible

A range of campaigns to get involved with:

- Political campaigning e.g. welfare reforms
- Trying to get a crisis centre in West Lothian
- Campaigning for drop-in centres
- Protect local day services
- Looking at the mental health impact of insecure work
- “Sense of Belonging” is a waste of money because nothing’s happening – invest more money in services that keep you well
- More illness/symptom specific groups like the Personality Disorder Project and the Psychosis Project run by CAPS. There need to be more projects like these
- Mad Pride.

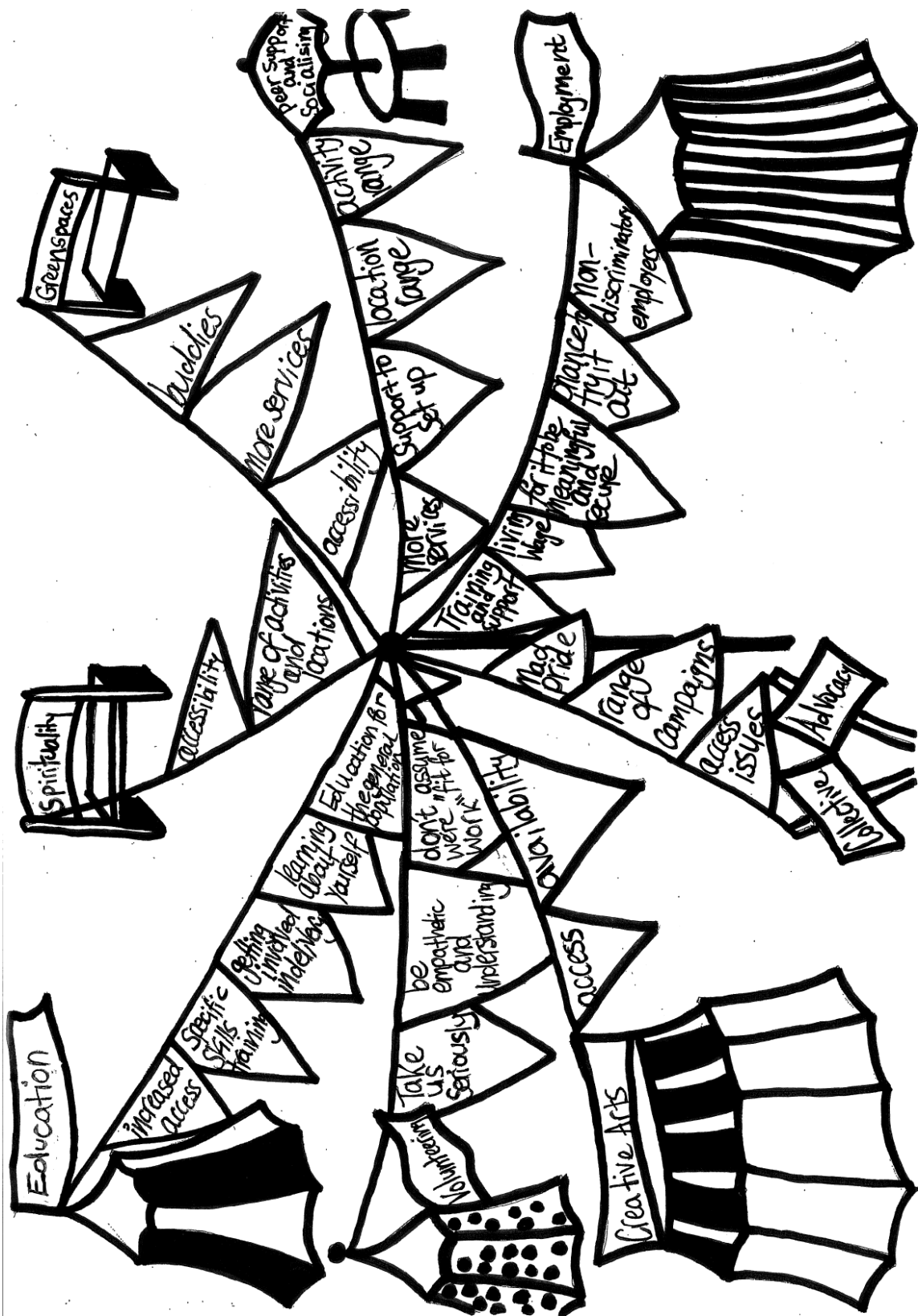
People also made comments about the way that collective advocacy should work:

- Collective advocacy if authentic should not be structured by funder-defined outcomes.
- Listening to the voices of people with mental health issues.
- Agencies need to talk to each other

Anything else

People used this section to talk about the types of things they would find helpful in general:

- Chocolate on prescription. It cures many ills. Also pictures of cute animals.
- A resource drop-in/hub will enable all of these options
- A way to easily know what is going on
- Free bus passes
- Ways to feel comfortable and safe taking part in things: spaces being safe and supportive, easy to get to, and someone to go along with you
- Money to be able to take part in things
- No time limits on services



What was said at *The People's Conference*: Improving services

What was the activity?

We invited people to think about whether services have improved since 2011 (when the Sense of Belonging strategy started).

To make it easier to think about services, we divided them into 5 areas:

- Community services (a BIG area- for example, spirituality, peer support, safe places to go, GPs, access to therapies; access to information)
- Crisis services
- Hospital services
- Employment, benefit and education services
- Services for families, carers, friends, or other supporters

We asked people to think about these questions:

- Have services improved since 2011? How/ why?
- What else needs to be done?

People chose the topics they were interested in talking about and discussed them in small groups. A number of themes came up across the different areas, so in this report we have grouped by theme the issues that came up.

Improved access

- Hospital is harder to get into – there needs to be out of hours, outreach, crisis and prevention services across Lothian designed around people's needs not professional's hours.
- Midlothian services are not LGBT+ friendly
- There isn't anywhere to go if you don't fit the criteria.
- More safe places to go, drop-ins, peer support groups and specific peer support groups like one for Borderline Personality Disorder.
- Better access to talking therapies and choice in what is offered. Don't penalise people if they miss appointments and put them back at the bottom of the list.

There is a postcode lottery for services

It is cruel to expect someone to recover in 9 months

- Talking therapies need to be local. There are transport and accessibility issues.
- There is over reliance of 'by the book' therapy.
- IT therapies are not appropriate.
- Midlothian's Orchard Centre is held in high regard but why is Tynepark in Haddington considered a bad idea? There is no funding or support for people who still meet there.
- More services are having to rely on volunteers to keep running.
- There is only an LGBT+ centre in Edinburgh, there should be local hubs.
- There is a postcode lottery for services.
- There should be quicker, earlier intervention services for eating disorders and more education in schools
- Waiting lists stop people getting the help they need, when they need it. It makes drop-ins and places like Redhall Walled Garden so valuable.
- Self referral is so important. Gate keeping is really unhelpful.
- There is an unevenness of services. You have to find out about things yourself then suggest it to your GP.
- Services are becoming about ticking boxes and are time limited. It is cruel to expect someone to recover in 9 months.
- Going to community centres can be frightening. There needs to be specialist drop-in centres where there are staff who are trained in the needs of people with mental health issues. You need a safe place to go where you can be upset and unwell and this be tolerated.
- There should be a buddy system where people can accompany you to places. They should have lived experience of mental health issues.

There isn't anywhere to go if you don't fit the criteria.

Don't penalise people if they miss appointments and put them back at the bottom of the list.

Better information

- There should be more focus on advance statements, it should be part of the initial assessment.
- There should be information on advocacy.
- Services are fragmented; it's not clear what's out there. If you're homeless and have mental health issues it's hard to know where to go.
- There is support out there but you have to know about it.
- We need more information and signposting to all sorts of services.

You have to find out about things yourself then suggest it to your GP.

- We need more information about what happens to benefits if you go into hospital – not everyone can read a leaflet
- There needs to be more and better information of what is out there. More cohesion and a dedicated phone line.
- On leaving hospital, people should have a specific person to help them know about what's out in the community. There should be hospital co-ordination for families when patients are discharged
- There is an unevenness of services. You have to find out about things yourself then suggest it to your GP.

There is support out there but you have to know about it

A more holistic approach

- General hospitals need to recognise mental health
- Psychiatrists need to listen and stop over medicating people.
- We should be thinking about how things could be done better rather than just building a new hospital. Local hubs, a range of services and safe places to go.
- Wards are not good at picking up on physical health issues. You need an alarm bell to get noticed especially if you're disabled. People are often neglected.
- People leave too early from hospital and the support isn't there when we get out. People have social and welfare needs. There needs to be another team for social needs. It is a revolving door.
- There is more to life than just medication. Other services are important like physio, dietician, gym, occupational therapy, podiatry and dentistry. Some of these services are difficult to access when you're in hospital.
- There needs to be better links and more co-ordination with community services. When you are discharged you are lost. Everyone should have a proper care package.
- People need to have access to chaplaincy services as and when they want them: people have been told "the chaplains are only for emergencies" or that they can't see one "until after you've been seen by a psychiatrist"
- Organisations should know the person they're working with, they often don't know friends and family. There are often multiple people caring for each other.
- Self-care should be the default position. Don't assume people have others in their life to look after them.
- Informal support can be difficult to manage for supporters. You need an organisation to turn to/help step in and help you manage the relationships and how much you can give.

General hospitals need to recognise mental health

When you are discharged you are lost

Don't assume people have others in their life to look after them

- Welfare reform and benefit claims issues are taking over people's lives.
- Employment, benefit and education services need more funding for welfare rights, benefit advisors and advocates so that mental health services can concentrate on helping people recover instead of dealing with the fallout from welfare reform and DWP screw ups.
- There needs to be more support for part-time working or self-employment. More flexibility needs to be built into the benefits system
- The sanction system needs reworked it's not fair that people lose such a large amount for very little things
- Access to benefits and welfare needs to be a core part of planning, with one person who has responsibility for this.
- There is not enough employment support for mental health, there needs to be increased awareness in Human Resources for the types of accommodation that can be made.
- The demand on advocacy, welfare, benefits advice is going up. We need to look at the big picture and the impact of external factors, like housing and not having enough food, on mental health. We need a more holistic approach
- We need to look at the impact of Personal Independent Payments and how the low rate DLA is being phased out. The severe disability premium of Employment Support Allowance is being phased out with universal credit
- People are opting out of benefits applications, as it's just too much.
- Medical evidence to assessors needs to be better coordinated.
- Religious places don't understand mental health issues.
- On leaving hospital, people should have a specific person to help them know about what's out in the community. There should be hospital co-ordination for families when patients are discharged
- The self-directed support options need to be given in more detail. There should be a service that provides this kind of support to people including help with banking.
- There should be a service that allows people to come off psychiatric medication in a controlled and safe way and does not allow people to stay on medication for years.

Welfare reform and benefit claims issues are taking over people's lives

People are opting out of benefits applications, as it's just too much

Greater Partnership working and better communication between services:

- There is a lack of communication between Health and Local Authority.
- Funding cuts have reduced the quality of services. Services seem in competition. There needs to be long term funding for security and continuity of care.
- There is poor communication and things are mismanaged (within Community Mental Health Teams)- there needs to be two way communication.
- There needs to be better community links.
- Knowing what is out there in the community should be part of the GP's work
- The voluntary sector is fragmented. It's political and in competition, it's not useful when you are using them.

Knowing what is out there in the community should be part of the GP's work

Training, awareness raising and ways of working

- General A&E staff need more mental health training: whilst it's specialists who assess you, the general care you receive is from general staff who haven't had much mental health training. As a result, there is often an assumption made that all symptoms are mental health related, and people experience very negative/ judgemental attitudes, for example being told to "shut up, I'm busy with people who are really ill".
- Midlothian services are not LGBT+ friendly
- More training courses about mental illnesses so that friends, family, carers, GPs, support workers, and DWP staff can support us more effectively. This should include courses for people with a diagnosis so they can find out more about it. Information is power!
- There is a difference between what employers consider as a person fit to work and what the benefits system does
- What is done in schools? What should be done? – support from a young age, life skills support, community building, there is prejudice from a young age.
- There should be quicker, earlier intervention services for eating disorders and more education in schools and at an early age
- Some Community Psychiatric Nurses are very negative. They were condescending, judgemental and had poor communication skills. It is assumed that you are at fault and you are the problem.

Knowing what is out there in the community should be part of the GP's work

What was said at *The People's Conference*: Setting priorities

Finally, we asked people to write on paper aeroplanes what they thought the most important thing that needs done is. We all threw the aeroplanes together towards a big sign saying

The Future of Mental Health

What people said can be broadly split into the following categories

Education about mental health

- 4 comments said this was the top priority

Examples people gave of the type of thing that can be done are:

- Work to increase general understanding in the community;
- Specific training for the police
- Educating non-psychiatric professionals in working with people who have mental health issues

Better information about the services which are available

2 comments said this was the top priority

Services need to look at people holistically

5 comments said this was the top priority

Examples people gave of the type of thing that can be done are:

- Educating non-psychiatric professionals in working with people who have mental health issues
- Joint working between organisations- not just health related, but welfare, housing, social work, occupational therapy. Not just asking 'how's your mood?' but 'do you have food?'
- Better communication and support for people when they leave hospital

A number of people suggested specific services as a priority

- Crisis Centre in West Lothian.
- More support required in primary schools for children to talk about their problems and receive advice.
- More LGBT+ support groups
- Two people said a drop-in would be a priority
- Support of any kind for people who have been given a diagnosis of borderline personality disorder



For people with lived experience to be involved in running services

- 1 comment said this was the top priority

Examples people gave of the type of thing that can be done are:

Peer support workers

Peer support groups

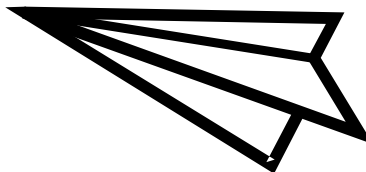
Feeling involved in your own treatment makes it seem more realistic and that it is a possibility as you are taking ownership.

Activism

- 4 comments said this was a top priority

Examples people gave of the type of thing that can be done are:

- Mad Pride
- Working to reduce prejudice and discrimination
- Strength in numbers/ collective advocacy
- Revision of mental 'health' paradigm.



Next steps

This report will be launched at CAPS' AGM 2014, and distributed through CAPS networks. CAPS will ask for it to be distributed wherever the general Taking Stock report has been distributed. It is hoped that this report will prioritise and inform any work around mental health.

The experiences collected in this report were presented by people who had taken part in the People's Conference at Taking Stock on the 15th May 2014, and at NHS Lothian's Joint Mental Health and Wellbeing Planning Programme Board on the 24th July 2014. The findings are also being raised at other relevant meetings, and used to inform CAPS' responses to consultations etc.

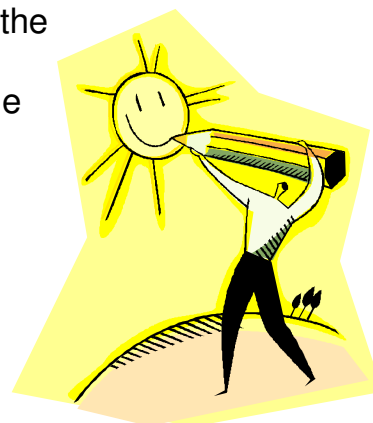


CAPS would like to continue to build on the work done in this report. We hope to organize further fun, creative and inclusive events with people with lived experience of mental health issues. We hope these events will be a space owned by people with lived experience, with the focus explicitly on getting their voices across and giving their views on NHS Lothian's Mental Health and Wellbeing Strategy.

If you are interested in getting involved please get in contact with lili@capsadvocacy.org. Getting involved would be flexible around what you want to do, but could be with all stages of the process, for example, deciding what we do, organizing events, running events or activities, writing up reports, giving presentations about the events, doing illustrations, or simply giving your opinions.

Acknowledgements

CAPS would like to thank everyone who was involved in the People's Conference and related activities. It's been incredible seeing how passionate and dedicated everyone has been in their own way: people have given so much time and energy to the conference; to discussing the findings and writing up this report; and to speaking about the findings at various events. It's been a real chance for us to learn from you all, and a real pleasure. Thank you.



Contact details

CAPS- The Consultation & Advocacy Promotion Service
Old Stables
Eskmills Park
Musselburgh
East Lothian
EH21 7PQ

phone: 0131 273 5116

fax: 0131 273 5117

e-mail: contact@capsadvocacy.org

web: www.capsadvocacy.org

follow us on twitter@[capsadvocacy](https://twitter.com/capsadvocacy)

follow us on facebook: <http://www.facebook.com/capsadvocacy>

This resource has been produced by The Consultation & Advocacy
Promotion Service (CAPS)

The People's Conference Report © CAPS-The Consultation and Advocacy
Promotion Service 2014

CAPS grants permission to reproduce sections of this work for personal
and educational use only, in which case CAPS expects to be fully
acknowledged as the author of this work. Commercial publications,
copying, hiring or lending is prohibited and constitutes a breach of copyright

Scottish Charity Number SC021772

