

Reflections and feedback

At the end of the People's Conference everyone who attended was given an opportunity to give feedback about their experience of the day and anything else they would like to say about Mental Health in Lothian. To ensure everyone felt comfortable, all feedback was anonymous.

"Terrible cutbacks are affecting services"

"There needs to be more input from people with lived experience of mental health problems, more information on how services interact with each other"

"People were included and heard"

"It's too fragmented – the dissemination of information in Lothian needs improvement – It needs to be a much more individual approach – not one size fits all"

"Very thoughtfully prepared and arranged. Providing materials for creativity for example"

"The speakers were really good, good support from the workers"

"I'm so glad they appear to be listening to us"

"Met many people today with lived experience and heard about their difficulties"

"Felt empowered and listened to, and that my experiences and opinions were valued and listened to"

"Better insight into the problems faced by people with Mental Health Issues"

"Thought about how my mental health interacts with other aspects of myself/my life. Meeting other people and sharing experiences in a comfortable and understanding place"

"Whole day went well – enjoyed the activity tables. Really enjoyed presentation from Polish community"

"Talks, I enjoyed the exercises and found the crafting technique a useful way to express myself rather than through a discussion"

"Bit of hope that MH services can be influenced by the people who use them"

"Identifying key points for change"

Further Information

If you would like a full version of this report, or are interested in finding out more and getting involved in independent advocacy and the projects that CAPS facilitates, please contact:

Lili at CAPS on 0131 273 5116, or lili@capsadvocacy.org.

You could also look on our website www.capsadvocacy.org



The People's Conference 2015

A short report

What is 'all of me'?

How can our healthcare be more holistic?

What people in Lothian with experience of mental health issues think.



Scottish Charity number SC 021772

The People's Conference is a one day inclusive event for people with lived/living experience of mental health issues in Lothian.

It is about creating a space where people feel safe, able and welcome to be honest about their lives. It took place at the Walpole Hall, Edinburgh on 11 May 2015. Significantly, it was owned, organised and only open to those who identify with having their own experiences with mental health.

The topic and organization were done by a steering group and on the day staff from CAPS Independent Advocacy and AdvoCard facilitated with activities. The topic was **'all of me'** which involved looking at how services work with us holistically, with every thing that is going on in our lives, including for example the interaction between physical and mental health. The day was a great success and through discussion, individual thought and creative art and design valuable information was gathered. The information was collated and a list of eleven priorities for change, along with how these changes can be made possible was compiled. A group of speakers who had participated in the event went on to present the priorities at the 'Sense of Belonging - Taking Stock Year 4' conference on 28 May 2015.

'A Sense of Belonging' is the joint strategy developed by NHS Lothian, Local Authorities, 3rd Sector agencies and collective advocacy working together to improve the mental health and wellbeing of people in Lothian. It began in 2011 and is currently continuing until 2016.

Taking Stock is the annual event which creates the opportunity to make sure that all stakeholders (defined as people and groups affected by the strategy) are "informed of progress and to sense check the priorities within a rapidly changing context"

This page shows the 11 priorities and the suggested solutions.

Challenge the current benefits system.

- Give us appropriate levels of support if and when we move through the benefits system.
- Don't penalise us for volunteering or taking part time work.
- Don't assume we are playing the system.
- Benefit staff need to be educated about our needs and shouldn't make us feel bad for getting better, it's not a crime!

Use of language is important.

- Language should be clear and non-judgemental
- Make documents and forms accessible
- Promote and offer us interpreters or buddies.

Services should consider how people want their families and carers to be involved in their care and what services are provided for them.

- Respect our decisions about how much involvement we want our family and carers to have and support us in the choices we make.
- Recognise that we may not want certain people involved in our care and have systems in place to support us to identify and deal with these relationships.
- Provide access to support for our families and carers.
- Support us to write care plans with our carers if we want to, and respect these.
- Recognise that we may also have caring responsibilities for people and pets and support how we want this to be managed.
- Support communication between us and our carers when we are in hospital.
- Respect who we say we want and don't want to visit us when we are in hospital, and realise this may change.

Greater access to good quality peer support.

- Workers should be trained, supervised, mentored, valued and well resourced.
- All agencies should make referrals to peer support an opportunity from the start.
- GP surgeries should provide peer support drop ins.
- Peer support workers as advisors should be embedded within NHS 24.
- Peer support workers need to be well informed about what's involved and contribute to training and recruitment.

For there to be better early intervention And crisis provision.

- There need to be more services available local to us which can be accessed before we are in crisis. This includes safe spaces with drop-in facilities and community based peer support.
- Improved Mental Health education is needed or a wide range of public and community services.
- Schools, colleges and universities need improved mental health support provision.

Help us to manage our finances.

- Help us with budgeting including access to budgeting workshops where needed.
- Give us the choice of how often we receive our benefits.
- Give us enough to live on, we shouldn't have to use food banks.

Listen to our voices!

- It's our right to access independent advocacy, and you should tell us this!
- Make it easy to access our medical records.
- Provide information and support to make an advance statement.
- Create an environment where it is ok to ask for what we need.
- Try to understand our perspectives and accept them as valid, even if you don't agree with us!
- If we ask questions or disagree with you don't assume this is because of our condition.
- Provide and promote longer GP consultations or train up nurses to listen.
- Provide greater funding for Mental Health services.
- Make it easy to make a complaint if we need to.

Services need to work better together.

- Recognise that physical health and mental health interact and overlap.
- Make it easier for services to work together, instead of competing with each other, for example by providing a shared space for collaboration.
- Continually develop your knowledge of other services and signpost us to them when appropriate,
- Make information about your service available and show how it relates to other services

The availability of more and better mental health training.

- Compulsory mental health training should be part of GP training.
- Continual Professional Development training must incorporate mental health issues.
- There should be at least one key mental health specialist, and also provision of peer support allocated to each GP practice.
- More and improved quality of mental health education in schools.

Non-judgemental service provision.

- People with mental health experience should be given the respect they deserve.
- Stop judging us based on our diversity, e.g. mental health, class, gender, sexuality, race or other minority group.
- Recognise that social attitudes, systems and structures interact and affect our mental health.
- Respect and be understanding to us even when we don't want to interact.
- Mental Health and physical health should be given equal funding and viewed holistically.
- Encourage positive ideas about mental health.
- Challenge false information about mental health across all forms of media.
- Trust people to make their own decisions about their lives.

For front line services to work in a more flexible way which is needs-led not diagnosis-led.

- Recognise that timescales are individual so don't discharge us if we don't follow expectations for movement or change. Mental health and its progression is not a linear process.
- Provide access to a wide range of therapies, in addition to or instead of medication, that are not time limited, and can be accessed more than once such as acupuncture and counselling.
- Ask us what we need, based on what we feel is safe and effective for us, rather than what our diagnosis says we need.
- Respect the cultural background of people you are working with.
- Regularly review our need for medication and better inform us of the side effects.
- Where there are waiting lists for services provide other support until we are seen.
- Make sure people are aware of the availability of other training.
- Finally, don't discharge us completely, keep us 'on the books' so that it is easier to access help if we need it.